2010

EXPLORING FORMAL DEMENTIA CARE AMONG FIRST NATIONS IN SOUTHWESTERN ONTARIO: A GROUNDED THEORY STUDY

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Recommended Citation

Finkelstein, Sara A., "EXPLORING FORMAL DEMENTIA CARE AMONG FIRST NATIONS IN SOUTHWESTERN ONTARIO: A GROUNDED THEORY STUDY" (2010). *Digitized Theses*. 3881.
https://ir.lib.uwo.ca/digitizedtheses/3881

EXPLORING FORMAL DEMENTIA CARE AMONG FIRST NATIONS IN SOUTHWESTERN ONTARIO: A GROUNDED THEORY STUDY

(Spine Title: Formal Dementia Care among First Nations)

(Thesis format: Integrated-Article)

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Graduate Program in
Health and Rehabilitation Sciences – Field of Health and Aging

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A thesis submitted in partial fulfillment
of the requirements for the degree of
Master of Science

School of Graduate and Postdoctoral Studies
The University of Western Ontario
London, Ontario, Canada

THE UNIVERSITY OF WESTERN ONTARIO
SCHOOL OF GRADUATE AND POSTDOCTORAL STUDIES

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The thesis by

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entitled:

Exploring Formal Dementia Care among First Nations in Southwestern Ontario: A Grounded Theory Study

is accepted in partial fulfillment of the
requirements for the degree of
Master of Science

Date_________________________

Chair of the Thesis Examination Board

Abstract

This research aimed to understand how formal dementia care is being provided to First Nations communities. This was achieved by conducting in-depth interviews with healthcare providers and then qualitatively analyzing the data using a constructivist grounded theory approach. Results indicated that numerous barriers impede dementia care delivery, including lacking resources, difficulties collaborating among healthcare providers, encountering mistrust, and persons with dementia (PWD) not accessing care. However, numerous care strategies were identified, many of which serve to directly overcome these barriers. Many aspects of care delivery hinged upon effective knowledge sharing between healthcare providers, PWD, informal care providers, and the First Nations community. Future research needs to incorporate the perspectives of First Nations PWD and their informal care providers, to broaden our understanding of this process. Going forward, healthcare providers and administrators should focus on creating a body of First Nations-specific dementia care literature and other culturally appropriate care resources.

Keywords: dementia care; First Nations health; knowledge sharing; grounded theory

Co-Authorship Statement

The written material in this thesis is the original work of the author. Sara Finkelstein participated in all aspects of the work, including reviewing the literature, designing the project, collecting and analyzing data, and preparing a manuscript (see chapter 2) for publication to a peer-reviewed journal. Conception of this study was shared by Sara Finkelstein and Dr. Dorothy Forbes. Dr. Dorothy Forbes and Dr. Chantelle Richmond served in an advisory capacity throughout the study and are co-authors to the manuscript in chapter 2 of this thesis.

Dedication

To my parents

Acknowledgements

I would like to take this opportunity to acknowledge the individuals and organizations who helped transform my tentative ideas and ambitions into reality.

First, thank you to Dr. Dorothy Forbes for serving as my master's supervisor and giving me numerous opportunities to become involved in First Nations dementia research. I could not have achieved this without your knowledge, guidance and encouragement. Thank you to Dr. Chantelle Richmond, the second member of my thesis committee, for lending your expertise and helping me to pave a path towards becoming a researcher in First Nations health. Thank you also for your guidance and support.

I would like to thank the University of Toronto/McMaster University Indigenous Health Research Development Program (funded by the CIHR-IAPH) and The University of Western Ontario for their generous financial support of my research.

Thank you to all the healthcare providers who took time out of their busy schedules to share their voices and stories by participating in this research.

I have had many wonderful experiences as a graduate student, and truly enjoyed these past two years. This is in great part to everyone in HRS. To the faculty and administrative staff: thank you for going out your way to be supportive of my endeavours and for making me feel that I am a valued member of the department. To my fellow graduate students: thank you for your support, friendships, and all the good times.

Thank you to my family and friends, for being there more now than ever. Your support and love mean the world to me.

Finally, thank you to everyone at SOAHAC for your continuing support of this project, for being so welcoming, and for making me an honorary member of your family. It was a privilege working with you and getting to know you all. Without you, this work truly would not have been possible.

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List of Abbreviations

AD = Alzheimer's Disease
CCAC = Community Care Access Centre
CHA = Canada Health Act
CHR = Community Health Representative
CSI 'D' = Community Screening Interview for Dementia
DSM-IV-TR = Diagnostic and Statistical Manual of Mental Disorders, 4th Edition – Text Revision
FNIHB = First Nations and Inuit Health Branch
FTD = Frontotemporal dementia
HIV = Human Immunodeficiency Virus
INAC = Indian and Northern Affairs Canada
KTA = Knowledge-to-action
MMSE = Mini-Mental State Examination
MoCA = Montreal Cognitive Assessment
PARiHS = Promoting action on research implementation in health services
PSW = Personal Support Worker
PWD = Person(s) with dementia
RN = Registered Nurse
RPN = Registered Practical Nurse
T2D = Type 2 diabetes
VaD = Vascular dementia

1 INTRODUCTION

While there has been a heightened interest in First Nations health research over the last decade, studies often focus on the younger or middle-aged generations, but rarely on First Nations persons over the age of 55. This is despite the fact that seniors are a rapidly expanding demographic within the First Nations population (Indian and Northern Affairs Canada, 2008a). Chronic disease research in the First Nations population tends to concentrate on illnesses acquired during mid-life, such as type 2 diabetes (T2D). However, diseases such as dementia, which affect the older demographic, are often overlooked. While there is a vast dementia literature emerging from multiple healthcare fields, there is a paucity of knowledge regarding how this disease, that affects 1 in 3 Canadians over the age of 85 (Canadian Study of Health and Aging Working Group, 2000), is experienced by the First Nations population.

1.1 Review of the Literature

1.1.1 Terminology

Prior to reviewing the literature, several important definitions must be noted. Within Canada, the term 'Aboriginal' collectively refers to three groups of Indigenous peoples: First Nations, Inuit, and Métis. These groups are distinct with respect to their heritages, spiritual beliefs, languages, cultural practices, and historical relationships with governmental institutions (Indian and Northern Affairs Canada, 2009). In the United States, the parallel terms for 'Aboriginal' are 'American Indian' or 'Native American.' 'First Nation' is the preferred term in Canada for persons who were formerly (and continue to be legally) referred to as 'Indian.' First Nations persons can be either 'Status' (Registered) or 'non-Status' (non-Registered), which are legal terms used to refer to their registration under the *Indian Act* (Indian and Northern Affairs Canada, 2009).

Throughout the following literature review, these terms are used as specifically as possible. However, the body of literature concerning Aboriginal health does not always recognize distinctions between Aboriginal groups in Canada, and in many instances separate statistical data for First Nations do not exist. As such, while this thesis is focused on dementia as experienced by the First Nations population specifically, some of the data presented in the literature review refer more generally to Aboriginal health.

For the purposes of the study in the second chapter of this thesis, the term 'First Nations' is used. This term was chosen as most appropriate given that the geographic area in which the study was conducted has several First Nations communities, but does not have significant Inuit or Métis communities.

1.1.2 The Health of First Nations Seniors

1.1.2.1 Life expectancy and demographics.

Numerous health disparities exist between Canada's Aboriginal peoples and the general Canadian population, with Aboriginal communities experiencing a disproportionate burden of illness (Adelson, 2005; Newbold, 1998). The life expectancy for First Nations persons exemplifies these disparities; as of 2001 life expectancy for Registered First Nations persons was 70.4 years for men and 75.5 years for women (Indian and Northern Affairs Canada, 2005), roughly 7 years below that of the general population (Statistics Canada, 2008). The gap in life expectancy is more pronounced for First Nations persons living on reserves, where it is a full 9 years behind that of the general Canadian population (National Advisory Council on Aging, 1999). While this gap still remains large, it is important to note that First Nations life expectancy has drastically improved over the last half-century, and is slowly catching up to that of the general Canadian population (Waldram, Herring, & Young, 2006).

Until recently, seniors comprised a very small percentage of the First Nations population. Due to the lower life expectancy of the First Nations population, it is typical to define a 'senior' as anyone over 55 years of age (National Advisory Council on Aging, 1999). Currently, among First Nations living on-reserve, 9% of the population is 55 years or older, and 4% is over 65 years (national rates are 24% and 13%, respectively) (First Nations Centre, 2006b). However, as in the general population, the number of First Nations seniors is increasing and is expected to triple over the next two decades (Indian and Northern Affairs Canada, 2008a).

1.1.2.2 Burden of chronic disease.

Over the last several decades, chronic disease has begun, in great part, to replace infectious disease as a major cause of mortality and morbidity in the Aboriginal population (Adelson, 2005). Eighty-five percent of First Nations seniors have at least one chronic medical condition, the most prevalent being arthritis, hypertension, diabetes, hearing impairment, chronic back pain, allergies, cataracts, and heart disease (see Table 1) (First Nations Centre, 2006b). According to the 2001 Aboriginal Peoples Survey, First Nations seniors experience a higher prevalence of chronic diseases, including hypertension, diabetes, arthritis, cancer, and rheumatism than the general Canadian population (Statistics Canada, 2007). The dramatic increase in type 2 diabetes (T2D) is of particular concern, as it represents one of the leading causes of illness and disability among First Nations persons (Kirby & LeBreton, 2002). While statistics are collected for the prevalence of the aforementioned chronic conditions, there is no data available noting the prevalence of dementia in First Nations or Aboriginal populations.

Table 1

*Prevalence of Chronic Conditions in First Nations Seniors (55+)**

Chronic Condition	Prevalence (%)
Arthritis	43.4
High blood pressure	38.5
Diabetes	36.2
Hearing impairment	23.3
Chronic back pain	22.4
Allergies	21.9
Cataracts	21.5
Heart disease	18.1
Stomach/intestinal problems	13.6
Asthma	13.5
Osteoporosis	10.2
Rheumatism	10.0
Thyroid problems	8.3
Glaucoma	7.3
Blindness/severe vision problems	6.8
Tuberculosis	6.0
Chronic bronchitis	5.3
Effects of stroke	4.9
Cancer	4.4
Psychological or nervous disorders	3.8
Liver disease (excluding hepatitis)	2.4
Emphysema	2.3

*Adapted from "RHS Report on First Nations Seniors' Health and Wellbeing" (First Nations Centre, 2006b, p. 5)

1.1.2.3 Healthcare services and access.

The delivery of health services to Aboriginal people is jointly administered by the federal and provincial/territorial governments. On the one hand, provincial governments are responsible for providing insured health benefits listed under the Canada Health Act (CHA) to all citizens of the province, including First Nations persons living on-reserve and Inuit. Normally, provinces are also responsible for additionally providing any health benefits not covered by the CHA (Kirby & LeBreton, 2002). However, in the case of reserves and rural/remote communities, the First Nations and Inuit Health Branch (FNIHB, formerly the Medical Services Branch) of the federal government may directly administer non-insured health services in a regionalized manner (Waldram et al., 2006). Whether the provincial or federal government delivers a service depends on a number of factors including status (Registered or non-Registered), place of residence (on- or off-reserve), location of community (urban, rural, or remote), and agreements with Health Canada (Kirby & LeBreton, 2002). Due to the fragmented nature of service administration, overlap in services, neglect of services, inconsistencies, lack of integration, and lack of a holistic approach to health all tend to occur (Kirby & LeBreton, 2002). In addition, Métis and non-Status First Nations persons are excluded from federal legislation governing Aboriginal healthcare services, and thus fall into a jurisdictional void, leading to additional barriers to healthcare access (Kirby & LeBreton, 2002).

Aboriginal communities frequently struggle to gain more autonomy over their healthcare services, in part because conventional health models may not reflect the Aboriginal understanding of health or the reality of the health problems Aboriginal communities face (Adelson, 2005). The traditional First Nations understanding of health favours a more holistic approach incorporating physical, mental, emotional, and spiritual aspects of health and focusing on wellness (as opposed to the Western biomedical focus on disease). From the Aboriginal perspective, health also tends to be approached from the community, as well as individual, level (Adelson, 2005). Furthermore, these traditional views of health meld with the Western model of health – to greater or lesser extents depending upon the person – and First Nations persons may interact with health and illness through a mixture of both First Nations and Western cultures (Roberts, 2006; Wilson, 2003). Given their unique understanding of health, First Nations groups and researchers alike have advocated for more culturally appropriate health services for their communities.

Geographic location, cost, and language all represent barriers to healthcare for First Nations seniors (Hotson, Macdonald, & Martin, 2004). Due to the lack of local resources in rural, remote, and reserve communities, seniors have difficulty accessing doctors, nurses, and hospitals in their area, forcing them to travel long distances to receive care.

Furthermore, the services that are available may not be culturally appropriate (Assembly of First Nations, 2007). Transportation to healthcare facilities outside of the community can be both difficult and costly to arrange (Assembly of First Nations, 2007). In terms of cost, accessing compensation for non-insured health benefits such as traditional medicines, transportation to healthcare services, dental care, medical supplies, and medications can be difficult (Assembly of First Nations, 2007). In a study by Kinch and Jakubec (2004), First Nations women with poor financial means were interviewed about healthcare and access to appropriate services. The authors reported that senior First Nations women with low financial means had little agency to successfully negotiate the healthcare system and enact desired changes to improve their health. Thus, poverty can be seen as not only a barrier to healthcare access, but as a barrier to having a strong enough voice to facilitate appropriate improvement in healthcare services (Kinch & Jakubec, 2004).

Seniors, in addition to requiring standard healthcare services (e.g., access to doctors, nurses, and hospitals), are often in need of home and palliative care services. For First Nations seniors who live on reserves and/or in rural and remote communities, resources for these services within the community are often scarce. As such, many seniors in need of long-term care are required to leave their homes and communities, resulting in isolation from friends and family (National Advisory Council on Aging, 1999). Seniors living on reserves have identified needs for various home care services including home maintenance, housekeeping, nursing care, personal care, and meal preparation and delivery (First Nations Centre, 2006a). Regional Health Survey data (2002-2003) indicate that while 47.7% of seniors living on reserves have a need for home care, only 34.2% are receiving any (First Nations Centre, 2006a). Given the lack of long-term care resources in some First Nations communities, providing adequate home care is essential to allowing seniors to live within their communities for as long as possible.

In the late 1990s, the federal government created the Health Transition Fund Project on First Nations and Inuit Home Care to assess the needs of Aboriginal communities with regard to home care services, and to develop a service delivery plan. Research for the project found that staffing, training, and infrastructure were all insufficient and needed further development (Wentworth & Gibbons, 2000). This, and other reports, has led to the development of the Home and Community Care program for First Nations and Inuit persons living on reserves or in remote northern communities, currently being piloted by Health Canada (Health Canada, 2005). Additionally, Indian and Northern Affairs Canada (INAC) currently runs the Assisted Living Program (formerly the Adult Care Program) which provides in-home care for status First Nations persons living on-reserve who have functional limitations due to age, health, or disability. The program is designed to allow First Nations persons to continue to live independently in a safe and healthy environment (Indian and Northern Affairs Canada, 2008b).

1.1.2.4 Social, economic, and political determinants of health.

Health disparities that exist between the First Nations and national populations are influenced by a number of factors, many of which are social, economic, and political in nature. The Canadian government recognizes that health services, income and social status, social support networks, education, employment and working conditions, social environment, physical environment, culture, and gender all act as non-biological determinants of health status (Federal Provincial and Territorial Advisory Committee on Population Health, 1996).

Aboriginal persons have experienced a long history of severe social, economic, and political marginalization, including removal from lands, forced attendance of children at church-run residential schools, systemic racism, inadequate health services, and poor infrastructure on reserves (Adelson, 2005; Warry, 1998). Housing conditions and water supplies in many First Nations communities and particularly on reserves continue to be inadequate (Health Canada, 2009).

Scholars in the field of First Nations health tend to agree that historical and current social, economic, and political disadvantages – fuelled by the colonial legacy of Canada's assimilationist policies toward First Nations peoples – are the root cause of the disproportionate number of health problems currently facing First Nations communities. The lack of employment opportunities, lack of housing, and barriers to education experienced on reserves and in rural or remote communities all contribute to poorer health outcomes, and significantly reduce access to important health resources in First Nations communities (Schmidt, 2000). Economic inequities have influenced various health behaviours, such as diet (Adelson, 2005). Furthermore, scholars argue that the high rates of suicide, substance abuse, injuries, sexual violence, and certain chronic diseases are systemic, societal problems, rather than problems of the individual (Adelson, 2005). As such, various non-biological determinants of health, including education, and social and economic conditions need to be improved, in addition to improving health resources, in order to truly improve the health of First Nations persons and communities. This belief is substantiated by evidence from Community Health Representatives (CHRs) working in First Nations and Inuit communities across Canada, who identified, among other factors, social resources, material resources, and education as primary health determinants for Aboriginal populations (Richmond & Ross, 2009).

1.1.3 Dementia in the First Nations Population

1.1.3.1 What is dementia?

Dementia is a clinical syndrome of the brain, characterized by cognitive and functional decline in areas of higher cortical function including memory, thinking, orientation, comprehension, calculation, language, and judgement. Commonly, these impairments are also associated with changes in behaviour, personality, and emotional control (Bouchard, 2007; Brown & Hilliam, 2004). Due to the heterogeneous nature of its aetiology, dementia is considered a syndrome, which denotes a range of disease conditions rather than a single disease (Brown & Hilliam, 2004). Dementia is generally acquired later in life, and tends to be both chronic and progressive. Contrary to popular belief, normal changes in memory function and cognitive abilities due to aging are very modest and sub-clinical. Thus, while the prevalence of dementia strongly increases with age, it is not an inevitable consequence of aging (Agronin, 2004).

Most clinicians and researchers in North America use the criteria outlined in the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition – Text Revision (DSM-IV-TR) to define dementia. According to the DSM-IV-TR, all forms of dementia include:

1. Memory impairment
2. **At least one** of the following cognitive disturbances:
    a. aphasia (language impairment)
    b. apraxia (coordinated, complex movement impairment)
    c. agnosia (impairment in ability to recognize familiar objects or stimuli)

    d. disturbance in executive functioning (ability to think abstractly, plan, initiate, sequence, monitor, and perform complex behaviour).

3. Cognitive deficits severe enough to significantly impact social or occupational functioning.
4. Cognitive deficits that represent a decline from a previously higher level of functioning (American Psychiatric Association, 2000).

Multiple forms of dementia exist including Alzheimer's Disease (AD), vascular dementia (VaD), frontotemporal dementia (FTD), substance-induced persisting dementia, and dementia due to other general medical conditions including HIV, head trauma, Parkinson's Disease, Huntington's Disease, Pick's Disease, Creutzfeldt-Jacob Disease, and dementia with Lewy Bodies (Alzheimer Society of Canada, 2010; American Psychiatric Association, 2000). Dementia may also be due to multiple aetiologies (American Psychiatric Association, 2000). AD is the most common type of dementia, representing about 63% of all cases, followed by VaD (Alzheimer Society of Canada, 2010). In some cases, dementia is secondary to a primary illness such as kidney disease, and may be reversible if the primary condition is treated successfully (Alzheimer Society of Canada, 2010).

1.1.3.2 First Nations understanding of dementia.

Understanding how dementia is culturally constructed is important, as it determines in part the rate of patients/clients reporting memory-loss symptoms and how patients/clients respond to and follow through with proposed treatments (Henderson & Henderson, 2002). How dementia is conceptualized by First Nations persons is not well understood, as dementia research primarily has been conducted with persons of European ancestry. It is also important to bear in mind that dementia is a relatively new disease for the First Nations population, as their life expectancy was historically such that few individuals lived long enough to experience it. Thus, Aboriginal communities have only just begun to experience dementia at a community-wide level (Henderson & Henderson, 2002).

While there are currently no studies exploring how First Nations individuals and communities understand dementia, a U.S. study by Henderson and Henderson (2002) in a Native American community reported a variety of perceptions of dementia. These included viewing dementia as a 'naturalized' phenomenon (dementia seen as an inevitable and natural part of the aging process), as an imbalance in a person's emotional, social, and spiritual environment, or as the spirit already having 'crossed over' into the next world (dementia as a form of communication with the spirit world). The study noted that participants typically had an understanding of dementia that combined biomedical knowledge with a cultural understanding of the disease, and thus each person had a unique understanding based on personal experiences and their degree of acculturation (Henderson & Henderson, 2002). This dual conceptualization of disease from both Western biomedical and traditional cultural viewpoints appears to be not uncommon for First Nations individuals, as it has been noted in studies concerning other diseases such as cancer (Roberts, 2006).

1.1.3.3 Epidemiology.

In the general Canadian population, dementia occurs in 7% of persons over 60 and in 49% of persons over 90 (Alzheimer Society of Canada, 2010). Overall, nearly 500,000 Canadians have dementia, representing 1.5% of the total population (Alzheimer Society of Canada, 2010). AD is 2.29 times more prevalent in women that in men; however, the female to male ratio for VaD is 0.85 (Alzheimer Society of Canada, 2010).

Within the First Nations population, the prevalence of dementia is uncertain. Two Canadian studies have attempted to ascertain the rate of dementia in Cree populations. The first was a study by Abas et al. (1985) in which 1,716 Cree subjects aged 65 years and older were screened for dementia. Only 30 individuals met the clinical description for dementia, indicating a rate of 1.75%, far below that of the general population (Abas et al., 1985). Given the significant change in First Nations demographics and health status over the last 25 years, these results can be considered out of date. A decade later, due to anecdotal evidence in Manitoba suggesting lower levels of dementia in Aboriginals, Hendrie et al. (1993) conducted a study in two northern Manitoban Cree populations to determine dementia prevalence. Interviews were conducted with 192 Cree to ascertain potential dementia cases, followed by clinical assessments to confirm or rule out the diagnosis. Eight Cree subjects were diagnosed with dementia, with only one meeting the criteria for AD. This represented an overall rate of dementia of 4.2%, the same as the national average at the time the study was conducted. The rate of AD, however, was only

0.5%, significantly lower than the 3.5% prevalence rate in the national population (Hendrie et al., 1993). These results should be interpreted with caution, however, as even one or two missed cases of AD in this population could change the conclusions drawn by the authors (Jervis, Cullum, & Manson, 2006). Several studies have also been conducted among Native Americans living in the United States to determine dementia prevalence, age of onset, and survival rates, but results have been conflicting (Jervis & Manson, 2007; Sabbagh et al., 2004; Weiner, Hynan, Beekly, Koepsell, & Kukull, 2007; Weiner et al., 2003a). Due to the conflicting information presented in these studies, the epidemiological statistics for dementia in Aboriginal populations in both Canada and the United States thus remain largely debatable.

1.1.3.4 Risk factors and prevention.

With the exception of several early-onset dementias (e.g. familial AD), it is difficult to accurately predict if any given individual will develop dementia due to the heterogeneity of dementia types and the large number of risk factors that have been associated with the disease (Patterson et al., 2008). Several risk factors have been well established, with advancing age being the most strongly correlated (Diamond, 2008).

First Nations peoples are subject to a number of well-established non-genetic risk factors for cognitive impairment (Henderson & Henderson, 2002; Jervis et al., 2006). Diabetes, substance abuse, heart disease, hypertension, smoking, and traumatic brain injury all have high prevalence rates in the Canadian First Nations population (First Nations Centre, 2005; Weiner et al., 2003b) and all represent significant dementia risk factors (Craft, 2009; Diamond, 2008; Li, 2008; Patterson et al., 2008). First Nations people are also susceptible to socioeconomic risk factors for dementia, such as lower levels of education (Diamond, 2008; Jansson, 2005; Reading, Kmetic, & Gideon, 2007; Solfrizzi et al., 2008). Finally, many First Nations communities have been exposed to environmental toxins (Richmond & Ross, 2009), which have been linked to an increased risk of dementia (Diamond, 2008; Jansson, 2005; Solfrizzi et al., 2008).

Only one study has identified the presence of a genetic risk factor for dementia in the Aboriginal population. A novel presinilin 1 mutation was found among many members of an extended Aboriginal family in northern British Columbia (Butler et al., 2009). Such a mutation predisposes individuals to early-onset AD (Patterson et al., 2008).

Several lifestyle interventions have been suggested to reduce the risk of certain dementias such as AD, including healthy eating, physical activity, maintaining normal blood pressure and cholesterol levels, and participating in stimulating social and intellectual activities (Diamond, 2008). As yet, no pharmaceutical agents have demonstrated an ability to prevent or delay onset of dementia and more research is needed in this area (Patterson et al., 2008).

1.1.3.5 Diagnosis.

In diagnosing dementia, healthcare providers are faced with two opposing forces: on the one hand, due to the heterogeneity of dementia subtypes, making an accurate diagnosis of dementia can be difficult (Bouchard, 2007; Feldman et al., 2008). On the other, diagnoses need to be made as early as possible in order to ensure the best therapy for patients/clients (Feldman et al., 2008). In March 2006, the Third Canadian Consensus Conference on the Diagnosis and Treatment of Dementia was held. Following this, an article outlining evidence-based guidelines for physicians diagnosing dementia was published based on the recommendations made at the conference (Feldman et al., 2008). Three conceptual components to diagnosis were outlined: the clinical diagnosis, the logical search for a cause, and the identification of treatable co-morbidities. Six main steps in diagnosing dementia were recommended: patient history, an interview with a family member or caregiver, a physical exam, brief cognitive tests, basic laboratory tests, and structural imaging for certain patients (Feldman et al., 2008). In diagnosing dementia, attention also needs to be paid to the possibility of frequently existing co-morbidities, including depression, cardiovascular disease, infections, delirium, falls, incontinence, and anorexia (Doraiswamy, Leon, Cummings, Marin, & Neumann, 2002; Fu et al., 2004).

The Mini-Mental State Exam (MMSE) is an instrument widely used in Canada to assess cognitive function, and requires the person with dementia (PWD) to complete tasks and answer questions focusing on memory, attention, construction, and orientation (Folstein, Folstein, & McHugh, 1975). The Clock Drawing test is also widely used to evaluate executive functioning and visuospatial abilities (Feldman et al., 2008). A number of new tests have been developed to better detect mild dementia, including the Montreal Cognitive Assessment (MoCA) (Nasreddine et al., 2005), the DemTect (Kalbe et al., 2004) and the 7-minute screen (Solomon et al., 1998).

Several barriers to accurate dementia diagnosis currently exist. First, a number of factors including sensory disorders, pre-existing psychotic symptoms, aphasia, dysarthria (slurred, slow speech), language barriers, and developmental disability can act as confounders in diagnosis (Organizing Committee - Canadian consensus conference on the Assessment of Dementia, 1991). While in time biomarkers may help to diagnose various dementia subtypes, currently no ideal biomarkers exist for dementia diagnosis (Feldman et al., 2008). Lastly, the DSM-IV-TR criteria used to make a formal diagnosis of dementia do not currently represent our knowledge regarding dementia subtypes (Bouchard, 2007). The DSM criteria hinge upon memory impairment, which may be absent or minor (especially in the early stages) of VaD and FTD dementia subtypes (Bouchard, 2007). Furthermore, the DSM-IV-TR may underestimate the importance of psychiatric symptoms which can precede a period of cognitive decline (Holmes, Cairns, Lantos, & Mann, 1999).

In addition to the usual problems associated with diagnosis of dementia, special issues exist when attempting to diagnose dementia accurately in culturally distinct groups such as Canadian First Nations. Significant misdiagnosis or under-diagnosis of dementia may be occurring in the First Nations population for a variety of reasons (Griffin-Pierce et al., 2008). Because dementia is a relatively new phenomenon in First Nations communities, there may be decreased awareness of its signs and symptoms. Furthermore, culturally distinct ways of understanding dementia may not make it stand out as a ‘disease’ that requires ‘treatment’ (Griffin-Pierce et al., 2008). Confounding factors such as lower levels of education, language barriers, and cultural norms differing from those of Western culture may lead to a false diagnosis. Conversely, physicians may disregard signs of dementia by wrongly attributing them to cultural or demographic factors and fail to make a diagnosis when dementia is in fact present (Griffin-Pierce et al., 2008).

Perhaps the most important issue in diagnosing dementia in First Nations patients is that of the appropriateness of available cognitive tests. A number of cultural factors may influence scores on tests such as the MMSE, making them less than ideal for use in First Nations populations. Cognitive test results are known to be sensitive to various factors such as education, socioeconomic status, ethnicity, literacy, and culture (Dick, Tend, Kempler, Davis, & Taussig, 2002; King & Fletcher-Janzen, 2000; Manly, Schupf, Tang,

& Stern, 2005). Scholars have noted that some elements of Aboriginal cultures may be incompatible with the content of existing cognitive tests. For example, many Aboriginal cultures value the ethic of non-competitiveness, which may lead to a tendency to underachieve on tests (Cattarinich, Gibson, & Cave, 2001). Cultural attitudes towards gratitude and approval may also be at odds with available cognitive assessments. Many cognitive tests direct the assessor to provide encouragement and positive feedback during the assessment. However, it may be difficult for certain Aboriginal persons to accept praise or reinforcement due to cultural norms, which in turn can make the person being tested uncomfortable (Cattarinich et al., 2001).

First Nations persons may have a different understanding of geography, place, and time. Those who grew up in rural areas may tend to remember things such as landscape markers better than street addresses, because they attribute more importance to the former (Griffin-Pierce et al., 2008). Aboriginal persons may also count years in terms of lunar cycles and have different ways of identifying months and years (Cattarinich et al., 2001). What is retained in memory may thus be different from the information generally retained by an urban-dwelling, European Canadian, which can affect cognitive testing that has a large memory-based component. Individual test items may also be inappropriate for use in First Nations populations, especially where language barriers are present. Questions often ask a person to categorize two things by similarities or differences (Griffin-Pierce et al., 2008). Griffin-Pierce shares a telling example where this may not be appropriate. An elderly Aboriginal woman is asked to describe the difference between a canal and a river. The woman replies that a canal has water while a river is dry. While this is, in fact, entirely true based on the woman's arid geographic location, where canals are used for irrigation as rivers are generally dry, this response would be marked as 'wrong' on the cognitive test (Griffin-Pierce et al., 2008). Test items may also not be contextualized, such that they lose meaning for a person for whose culture includes an emphasis on story-telling (and thus contextualization), as in many First Nations communities, or for whom English is a second language (Griffin-Pierce et al., 2008).

Many questions on cognitive tests ask for the persons being tested to perform various arithmetic calculations. First Nations persons often have difficulty with these types of questions, possibly because their cognitive skills tend to be less linear-sequential-analytic and more global-holistic, but also likely due to the fact that many were not afforded strong educations in the residential school system (Cattey, 1980; Griffin-Pierce et al., 2008; Tharp, 1994). Thus, "health professionals may misinterpret familiar yet culturally appropriate behaviors as manifestations of psychopathology" (Cattarinich et al., 2001, p. 1470).

Due to these multiple issues with available cognitive tests, many researchers advocate for the development of more culturally appropriate instruments for diagnosing dementia in Aboriginal populations (Griffin-Pierce et al., 2008). In a study by Jervis et al. (2007), results indicated that a separate set of population-specific norms for American Indian populations on the MMSE may be appropriate. The CSI 'D' is a 'culturally neutral' instrument that was developed specifically for diagnosing dementia in First Nations and other ethnic populations (Hall, Hendrie, & Brittain, 1993). The Grasshoppers and Geese Test is also being developed as an instrument that is geographically and culturally appropriate for First Nations persons living in rural areas (Lanting, Crossley, Morgan, & Robertson, 2006).

In screening First Nations patients/clients for dementia, several recommendations have been made by leading authors in the field. First, it is important for the person administering the cognitive test to develop trust and rapport with the patient/client (Griffin-Pierce et al., 2008). The assessor should take into consideration the degree of bilingualism (if English is a second language) and the level of literacy of the patient/client, as these may impact test scores (Griffin-Pierce et al., 2008). Finally, the communication style and taboos of First Nations cultures should be considered. For example, an Aboriginal patient/client may take time to reflect and speak softly due to cultural norms, and should not necessarily be labelled as "slow" or "withdrawn" as a result (Garrett & Garrett, 1994).

1.1.3.6 Treatment.

Currently, clinicians and researchers widely believe that early diagnosis and treatment to slow decline is the best strategy for helping PWD (Knopman et al., 2001). Unfortunately, current therapies can only help with the management of symptoms – no treatment exists to halt or reverse the dementia process (Hogan et al., 2008). In addition to treating primary dementia symptoms, healthcare providers also have to treat any co-morbidities that may be present.

Few non-pharmacological therapies exist for treatment of primary dementia symptoms. Some evidence exists demonstrating that regular exercise in persons with mild to moderate dementia can help slow cognitive decline (Bocti, Black, & Frank, 2007). However, it has been argued that this evidence is insufficient to positively conclude that physical activity programs are beneficial for PWD (Forbes et al., 2008). Medications available for the treatment of dementia are only modestly effective in slowing cognitive decline. Currently, two classes of drugs for the treatment of dementia exist: cholinesterase inhibitors and non-competitive N-methyl-D-aspartate (NMDA) receptor antagonists (memantine) (Alzheimer Society of Canada, 2010).

Little research on treatment of dementia in Aboriginal populations has been conducted. Throughout the course of treatment, healthcare providers will need to continually test cognitive function in patients/clients with dementia. Using a culturally sensitive test, such as the CSI ‘D’ or the Grasshoppers and Geese Test, would help ensure more accurate cognitive assessments (Hall et al., 1993; Lanting et al., 2006; Whyte et al., 2005). Clinicians should try to be culturally sensitive to Aboriginal PWD with regards to discussions of dementia diagnosis, prognosis, and treatment. Given the novelty of this disease in the Aboriginal population, Aboriginal patients/clients and their families may have limited dementia knowledge (Jervis et al., 2006). Furthermore, some First Nations cultures, such as the Cree, may view speaking negatively about one’s health as leading to poor health outcomes (e.g., to speak about death is to precipitate it) (Cardinal, 2000). When culturally appropriate, healthcare professionals should phrase discussions concerning dementia in a way that highlights the benefits of treatment, in order to help enhance patient/client comfort and compliance (Cattarinich et al., 2001).

1.1.3.7 Dementia care by health professionals.

Aboriginal persons are underrepresented in medicine in Canada; in 2002, only 0.9% of first year medical students were Aboriginal, despite the fact that Aboriginal persons represent 3.3% of the population (Macaulay, 2009). Non-Aboriginal healthcare workers may have a hard time communicating with Aboriginal patients/clients for a variety of reasons, including differing understanding of disease/wellness, language barriers, differing social cues, differing historical contexts regarding contact with Western medicine, and lack of the patient/client's belief in the ability of Western medicine to help (Adelson, 2005; Elliott & de Leeuw, 2009). These communication issues, especially when compounded with the existing difficulty of communicating with any PWD, can lead healthcare workers to view Aboriginal patients/clients as non-compliant or "difficult" when in reality they may not be able to follow instructions for any or all of the reasons mentioned above (Adelson, 2005). Furthermore, owing to different cultural understandings of disease, Aboriginal patients/clients with cognitive impairment may not present with complaints of loss of cognitive function. It is only when these patients/clients enter the healthcare system for another reason, such as help controlling diabetes, hypertension, or arthritis, that healthcare providers are able to recognize the signs of cognitive decline and make an appropriate diagnosis (Hendrix & Fee, 2004). Thus, when interacting with Aboriginal patients/clients and performing cognitive assessments, health professionals should be aware of and sensitive to differing communication styles and cultural contexts (Garrett & Garrett, 1994). Many Aboriginal persons have additionally noted their desire for healthcare workers to properly understand their community, Aboriginal history, and the patient/client as an individual (Special Working Group of the Cree Regional Child and Family Services Committee, 2000; Towle, Godolphin, & Alexander, 2006).

Aboriginal patients may not show the same deference towards physicians as Western patients would, which may lead to a strained physician-patient relationship (Adelson, 2005). Additional factors impacting the healthcare worker-patient/client relationship include (sometimes misguided) assumptions about Aboriginal health and socioeconomic status on the part of the physician (Elliott & de Leeuw, 2009). Healthcare providers should be respectful when interacting with Aboriginal patients/clients (Adelson, 2005). Healthcare providers should also strongly consider adopting a holistic approach in offering advice and care to Aboriginal patients/clients with dementia, as this is more in line with the traditional Aboriginal understanding of health as encompassing physical, emotional, intellectual, and spiritual well-being (Macaulay, 2009). Healthcare providers may also need to build trust before the patient/client is willing to reveal personal information, and developing a rapport with Aboriginal patients/clients can take years (Kelly & Brown, 2002).

1.2 Gaps in the Literature and Rationale for Study

There is a paucity of research regarding dementia in the First Nations population, and most studies appear to focus on the appropriateness of using popular cognitive assessments such as the MMSE in the First Nations population. Only one study (in this case a Native American case study) by Henderson and Henderson (2002) has attempted to examine how Aboriginal persons understand and conceptualize dementia. While it is known that First Nations communities are subject to higher rates of dementia risk factors than the national Canadian population, the rate of prevalence and the relative proportion of dementia subtypes are unknown. Importantly, there is no data regarding how First Nations PWD are interacting with the Canadian healthcare system, including a lack of knowledge about treatment seeking behaviours, dementia resources that are available to them, relationships with healthcare providers and institutions, barriers to treatment and care, and informal caregiver dynamics.

There were also two gaps in methodology/methods that were noted throughout the course of the literature review. First, of the few studies available on dementia in the First Nations population, the majority have used quantitative methods. This focus has left a void in insights into the meanings, experiences, and world views of First Nations persons with dementia and their formal and informal care providers (Finlay, 2006; Pope & Mays, 1995). The second gap in methods is that there is a lack of community-based research, as First Nations community members were infrequently involved in the planning and implementation of the dementia studies that were reviewed. Community partners are important because their expertise helps to understand the phenomenon being studied in a culturally relevant manner and they can aid in translating knowledge gained from research into practical benefits for the community (Israel, Schulz, Parker, & Becker, 1998).

Given the lack of understanding regarding the delivery of dementia care to First Nations persons, a study was designed to fill this knowledge gap, taking into account the simultaneous gaps in knowledge and methodology/methods in First Nations dementia literature. This study uses a qualitative, constructivist grounded theory approach to explore the process of delivering dementia care to First Nations communities by healthcare providers.

In addition to filling a gap in methodology, a qualitative approach was deemed appropriate for several reasons. First and foremost, qualitative methodologies and methods are suitable to explore the subjective experiences, complex behaviours, attitudes, and interactions of dementia care providers (Pope & Mays, 1995). Second, qualitative research is often inductive, creating theories from data (Pope & Mays, 1995). This is in opposition to quantitative research, which generates data in order to test theories. Because there is so little theory regarding how dementia care delivery is accomplished in the First Nations population, a quantitative approach would be difficult to achieve whereas a qualitative approach allows us to begin filling this gap. Finally, a qualitative approach can serve as an “essential preliminary” to future quantitative studies, by providing a rich description of dementia care delivery and pointing to potential areas of quantitative interest (Pope & Mays, 1995, p.44).

Increased autonomy in healthcare and health research has been (and still is) strived for by First Nations communities (Fletcher, 2003; Smith, 1999; Sunseri, 2007; Waldram, et al., 2006). Historically, health research has been done *on* Aboriginal peoples in Canada, as opposed to *for* or *with* them (Fletcher, 2003). This research was often carried out in a manner disrespectful to Aboriginal knowledge, culture, and ethical values - for example, by collecting biological samples without the community’s consent (Kovach, 2005; Smith, 1999; Sunseri, 2007). As such, research is seen by many Aboriginal persons as strongly linked with colonialism (Sunseri, 2007) and “In many places there is a legacy of ill feeling and profound pain that has grown out of the historical process of being the objects of research” (Fletcher, 2003, p. 36).

Given these historical underpinnings, a community-based, constructivist grounded theory approach was chosen from among the large body of qualitative methodologies as most fitting. A constructivist approach emphasizes a co-construction of data and participants as partners in the research. It is thus appropriate as it helps achieve the goal of increasing the autonomy of participants and First Nations community members with respect to healthcare and health research (Mills, Bonner, & Francis, 2006). Because this study seeks to understand the process of providing care to First Nations PWD, a grounded theory methodology, which focuses on understanding processes, was chosen (Charmaz, 2006).

A community-based design was also employed, as it is consistent with a constructivist paradigm in emphasizing the participation and influence of community partners in knowledge creation (Israel et al., 1998). The goal of community-based research is to actively engage community members throughout the research process, such that they contribute to and hold ownership over knowledge creation; collaborative partnerships are stressed throughout all phases of a study, and reciprocal sharing of knowledge and power between researchers and community partners is promoted (Fletcher, 2003; Israel et al., 1998; Lillie-Blanton & Hoffman, 1995; Nyden & Wiewel, 1992). In taking this approach, it has the potential to develop existing community strengths and resources, benefit community health by increasing control over the research process, overcome distrust on the part of communities that have historically been research "subjects", and empower the community (Israel et al., 1998). With respect to Aboriginal communities in particular, community-based research seeks to accept and incorporate Indigenous ways of knowing into the research process (Fletcher, 2003; Sunseri, 2007).

The community partner involved in this project was the Southwest Ontario Aboriginal Health Access Centre (SOAHAC), which:

> strives to provide quality, wholistic health services by sharing and promoting traditional and western health practices to enable people to live in a more balanced state of well-being. The Centre services on and off reserve, status, non-status, and Metis Aboriginal populations of the Southwest Ontario region and associate First Nations with the mandate of ensuring that health services are accessible, of high quality and culturally appropriate. (Southwest Ontario Aboriginal Health Access Centre, 2008).

In addition to having a pre-existing research relationship with SOAHAC, it was included as a community partner because it is one of the few organizations in southwest Ontario that provides care solely for Aboriginal persons. As such, it was acknowledged as both an expert in how to best conduct this research project and as a gatekeeper to recruiting desired participants. Furthermore, upon being approached about the possibility of collaborating with researchers, their staff members and administration were enthusiastic about the project, and from this enthusiasm a fruitful relationship was able to develop.

Throughout the process of this partnership, SOAHAC played an integral role in developing the research study. After researchers initially liaised with the Executive Director, a presentation was made to the Board of Directors explaining the goals, methods, and potential benefits of the project. Following their approval, informal focus groups were held with staff members in order to develop interview questions for participants. SOAHAC was instrumental in securing funding and in recruiting initial participants by advertising the study through emails sent out to staff members. Throughout the project, the Executive Director and Board of Directors were given updates on progress.

Many participants involved in the research worked on a reserve community. This reserve was not an official community partner of the project, and their involvement in the research while crucial, was incidental; snowball sampling was used as a recruitment method, and one participant recruited through SOAHAC was a key informant in accessing healthcare providers working on this reserve. Currently, the researchers and staff members at both SOAHAC and the reserve healthcare centre are working towards creating useful knowledge exchange strategies to disseminate and implement results of the study.

1.3 Thesis Outline

Taking into account the vast gaps in First Nations dementia literature, the purpose of this thesis was to gain an understanding of First Nations dementia care from the perspective of healthcare providers. More specifically, the objectives of this study were to 1) outline the interactions healthcare providers have with First Nations patients/clients, their families, and other healthcare providers, 2) identify barriers to care, and 3) identify successes in providing care.

In chapter two, the results from a research study designed to meet these objectives are presented. A qualitative, constructivist grounded theory approach (Charmaz, 2006) was used to gain an in-depth understanding of how healthcare workers provide First Nations dementia care. The project described in this chapter took place in an urban centre and on a reserve in southwestern Ontario. This chapter is presented in an integrated-article thesis format, and within the article specific details concerning the background, methods, findings, and limitations are described. The findings of this study are separated into care delivery and knowledge frameworks, followed by a discussion regarding how these two frameworks are interrelated.

The third chapter of this thesis focuses on a general discussion of the results and contributions to the field. Contributions to theory, method, and health policy are considered. In addition, because a qualitative methodology was used to conduct this research, a discussion of researcher reflexivity is included.

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2 FORMAL DEMENTIA CARE AMONG FIRST NATIONS IN SOUTHWESTERN ONTARIO

2.1 Background

Over the next two decades, the number of First Nations persons over the age of 65 is expected to triple (Indian and Northern Affairs Canada, 2008). Paralleling this is a projected increase in chronic diseases, including dementia (Hendrix & Cloud-LeBeau, 2006). However, our current knowledge regarding how the First Nations population experiences dementia or dementia care is virtually nonexistent (Jervis, Cullum, & Manson, 2006). While the current rate of dementia in the First Nations population is not known, there is a high prevalence of diabetes, substance abuse, heart disease, hypertension, and smoking (First Nations Centre, 2005; Weiner et al., 2003), all of which represent significant dementia risk factors (Craft, 2009; Li, 2008; Patterson et al., 2008). Dementia is a relatively new phenomenon in First Nations communities (Henderson & Henderson, 2002), and as such there may be a lack of community knowledge regarding its signs and symptoms. First Nations persons with dementia (PWD) may also desire to have traditional healing incorporated into their treatment regimens.

This study aimed to start filling the knowledge gap regarding how First Nations communities experience dementia care. The objective of this study was to explore and describe the experiences of health professionals in providing care for First Nations PWD through a qualitative grounded theory framework. More specifically, the study aimed to 1) outline the interactions healthcare providers have with First Nations patients/clients, their families, and other healthcare providers, 2) identify barriers to care, and 3) identify successes in providing care.

2.2 Methods

2.2.1 Constructivist Grounded Theory Framework

A qualitative approach was chosen for this study as it is suitable to explore the subjective experiences, complex behaviours, attitudes, and interactions of dementia care providers and can be an "essential preliminary" to future quantitative studies (Pope & Mays, 1995, p.44). Because this study endeavoured to understand the process of providing care to First Nations PWD a constructivist grounded theory methodology, which focuses on understanding processes and co-construction of data, was used (Charmaz, 2006; Waldram, Herring, & Young, 2006). Constructivist grounded theory attempts to explain processes by synthesizing analyzed data into an overarching theory that gives an abstract, theoretical understanding of the experience studied (Charmaz, 2006). The theory generated through this research represents a construction based on the interactions of the researchers and participants, and is influenced by their interpretations, assumptions, and circumstances (Guba & Lincoln, 1994). A constant comparative method of data analysis was used, with comparisons between data segments made at each stage of analysis – the study was thus iterative, moving through data collection, analysis, and theory building stages multiple times and non-sequentially (Charmaz, 2006).

2.2.2 Creating Community-based Research

This research also attempted to enhance the autonomy of the First Nations community with respect to healthcare and health research by using a community-based approach. Community-based research is consistent with a constructivist paradigm as it emphasizes the participation and influence of community partners in knowledge creation (Israel, Schulz, Parker, & Becker, 1998). In taking this approach, it has the potential to develop existing community strengths and resources, increasing community control over the research process, overcome distrust on the part of the First Nations communities that have historically been research "subjects", and empower the community (Fletcher, 2003; Israel et al., 1998).The community partner involved in this project was a local Aboriginal health access centre. Rapport was developed through existing relationships with one of the researchers (CR), and volunteering at and attending community events hosted by the centre (SF). Prior to beginning the project, a presentation was made to their Board of Directors explaining the goals, methods, and potential benefits of the project. Following Board of Directors approval, informal focus groups were held with staff members in order to develop interview questions for participants. Their support was instrumental in securing funding for the study and in recruiting initial participants. Throughout the project, the Executive Director and Board of Directors were given updates on progress.

2.2.3 Defining Dementia and Developing the Interview Guide

Because dementia is often under-diagnosed, and the rate of diagnosis in the First Nations community in particular is unknown, it was necessary to use an operational definition for dementia. Thus, for the purposes of this study, dementia was defined as 'persisting memory and/or cognitive problems,' and participants were asked to describe their experiences with clients whose symptoms met these criteria. This definition was arrived at and mutually agreed upon during the informal focus groups held with the community partner's staff members.

The semi-structured interview guide used for initial interviews with participants was also developed during these meetings. One of the researchers (SF) presented a draft of potential interview topics and questions to the community partner's staff members. Staff members and the researcher proceeded to discuss the list of topics and ensure that it covered all relevant areas. Questions and prompts surrounding the topics were then discussed item by item and edited/added to.

For participants who were interviewed twice, the second interview did not follow an interview guide. Rather, participants were asked to expand on and confirm/disconfirm themes and theories that arose during other interviews and throughout data analysis.

2.2.4 Participants

Seven participants were recruited through health centres in an urban centre (city) and on a reserve in southwestern Ontario. To be included in the study participants had to work, or within the recent past have worked, in a healthcare capacity with First Nations PWD. Convenience sampling was initially used to recruit participants. The study was advertised through emails sent to staff members of the community partner and all eligible respondents were included in the sample. Snowball sampling was also used, and initial participants were encouraged to ask any colleagues who may be interested in the study for permission for the researcher to contact them (Appendix C). Theoretical sampling was used near the end of the study to expand on themes and develop theoretical categories. This was achieved by purposely seeking out participants who could provide alternative viewpoints, thus lending more depth to understanding of themes, and re-interviewing participants in order to confirm or disconfirm emerging theories. Pseudonyms were used to protect the identities of all participants. The sample included: Rose, a registered nurse (RN); Elana, a personal support worker (PSW); Jane, a registered practical nurse (RPN); Aragorn, a social worker; Linda, a community health worker; Alfred, a traditional healer; and Mary, a health educator. Participants had varying levels of work experience ranging from six months to over 10 years working in the community. Five participants self-identified as First Nations. The majority of participants provided care only to First Nations seniors living in the community, although two participants also provided care to children and adults of all ages. One participant focused solely on providing care to First Nations PWD.

2.2.5 Data Collection

Rich data was collected through 11 in-depth, semi-structured interviews. These were held in a private office at the participant's place of work, and were roughly 1-1.5 hours in duration. Questions were open-ended and allowed for flexibility to pursue interesting topics raised by participants (Appendix E). Four of the participants were interviewed twice as part of the theoretical sampling process, in order to develop themes and confirm or disconfirm emerging hypotheses and theories. Interviews were digitally recorded and transcribed verbatim. Additional sources of data included field notes that were written up directly following the interview (Appendix F). Data collection continued until saturation was reached, defined as the point at which no new themes were raised during interviews (Steward, 2006). Throughout the theoretical sampling stage of data collection, participants were asked questions that took the form of "Other people have told me [blank], has this been your experience? If not, how has your experience differed?" The researchers concluded that saturation had been reached when developed theory was resonating strongly with participants and when this theory appeared to be incorporating the depth and breadth of participants' experiences.

Given that the interviewer was non-Aboriginal, it was important to acknowledge and be sensitive to the cultural and ethnic divide between interviewer and participant. Dunbar, Rodriguez, and Parker (2002) suggest that disclosing information about the interviewer can help to build rapport and trust in cases of cross-cultural interviewing. Developing this rapport is in line with qualitative constructivist research, which is by definition subjective, and may also encourage participants to disclose more about themselves and their own experiences (Charmaz, 2006; Dunbar et al., 2002). As such, before the beginning of the first interview with each participant, the interviewer (SF) told 'her story' by giving a brief personal background.

2.2.6 Data Analysis

Data analysis followed the guidelines outlined by Charmaz (2006), which employ increasingly complex and analytical levels of coding to synthesize data and generate a theory. Data was initially coded incident-to-incident (Charmaz, 2006), in which active codes (use of verbs) were used to help link interview statements to key processes described by participants. Focused coding was then used to synthesize data from across interviews and to highlight recurring themes in the data. Finally, theoretical coding was used to explore relationships between categories generated during focused coding and bring the focused codes together under a larger theoretical framework. Diagramming (Lofland, Snow, Anderson, & Lofland, 2006) and memo writing (Charmaz, 2002) were used to conceptually map and elaborate on the relationships between initial codes, focused codes, and theory. Memos were also used as a reflexive tool to openly acknowledge the researcher's preconceptions.

2.2.7 Ethical Considerations

Prior to study inception, ethical approval for this project was granted by The University of Western Ontario Health Sciences Research Ethics Board (Appendix A). Project approval was also granted by the community partner. To ensure confidentiality, participants were given pseudonyms and identifying information was removed from transcripts. Trustworthiness was achieved by adhering to the evaluation criteria of credibility, originality, resonance, and usefulness (Charmaz, 2006).[1]

2.3 Findings

Based on analysis of qualitative interviews, two frameworks have emerged as methods of understanding the process of providing healthcare to First Nations PWD. The first is a care delivery framework, which describes the elements of care being provided, barriers to care, and strategies to providing care and overcoming barriers. The second framework interprets healthcare delivery through the lens of knowledge, and outlines how knowledge having/not having, knowledge withholding, and knowledge sharing underlie First Nations dementia care.

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[1] For a more detailed discussion of how evaluation criteria were applied to the study, see section 3.3.2, pg. 76.

2.3.1 Care Delivery Framework

2.3.1.1 Elements of care.

In describing their day-to-day experiences, healthcare providers outlined the diverse elements of care that they provide. While aspects of care being provided differ depending on the field of the healthcare provider, several commonalities emerged, including similar care goals. Participants have two goals underlying their dementia care practice: ensuring client safety and keeping clients in the community. These goals are strongly intertwined, as maintaining a safe home environment is paramount to keeping clients living in their homes and in the community. Rose talked about major safety issues for clients with dementia:

> Interviewer: *Where do you draw the line of when it [memory or cognitive issues] starts to become a problem that needs to be addressed with your clients?*
>
> Rose: *We will see people maybe leaving something on the stove and forgetting it was there. So, I guess the safety concern there. Medications are starting to be missed, then um, there's a concern there.*

Depending on the client's physical capacity and stage of dementia, there are also safety concerns regarding mobility, balance, and falls, especially in later stages.

The second major goal of healthcare providers is to keep clients living independently or interdependently in the community for as long as possible. While this goal is encompassed by the mandates of several of the participants' affiliated organizations, it is also acknowledged that keeping clients at home is a community value and placement in a long-term care facility is seen as a last resort.

In order to ensure client safety and well-being, participants in their day-to-day care generally focus on assessing clients, managing symptoms, and dealing with crises. Clients are assessed both formally and informally by healthcare providers. Assessments are used as a tool to fill in gaps in information concerning the frequency and severity of symptoms and changes in symptoms and needs. Managing symptoms involves working with the client and informal care providers in order to find practical solutions. Participants also frequently support clients and their families in their emotional needs with respect to dealing with a dementia diagnosis and symptoms. Because the majority of clients with dementia have at least one other chronic condition, such as diabetes, symptoms management frequently involves concurrent management of co-morbidities.

Three of the healthcare providers interviewed have roles that encompass coordinating care for their clients. This role is important because clients may have multiple formal and informal care providers, all of whom require relevant information about client care and needs.

The traditional healer's role additionally encompasses diagnosing and investigating the cause of the dementia, and treating symptoms. Healing strategies include giving traditional First Nations medicines and spending time with the client to try to retrieve what has been lost mentally. Through traditional healing methods, he focuses on ensuring physical, mental, emotional, and spiritual health.

The health educator's role is focused on educating PWD, their family caregivers, and community members about dementia risk factors, signs and symptoms, progression of the disease, and available treatments and resources.

2.3.1.2 Encountering barriers.

Participants spoke about several significant barriers that impede their abilities to provide dementia care. Barriers to working effectively in the healthcare system include lacking resources, having difficulty collaborating, and experiencing burnout. Healthcare providers also face barriers with respect to their interactions with clients, including encountering mistrust and an unwillingness on the part of clients to access care.

Lacking resources.

A lack of basic dementia care resources is apparent in the reserve community where several of the participants live and work: respite care, crisis support, emergency services, long-term care, visiting nursing services, and medical transportation are all limited or absent. In addition, there is no physician practicing within the community. In both the city and reserve locations, participants noted that First Nations community health services have a lack of personnel, resulting in extremely heavy workloads. Linda explained how this limits the time she has available to spend with a client:

> *My type of work wouldn't be so much as a day to day, seeing them every day. Um, it would be nice but with the clientele, like, I think there was two workers and a hundred and twenty clients, so it's really hard.*

Heavy client loads are so common that six of the seven participants discussed not having enough time to deliver care, and feeling that they are always behind in their work. Crises, as simple as a co-worker taking a sick day, often lead to healthcare providers being behind schedule. Jane noted experiencing similar feelings of urgency and time pressure in trying to ensure that all of her clients receive care:

> *And sometimes I get behind. And right now, I'm way behind. And I know, it's just- you know, you end up- it sometimes just feels like you're running around putting out spot fires, but the forest is still burning.*

In addition to not having mainstream resources available to them, several participants noted that many of the resources that are available are not culturally appropriate. There are few dementia care programs and resources available that incorporate First Nations knowledge. Linda spoke about the dementia care training she received, for example:

> *I did take training with the Alzheimer's Society and...in that I don't remember them having any cultural appropriate material at all. It was all pretty general, yeah.*

As far as participants are aware, First Nations-specific dementia care literature does not exist. As such, healthcare providers do not always have the knowledge they need and further are unable to share potentially pertinent knowledge with clients and families.

> *You know, there's no written pamphlets, there isn't any guidelines, anything about this whole process. What's the beginning stages? Do you feel that you know someone with this? ...when I go out [to home visits] I say, well, it's about memory, you know, and without being able to present any kind of information or package or brochures on it, they really don't have any information. And neither do I. I haven't been presented with any information that I can pass along, you know, or any other items. Which I find would probably be helpful where they could read it.* (Rose)

Several participants spoke about how non-First Nations resources, including non-First Nations healthcare professionals, can be culturally inappropriate in the sense that they may not understand and/or respect, and are not guided by, the community's values and culture. Alfred spoke about the need for mainstream medicine to begin to understand traditional healing:

> *When it comes to Western doctors and medicines, they want to know how we do things, how we do ceremonies and healings. And in order for them to know they- I guess what they need to learn is cultural awareness.*

Aragorn spoke about the difficulty of working in a First Nations community while employed for a non-First Nations organization, and how he has to navigate the diverging values and beliefs regarding how care should be delivered.

Failing to collaborate.

Healthcare providers often encounter difficulties collaborating with mainstream healthcare workers and institutions. Healthcare personnel on the reserve are able to work together quite effectively, in part because of their proximity, as many of them have offices within the same building. However, when attempting to work with healthcare professionals or institutions outside of the community, collaboration falls short. Three specific situations in which collaboration is difficult were mentioned: with hospitals, with Community Care Access Centres (CCACs), and with physicians.

Several participants are responsible for transitioning clients home from hospital stays. These transitions almost never happen smoothly, because healthcare providers do not receive discharge information about what care has been provided to the client. Rose discussed how there is a lack of communication between hospitals and community healthcare workers such as herself:

> *...once in a while the hospital will call us and work with us and try to get them prepared to come home, other times they're just sent straight home...So, a lot of that communication is being lost now...Yes, hospitals in general, any more, they're not sending discharge papers home with the clients.*

CCACs have access to medical records from hospital stays. However, despite community members signing forms that legally allow for the distribution of this information, healthcare providers on the reserve often do not receive a copy from the CCAC. Receiving information about a client returning from hospital is vital, as other care providers need to be made aware of medication changes, changes in medical condition, and equipment needs. Jane spoke about how this lack of communication can create safety concerns:

> *One of the biggest gaps that I see right now is communication between the hospitals or CCAC and us. People get discharged from hospital and they're on our case load and we have absolutely no idea what changes have taken place, which can be dangerous. In this particular individual's case the person has liver issues and while hospitalized the medications that the liver specialist put that individual on were changed.*

Rose described how this difficulty collaborating and communicating, and the lack of continuity of care, can be discouraging:

> *It's frustrating that, you know, people are coming home and where's information, what can we expect, you know? It would be such a smooth transition if we just had information prior to their discharge*

The CCAC also sends out visiting nursing staff, occupational therapists, and physical therapists, and in many cases communication between these visiting healthcare providers and the staff on the reserve is insufficient. Rose spoke about her difficulties collaborating with the CCAC, in that their services are inconsistent.

> *Some of the work out here is the job of the CCAC and we're trying to still get them to commit to that and come out and do that, which we're having a hard time. And it gets harder as each month goes to get someone to come out.* (Rose)

Participants also frequently mentioned poor collaboration with physicians, with some finding it difficult to communicate with them about a client. Aragorn, for example, mentioned not always hearing back from physicians when he sends them clients' cognitive assessments:

> *When I sent that, those assessments, the doctor never said anything, didn't even contact me. I didn't even get a fax back.*

Jane also noted that doctors do not always seem to take her professional opinion seriously:

> *It's hard to get them- it can be difficult to get GPs to hear what you're saying.*

Finally, Alfred described how physicians do not always accept the validity of traditional healing and alternative medicines, making it difficult to collaborate with them on client care.

> *...but there are times it can be pretty tough because what's happening now is lots of Western doctors and say naturopaths, they don't get along well...Same way with traditional healers and doctors, some of them get along, some don't.*

Due to poor collaboration, participants are thus not always made aware of diagnoses, medications, and care plans made by other healthcare providers. This, in turn, makes it difficult for participants to provide quality continuous care and to ensure the safety of clients.

Burning out.

Healthcare providers spoke about experiencing feelings of stress and burnout, which impact their mental and emotional well-being. Participants often attributed these feelings to being overwhelmed with work.

> *...some days especially when a client's running into problems and the only time, only time when I have a hard day is when I'm behind schedule.* (Elana)

Linda spoke about how at one time there was only herself and one other community health worker providing care to 120 clients. Other healthcare providers mentioned similar circumstances:

> *I just hope I can keep doing what I'm doing without burning. 'Cause I haven't been there that long and I'm already stressed, I'm already tired. I'm the only dementia care person there is there and I'm getting tired already.* (Aragorn)

Having an emotional investment in clients can compound these feelings of burnout, because healthcare providers then start to worry that clients are not receiving quality care from the healthcare system due to their (and other practitioners') lack of time. Jane described the feeling of emotional burnout well:

> *It relates to work load versus staffing. It also relates to how much do you care? I think that people who care are more prone to getting burnt out...I mean, what makes me good at what I do also makes me not good at what I do, if that makes sense.*

Encountering mistrust.

Healthcare providers encounter mistrust on the part of clients and community members in several situations. This was described in particular by health workers that are relatively new to the community. Mary spoke about this when describing her experiences meeting community members:

> *But there was a bit of that maybe suspicion about, you know, again, really what's your agenda? You know, what's-what is it about your organization that you're bringing into the community? So I think again, just feeling that not push back but a bit of that resistance.*

Aragorn had similar experiences when he first started working in the community, and described it as feeling as though he was 'walking on thin ice:'

> *And if you step out of shape in one small way, all the work you've done goes down the toilet and they'll never trust you again. And it is like that. It is like that.*

However, participants also spoke about understanding this mistrust.

> *I think they have every right to be um, suspicious of everybody and I think they have every right to stand back and say: 'Before we participate or open up or take part let's see where this is really going. Let's see if this is really real.' Um, like wouldn't you? If you lived in a- in a community and a culture where basically for the last 250 years you'd have the world pulled out from under your feet.* (Aragorn)

Participants also experience mistrust that is connected to a client's cognitive decline. Rose gave an example of this occurring and how it impacts care:

> *We have one client who's experiencing memory uh problems and she thought that the staff was taking her things, right?...You know, and then later on, after finding it, she remembers she's been moving it around...But then we realized we're changing worker after worker because now she distrusts the worker.*

This mistrust makes clients and community members less likely to seek or accept care. In addition, it makes it more difficult for healthcare workers to provide care, as they may encounter resistance when attempting to do so.

PWD not accessing care.

Participants noted that PWD are often unwilling to seek out available dementia care resources, and often keep symptoms 'to themselves.'

> *I think people are embarrassed about that or what have you. And I've seen that in a lot of people I work with...so I think that kind of general 'let's just keep it to yourself' is still pretty predominant, even in the general community, and especially with the older generation.* (Mary)

There is wide agreement among participants that PWD and their families frequently do not seek out care until a crisis occurs, such as burning a kettle on the stove or injuring themselves in a fall.

> *And you know in some cases it was- it would take a fall, you know, for them to fall and break a hip, you know, and they're in the hospital you know that they start to see that- the decline in their-in their memory and in their health.* (Linda)

Mary and Rose both spoke about how family members may not recognize that a PWD is showing symptoms, or try to cope with symptoms without seeking medical help, until such a crisis occurs:

> *...whereas with Alzheimer's...often it's when a crisis happens, when the family's going through a lot that we get a call. But before that they're like 'Oh, we can manage, it's fine, we're fine.'* (Mary)

Crises thus often lead to a significant change in dementia care, and it is at that point that healthcare providers begin to assess and address the needs of the PWD.

Participants cited several reasons for PWD not seeking care for symptoms. Many healthcare providers find that PWD and their families are lacking information. Rose spoke about how dementia as a disease is a new concept for the First Nations community:

> *I don't think that our community has ever had assessments for memory loss, you know. This is fairly new for them and sure it's scary to find out that 'Oh my gosh I just did this simple assessment and now we're going to the doctor and we're talking about it and now they're going to start giving me some medication and I didn't think it was that serious.'*

Denial of symptoms is also a factor in not accessing dementia care. Jane spoke about how this denial can lead to a crisis situation:

> *Or 'if I ignore it, it's not there.' And that's unfortunate because sometimes that leads to issues in the home, where they become dangerous. You know, huge safety issues. Or, sometimes it takes something terrible happening before anybody realizes there's even a problem, for someone that lives alone.*

Clients also fear a diagnosis of dementia, and the repercussions that such a diagnosis will have on their independence. Jane spoke about how First Nations community members fear being labelled as a person with dementia:

> *People are afraid of the word Alzheimer's. I think Elders are afraid of it because it's a label and it calls your ability to care for yourself into question.*

As Jane mentioned above, part of these fears revolve around not wanting to lose their independence and fearing placement in a long-term care facility. Aragorn also spoke about PWD fearing institutionalization and the stigma associated with dementia:

> *I'll tell ya, the biggest barrier we have to go forward is fear. There's still a stigma...People fearing we're going to put them in homes and things like that.*

Healthcare providers also noted that some PWD attempt to hide or downplay their dementia symptoms.

> *Sometimes they're not quite honest, so it really takes a lot of almost prying and asking or sitting with them for a little longer and say well, when's the last time you had forgotten about something? You know? How many times have you recalled that you might have forgot? You know? So it's more because without someone there telling me it's harder to detect.* (Rose)

It is clear that numerous factors may be impacting the decisions of PWD to seek help. Overall, this unwillingness to access care impacts both the ability of healthcare providers to give practical support to clients and their families, and also the ability of the medical establishment to recognize and diagnose these individuals.

2.3.1.3 Adopting strategies, finding solutions: successes in providing dementia care

Despite significant barriers impeding them, healthcare providers are able to provide dementia care through adopting effective care delivery strategies and successfully finding solutions to overcome roadblocks. These strategies and solutions include maximizing resources, creating culturally appropriate care, involving and relying on family, investigating, developing relationships, and encouraging action. Healthcare providers also have several effective coping strategies to deal with burnout.

Being proactive: Maximizing available resources.

In order to work around having limited funding, services, and personnel, healthcare providers maximize available resources through a number of creative strategies. Participants accomplish this, for example, by providing care at strategic times of the week or day in order to maximize client safety and effectively deal with issues such as nutrition and missing information about client care.

> *And we will fill the hours, that are, say, maybe some of the most high risk hours of the day, so morning for breakfast, medications, blood pressures, blood sugars, things like that. And then at lunch time, again, so they're not at the stove, and then again at supper time. Those'll be three. And if there's anything in between then, we'll try to fill those hours as well.* (Rose)

Participants also accompany clients to their referral appointments. As Rose explained, this allows healthcare providers to communicate and collaborate effectively:

> *With some of our clients we have to have a personal support worker go in with them to the doctor's, sit through the whole conversation with the doctor, so she will ensure that the points that need to be raised are, and answered.*

Healthcare providers also maximize resources by being proactive about client care. The most common example of this among participants is booking medical transportation services on behalf of the client, as clients often have trouble getting to appointments outside of the community and medical transportation is limited. With the client's permission, healthcare providers also book referral appointments on the client's behalf to increase the likelihood of clients following up on health issues.

Two participants who coordinate support worker care services maximize care by sharing knowledge with the support workers.

> *Our PSWs, when I have a new client come on board and we go through a care plan, and I sit them down and I read it with them. I like them to have a good understanding of why is this person at risk for infection or haemorrhaging or these are all the signs and symptoms I want them to continue to look for...so it kinda tweaks their mind that, oh yes, I gotta remember to look for these things with this client, too. Because they don't have the background that I have, I feel it's important that they understand why I'm looking for the haemorrhage, why I'm looking for the risk of infection here and why it's so important that we catch it right away if something happens.* (Rose)

In the reserve community, healthcare providers maximize resources by pooling available community health resources.

> *The Community Health Representatives here are very helpful in the way that if there's not a PSW available I can call them and say 'Can you do this for me? Can you go out into the community and check so and so, she's having some problems...And a lot of times they'll say 'Well sure, I can be out there, give me fifteen minutes.' So they'll go out.* (Rose)

Participants will often also try to ensure continuity of care by filling in these care gaps themselves, at times directly performing the role of another healthcare provider.

> *I do everything. We do- we're not supposed to be doing wound care, but we do wound care. The visiting nurses do it, but when they don't show up, they come two days out of five or seven, so who else but we do it. We do the bandaids, we do the dressings...* (Elana)

However, a few participants mentioned that unfortunately they are sometimes perceived as encroaching on another healthcare provider's territory when attempting to fill these gaps in care.

Finally, healthcare providers try to maximize dementia care by encouraging clients to utilize community resources, such as attending day programs run for seniors.

Joining two halves: Creating culturally appropriate dementia resources and care.

Given the paucity of First Nations dementia care resources, participants often take the initiative to create their own or adapt mainstream resources to make them more culturally appropriate. Aragorn, for example, created a bereavement program for the families of his clients, which draws from both Western and traditional methods of healing. Mary is also in the process of adapting mainstream dementia education resources to make them First Nations-specific, and has met with community Elders for suggestions:

> *But in terms of meeting with the other Elders, again, just wanting to look at things and making it more about dialogue...and even just changing the pictures to make it, you know, more like it belongs there...So, just going through and brushing it up to make it look like it's something that's designed specifically for- for First Nations.*

Healthcare providers also deliver culturally appropriate care by bringing together Western and traditional medicines in such a way that suits the client's needs. Elana, for example, collaborates with traditional healers:

> *I have two clients working with me as traditional medicines, and I work with their healers. I'll work with any healer that day, you know. I'll work with- just tell me what you need to do and I'll do it. So, whatever their healer says I'll do*

> *it. So, and if they want their house cleaned out with a seed of the sage, you know, I go in and I clean their houses out.*

Alfred, the traditional healer, also encourages his clients to seek out Western medicine, and strives to work in partnership with Western healthcare practitioners.

Caring for your own: Involving and relying on family.

Faced with a lack of time due to heavy client loads, healthcare providers prioritize clients with large safety concerns in order to cope. Because of this lack of time and resources, many healthcare providers also rely on family members to contribute care. Because having family members involved can positively impact care by ensuring client safety and prolonging independence, when family is available healthcare providers try to coordinate with them to ensure optimal care.

> *And if I find something while I'm on my reassessment what I do um explain to the family member 'What's your schedule like? Could you just be here- if you're here for breakfast with your mother, do you think that you could just ensure that she takes her pills before you leave for work?* (Rose)

Healthcare providers increasingly rely on the involvement of family members for clients with more severe dementia symptoms. As dementia progresses, clients begin to need more care than healthcare workers can realistically provide. Linda talked about trying to ensure the safety of clients with more severe symptoms:

> *Just did our best with trying to make sure that they're alright, like I said. So it was a lot of follow-up, you know, home visits, and talking with them on the phone. And it was just a real relief you know when their family would get involved...*

Family members can also serve as an important source of information about changes in the client's symptoms and care needs.

> *Course, I like to have the family members sit with me when I go out and do an assessment on an elderly client... And I'll ask these questions with both of- well, I'll ask the client first and then I'll see what the family member says. The daughter will say 'Remember Mom, you did this last week?' And she goes 'Oh yeah, that's right.' You know, so they kind of clue me in to what's really going on in the home. And again, you know, they're the first ones to see their behaviour change and they'll call.* (Rose)

In addition to family members being involved in care, participants also noted that at times the entire community will help to take care of a PWD.

> *And it's a small world out there, because if you don't know how they are and if they're not doing well, you're gonna get a call anyways, by somebody else*

> *saying 'I think you need to, you know, go see this person.' If we didn't know somebody else would be telling us – either if we didn't find out on our own. So, there was that sense of community amongst our people. They would call and check up on them as well.* (Linda)

Participants working on the reserve also mention that because community members watch out for each other, wandering, a common concern for PWD, is not a significant issue.

Being conscientious: Investigating.

Healthcare providers will investigate gaps in information about a client, often created by failures to communicate and collaborate between healthcare providers. Investigating involves conscientiously following up with other healthcare providers involved in client care, and trying to gain information from them. Rose spoke about how investigating is necessary upon a client returning home from hospital:

> *So it's a lot of, I wanna say footwork, it's a lot of 'Ok, what hospital are you in?' And then getting the information and then calling back to those hospitals, to those people and saying 'Alright. You directed them to where?' So we had to call CCAC office, trying to draw information out and work with them.*

Investigation is also a tool used to explore the breadth and depth of dementia symptoms in clients who withhold information by hiding or denying symptoms. It is also used as a strategy to provide everyday care. Because the general assessment form used is short, they will have to be alert to clients mentioning potential symptoms and probe them for more information.

Alfred also uses investigation in his traditional healing, in order to determine the cause of a dementia. He then uses this information to treat the client.

> *So it stems from somewhere, you know. So, um, to fix the solution, we have to go back to the beginning. We can't evaluate- we got to go back and start to unravel: where did it start, how did it start, what does it need to do?...It comes from somewhere. It's what we take in. It stems from what we take in and we get affected by it.*

Being persistent: Developing community and client relationships.

In order to overcome the mistrust of clients and community members, healthcare providers, particularly those new to the community, work hard to develop relationships and build trust. This is accomplished, for example, by purposely seeking out the expertise and support of Elders and Chief and Council, or by attending community events:

> *I try to go to congregate dining fairly regularly just to have a presence and I, you know, serve everyone with drinks and come out and visit...I try to have a presence and a lot of them have gotten to know me through that.* (Mary)

Healthcare providers also build trust by reassuring clients that they are committed to the community, and then following through by being available for clients in crisis, spending extra time with clients if needed, and 'being there' for clients and their families.

> *First Nations people are so sick and tired of programs or new people in the short term...And then what I do is I say 'I signed a three-year contract – I can guarantee you I'm here, for three years. I'm not going anywhere for three years.' That really seems to appease them and make them feel at ease.* (Aragorn)

In large part, healthcare providers attributed being accepted by the community to their friendly and honest attitudes:

> *People accept me because I'm genuine, they know I care about them.* (Jane)

> *I just go in and I be- I am myself...I don't shy away from speaking to people, you know? And whatever their opinion is of me is fine, but again, I think that unassumingness kind of gets you a bit further...they just want honesty and openness.* (Mary)

Healthcare providers also respect the values and autonomy of clients and community members, for example, by acknowledging their right to decide and direct their own care.

> *Do you want to see me once a week? Bi-weekly? Once a month? Whatever works out for you, that's what I do. And it's your time, it's your life, it's your relative, you have the ball, you tell me what you want to talk about or what you need.* (Aragorn)

Healthcare providers are thus not paternalistic and recognize their boundaries as a healthcare provider. This, in turn, helps to build trust with clients and community members and ensure culturally appropriate care.

> *And to really say, you know, I'm open to learning, I wanna learn as much about you know the language, the culture as possible. To really be sincere about that. And to really be just open to saying you know this is a collaboration, it's not me coming in and doing this, it's just something that we can work together.* (Mary)

Changing mindsets: Encouraging clients to take action.

As a means of encouraging them to access care, several healthcare providers spoke about the importance of changing community members' mindsets with respect to how they understand dementia. This is particularly important in light of the fact that community members and clients are often not seeking dementia care until a crisis occurs, due to fear and stigmatization of dementia, denial, and a lack of information about the disease. To counter missing information and misinformation, participants educate community members about the signs and symptoms of dementia, available treatments, and emphasize that it is not a normal part of aging.

> *And I guess that's one of the things we have to work at is to say, you know, this is not something you need to be ashamed about, this is something that is a disease, just like other diseases and there are supports out there.* (Mary)

Highlighting the positives of getting an assessment, such as retaining independence longer by addressing issues earlier, is another major strategy employed to encourage clients to seek out dementia care.

> *I try to answer all their questions and alleviate some of their anxiety or concerns. Just in order, you know, to reassure them that, you know, if this comes out that maybe you might need some help and maybe some medications that may help you with your memory or keep your memory where it is, so it doesn't get any worse. Then would they want that to happen, in the long run, you know? Think about next month, next year, you know.* (Rose)

By focusing on the positives of potentially undergoing a diagnosis, participants feel they have more success reaching their ultimate goal, which is to get the clients assessed and treated.

Alfred spoke about trying to transform clients' initial fear and negative emotions towards a dementia diagnosis, as these negative reactions help feed the disease.

> Alfred: *...not only dementia but could be diabetes or whatever, as soon as you find that you may have a history of it, or if you're diagnosed with it, you know what happens to people when they hear that they're diagnosed with whatever? Once you hear that from a doctor, how does it make most people feel?*
>
> Interviewer: *I think it scares most people.*
>
> Alfred: *Yeah. And that makes a lot of things happen after that. Once they leave here, their self-esteem goes down, they kinda wanna give up. So what happens there, it's funny how it works. When you allow yourself to feel down a lot, you're actually feeding that sickness, a lot. So what we teach our people is, hey it's ok if you're diagnosed with this, you know, here's how we should receive that: accept*

> *it, accept it for now, you know, and then find a solution. But if you're gonna get angry, upset about it or even down about it, you're gonna feed that more – it's gonna make it worse for you.*

Coping as a healthcare provider.

Although participants experience feelings of burnout, many of them have effective coping strategies. One strategy is to accept their limitations:

> *One of the people I work with is very fond of saying 'You can only do what you can do.' And I need to hear that. If you've done your best while you're here, and you've done as much as you can, then that's what you can do.* (Jane)

Similarly, when one of Aragorn's clients passed away he coped with it in part by accepting that he'd done his utmost to help that individual. At times, accepting limitations involves setting role boundaries, and being firm with colleagues or clients and their families about this.

Healthcare providers access personal resources to cope with job stress, for example by engaging in relaxing activities or sharing problems with and receiving personal support from friends and colleagues. Healthcare providers also work to change their attitudes when encountering setbacks and frustrations.

> *So it taught me, you know, when I get upsetting news like that to not just right away blame the nursing staff thinking that they weren't recording things like they should be...So, you know, instead of reacting that way I learned to just quickly chill out...and start putting the pieces together that way. Instead of challenging and questioning people* (Aragorn)

Finally, healthcare providers' passion for their work helps them cope with job stress.

> *I find that you get what you give in this field...So I find if you're a good person, you go in, you talk to them, you treat 'em good, you get good back. I don't care how sick they are, you get what you give.* (Elana)

Being there and spending time.

Despite having a lack of time due to heavy case loads, a strategy underlying many aspects of dementia care is to spend time with clients and community members. This strategy has already been discussed in various contexts. Healthcare providers spend time with the community, for example, in order to build relationships and gain trust. Extra time is also spent with clients in order to fill gaps in care, by investigating or fulfilling the role of another healthcare provider.

More time is spent with PWD who have greater needs, and healthcare providers increase care hours when necessary, for example if a client is in crisis. Participants also emphasize the importance of not rushing through an appointment and taking the time to work with clients to improve health.

> *Uh, a lot of them [clients with dementia] don't know how to smile, how to communicate, how to express words, how to speak, but we work with them. Yeah. We work with them. I spend more time with them.* (Alfred)

They also assure the client that they are not just there for them during an appointment: they make themselves available when a client needs them and have open-door policies.

> *Um, so it's like we promise them dementia's a journey, and we're with you right from the start to the end. You know, we're not going to leave. And so, that's about what I do. And then it's up to them, it's up to them and their families after that if they want the support, then it's there any time.* (Aragorn)

> *I see them once a month but I don't just leave – I take them under my wing, I provide that service to them. You call that service, but it's spiritual guidance as well. And I care for them like so I will be there for them, to give them that hope, I guess, that there is a chance, there is something there for them.* (Alfred)

In many cases, healthcare providers go beyond the call of duty in being there for their clients. This strategy is surprising because of the lack of time on the part of healthcare providers. Clearly, healthcare providers see spending this extra time as being crucial to client care, despite the fact that at times it contributes to their own stress of not having enough time in general to spend with clients.

2.3.2 Knowledge Framework

It is useful to conceptualize dementia care in the First Nations community as a care delivery framework based on elements of care, barriers to care, and strategies and solutions to providing care and overcoming barriers. Underlying these processes, however, is a framework of knowledge having and sharing between healthcare providers, clients, family caregivers, and community members. The elements of this framework are presented below and include knowing (having knowledge), not knowing (lacking knowledge), withholding knowledge, and sharing knowledge.

2.3.2.1 Knowing (having knowledge).

Healthcare providers, clients, informal care providers, and community members all hold important knowledge regarding dementia care. In the case of healthcare providers, they hold knowledge as a result of their professional training regarding the signs and symptoms of dementia, dementia risk factors, and typical progression of the disease. This knowledge allows them to recognize that a client may need a cognitive assessment, or that their dementia is progressing:

> *I guess noticing any, well it varies, but it [suggesting an assessment] would depend on noticing how we had found them- like the workers, how we found them changed. You know, if some were a little bit more confused than they normally were, then we knew that something was going on.* (Linda)

Healthcare providers have knowledge about care that is being provided to the client, including treatments and strategies for managing symptoms. Through experience, they also know about the needs of clients and informal care providers:

> *...we've known now for 10 to 15 years that First Nations families need respite services. There aren't any.* (Aragorn)

Finally, healthcare providers have an understanding of the values, beliefs, and culture of the client and First Nations community, either because they themselves are from the community or because they have gained this knowledge through their experience working in the community. Healthcare workers use this knowledge they hold about dementia, client care, and community culture to provide dementia care that is both comprehensive and appropriate.

PWD and informal care providers hold knowledge about the PWD's state of health, with respect to symptom frequency and severity, changes in health status, and care needs.

> *You know, they're [family] the first ones to see their behaviour change and they'll call. You know, 'I don't know what's going on with Mom, I want you to come out and see her' or 'I'm having trouble with her medication she's ah she can't tell me what she's taken today and I don't know what to give her.'* (Rose)

Members of the First Nations community hold traditional and culturally relevant knowledge that encompasses an understanding of how the community functions and of their values, traditions, beliefs, and attitudes. This knowledge is invaluable, as it can be integrated into dementia care models in order to create culturally appropriate care.

2.3.2.2 Not knowing (lacking knowledge).

As evidenced by the multiple barriers to dementia care, there are several important instances where healthcare workers providing care to First Nations communities do not have needed knowledge. Because of difficulties collaborating between healthcare providers and institutions, knowledge is often lacking with regards to client care. Healthcare providers also have varying degrees of professional knowledge with respect to dementia, which can impact healthcare providers' abilities to provide optimal care:

> *Ah, for myself, I- probably be better if I had some kind of education review for this type of thing- for the dementia and Alzheimer's. I mean, you've taken it but it's been a long time, you know, and you normally don't use those type of- I don't always use this unless I was working maybe in a long term care facility, and then it would come to you so quickly. But if you don't use it on an everyday basis you just need reviews. And I haven't seen any of that yet, you know, first hand information sessions geared for staff here.* (Rose)

PWD, informal care providers, and members of the First Nations community all often lack knowledge about dementia, including information about risk factors, symptoms, progression, and treatments. They may also have misinformation:

> *...when I spoke to the congregate dining group – and it was a much bigger group, so questions were a bit, you know, tougher cause it's a much bigger crowd, there was that – and a couple of people, again 'Isn't this just normal?' and kinda 'Why are we talking about it?' a sense.* (Mary)

As discussed in the care delivery framework, this lack of information can lead community members to put off accessing dementia care services until a crisis occurs.

2.3.2.3 Withholding knowledge.

Two important situations of knowledge being withheld to the detriment of dementia care were noted by participants. The first is the lack of communication and knowledge sharing between healthcare providers and institutions, as previously discussed. The knowledge is viewed as being withheld because healthcare clients on the reserve have signed release of information forms that allow healthcare providers to share their chart information. However, despite the theoretical intent and legal ability to do so, this sharing of information is failing to occur in many instances.

The second instance is that of PWD withholding knowledge about the symptoms they are experiencing.

> *There are so many factors out there that I think contribute to all of it. And that is one, where the people themselves don't wanna come forward. There's also family too, that, you know, maybe it's a stigma, maybe it's embarrassment, but they don't wanna show a sign of weakness, they don't wanna come forward and say this is happening to my mom, my grandpa, my dad. So it's kept a family secret.* (Aragorn)

Withholding this information impedes healthcare providers' abilities to effectively recognize PWD and the severity of symptoms. This, in turn, limits their abilities to manage symptoms and ensure that PWD receive appropriate care referrals.

Maintaining client confidentiality may be seen as a positive result of withholding information. Mary talked about how community Elders explained to her that community members may not attend dementia education sessions because they are concerned about a lack of confidentiality.

> *But also just saying very frankly to me that the model of doing a group-based education session may not fly in the community. Just because people might not be comfortable coming out, cause it's a small community, and sharing stories, 'cause people are worried about, you know, you know even though it's meant to be 'what's said here stays here' people are maybe a little more realistic about maybe that's not gonna happen.* (Mary)

Thus, by emphasizing that they are committed to maintaining confidentiality, healthcare providers can make community members feel more at ease in seeking care.

2.3.2.4 Sharing knowledge.

Healthcare providers share knowledge as a strategy to provide care and overcome barriers. Often, this involves the sharing of professionally acquired knowledge about dementia, such as the signs, symptoms, risk factors, and treatments available. Sharing this information helps to ease the fears of clients regarding getting a cognitive assessment and/or dementia diagnosis, and helps to counter denial about symptoms. This, in turn, can make community members more likely to access dementia care resources. Alfred also shares knowledge about traditional healing strategies for dealing with dementia symptoms:

> *The individuals that do have that memory loss at whatever level, according to you, I try to go and talk to them and explain to them about our ways of healing, methods of healing. And, what I say is, they need to go back, and live our old ways, because the way we're living now society's too fast for us.*

Healthcare providers will also share information with clients about available dementia resources. Rose lets clients know about cognitive assessment services:

> *I explain to them that we have a new program and we have a person here, in office, five days a week that can do the assessments for memory.*

Knowledge sharing between healthcare providers is also an important aspect of First Nations dementia care. Healthcare providers share professional knowledge with their colleagues regarding dementia, both formally and informally. Mary spoke about educating both healthcare providers and community members about dementia:

> *I've done some education with their [reserve healthcare centre] staff and I have another planned...I've been out to teach- to do some sessions with their personal*

> *support workers…And also just doing uh just doing some presentations for the Chief and Council, to get them more aware of our work and about the disease itself and how we can support those.*

This professional knowledge can be used to improve client care, through an enhanced understanding of dementia symptoms and progression, and can be passed on to clients and informal care providers.

Despite having difficulties, some healthcare providers are able to collaborate effectively by sharing knowledge about client health and care. Sharing this knowledge is useful as it makes healthcare providers cognizant of potential health issues:

> *I have one nephrologist who is absolutely fabulous because he carbon copies me on all the communications regarding that one client. That is the absolute only one that I have had do that. And it's really helpful to me, because I'm providing – you know, our program – is providing service to that individual and it helps us to know what the underlying conditions are, because then we can tell the support worker 'These are the things that you might see. These are things that should make you think 'Oh! Maybe someone needs to be contacted.'* (Jane)

This knowledge sharing is important, given that different health professions hold different types of knowledge and levels of training. By sharing their own knowledge expertise, they are helping each other to provide better care and to ensure that clients are safe and their needs are met.

Clients and informal care providers hold information regarding the client's symptoms and needs. By sharing this information, they alert healthcare providers to the need for cognitive assessments, changes in dementia care, referrals to other healthcare professionals, and care needs.

> Interviewer: *Is it usually you who notices things like the medication forgetfulness or is it a family member or is it the patient themselves who's expressing the concern?*
>
> Rose: *It's usually the patient – the community member – first. They will alert a support worker, if they're on our case load. And they'll go, 'I'm not quite sure what's going on.'…if they're not on our case load, they'll tell a daughter or someone…And then the daughter or the son will call us and say you know, 'Can you send somebody out? My mom's having problems remembering, you know, doing different things. She could probably use some monitoring of her meds.'*

Because PWD may withhold information about symptoms or may not be able to articulate changes in symptoms depending on their cognitive status, informal care providers are important secondary sources of information about the health status and needs of a PWD.

First Nations community members are also important holders of cultural knowledge. Because Elders shared cultural and community knowledge with Mary, she is able to create dementia education resources that are specific to the First Nations community:

> *And that's again, initially why I approached this group of Elders, to get feedback. And they did give me some great feedback about how to look at the caregiver [education] series.*

Knowledge held by community members can thus be integrated into the Western biomedical model in order to create culturally appropriate and relevant care.

2.4 Discussion

Ensuring safety governs a great deal of dementia care in the First Nations population. Detection of safety issues is crucial, as it allows healthcare providers to minimize safety concerns by spending more time caring for that client, maximize care resources, and implement care changes. However, First Nations PWD may not come to the attention of the healthcare system until a crisis occurs because they are unwilling to access care. This reluctance to seek dementia care may involve PWD withholding knowledge about the dementia symptoms they are experiencing. Participants attributed PWD not accessing care in part to a lack of knowledge about dementia and available treatments. This is in keeping with the current literature, which notes that First Nations persons do not always recognize dementia signs and symptoms as needing to be treated due to a naturalization of the disease process within the community (Griffin-Pierce et al., 2008; Henderson & Henderson, 2002). It has also been noted that healthcare providers may need to establish trust with First Nations clients in order for the client to begin sharing information relevant to their health status (Kelly & Brown, 2002). As such, the mistrust encountered by several participants may contribute to First Nations community members not sharing knowledge about their dementia symptoms.

Healthcare providers will often notice the development of or changes in dementia symptoms, and their related safety issues, when in the home. As Hendrix and Fee (2004) note it is common for First Nations PWD to enter the healthcare system for a reason other than dementia. Given this, it is important for healthcare providers to have current and relevant knowledge regarding dementia symptoms and progression in order to recognize potential dementia cases and progressing cognitive issues. Further, it is clear that the on-reserve Home and Community Care programs established by the federal government (Health Canada, 2005), for which several of the participants work, are important in dementia care as they help to ensure that PWD who would otherwise not seek care are recognized by the healthcare system.

To overcome some of these safety concerns, healthcare providers rely in part on family and community members to share knowledge regarding dementia symptoms, potential safety concerns, and take on some of the care responsibilities. This is a well-recognized strategy; by including family members in formal assessments, for example, healthcare providers are following best practice dementia care guidelines (Feldman et al., 2008). They also attempt to compensate for clients' reluctance to access dementia care by sharing knowledge with clients and family members about risk factors, symptoms, treatment, and available care resources. Highlighting the positives of seeking treatment in this manner has been recommended as an appropriate dementia care strategy in First Nations populations (Cattarinich, Gibson, & Cave, 2001).

Healthcare providers can only compensate for increasing safety concerns to a point. Given the lack of personnel available to provide care, healthcare workers are only able to spend a certain number of hours a week on one client without jeopardizing the health of others. The Home and Community Care program was designed in part to increase home care staffing, training, and infrastructure on reserves, which had been found insufficient (Wentworth & Gibbons, 2000). This program has clearly made a positive contribution to home care on reserves. However, as participants note that they are overworked due to a lack of funding, services, and personnel, it is clear that these original problems still persist. Indeed, the 2002-2003 Regional Health Survey notes that while 48% of seniors living on reserve require home care, only 34% are receiving any (First Nations Centre, 2006).

It is clear that lacking resources is a major barrier to dementia care. Geographic location plays a large role in this, as clients must travel to access care in many cases and medical transportation is limited. This has been noted as an important issue for all First Nations persons living in rural areas, not just those with dementia (Assembly of First Nations, 2007; Hotson, Macdonald, & Martin, 2004). Participants similarly echoed the literature when noting that resources that are available may not be culturally appropriate (Assembly of First Nations, 2007). Participants also found that available resources were fragmented, such that continuity of care was lacking. This is an interesting finding because while it has been noted that First Nations-specific healthcare services are fragmented (Kirby & LeBreton, 2002), it is clear that this issue extends to mainstream services as well. This fragmentation yields poor communication and collaboration between healthcare providers and institutions.

The lack of services and resources available for First Nations dementia care frequently prompts healthcare providers to take the initiative to create culturally appropriate resources. These resources often involve blending elements of Western medicine, traditional healing, and cultural practices. Healthcare providers either will rely on their own cultural knowledge in order to accomplish this or will seek out the knowledge of community members. Providing care that is a mixture of Western and traditional models – to greater or lesser extents depending on the client – has been recognized by the literature as culturally appropriate (Roberts, 2006; Wilson, 2003).

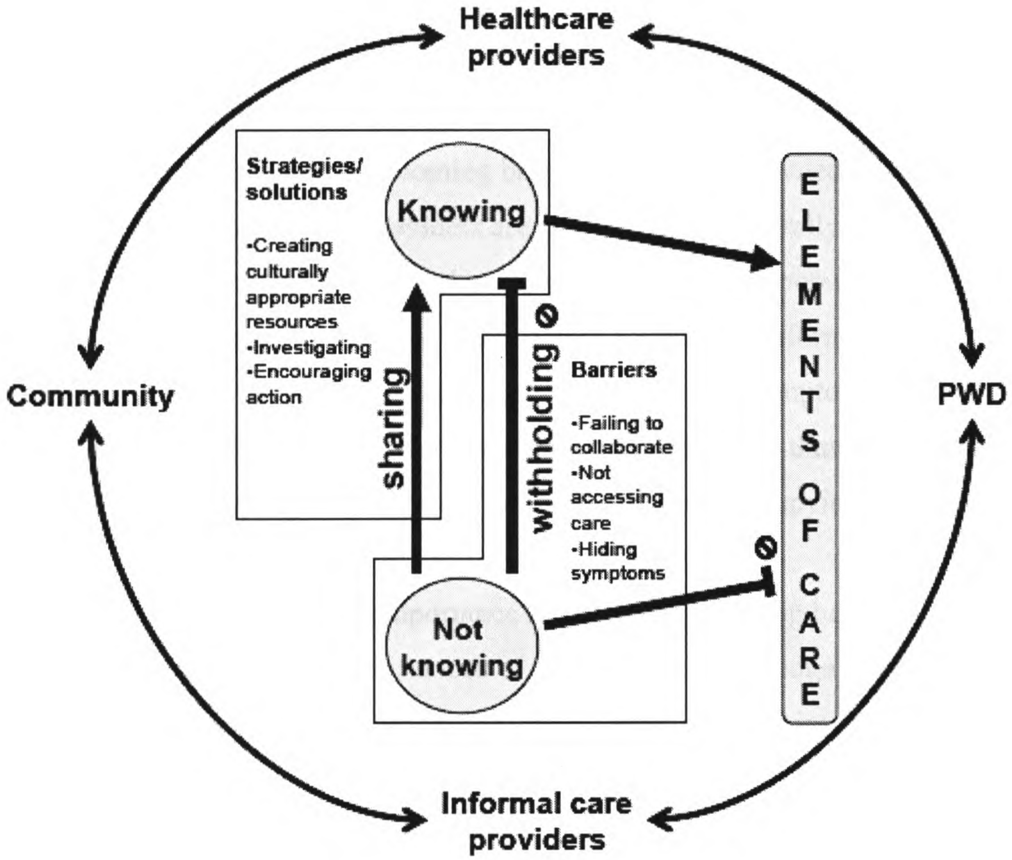

Figure 1. Integration of Care Delivery and Knowledge Frameworks.

↔ Multi-directional relationship; all elements within circle interconnected

→ Uni-directional, constructive relationship

⊘⊣ Uni-directional, inhibitory relationship

It is clear that the two frameworks presented in the findings section are strongly related to one another and intersect at numerous points (see Figure 1). The uni-directional arrow in Figure 1 between 'knowing' and 'elements of care' indicates how having knowledge – including knowing about dementia, client care being provided, and understanding culture – contributes positively to providing elements of care. Conversely, a blunted arrow in the figure indicates how lacking knowledge ('not knowing') adversely affects health workers' abilities to provide elements of dementia care. Having knowledge thus represents a strategy to providing quality care, while lacking knowledge represents a barrier to providing care.

Sharing is used as a strategy to go from lacking knowing to having knowledge, and is crucial to ensuring that elements of care are met and safety concerns are minimized. This is evidenced in two ways. First, sharing knowledge underlies a number of strategies and solutions to providing care and overcoming barriers. Through knowledge sharing with community members, healthcare providers are able to create culturally appropriate resources, understand the culture and values of their clients, and encourage clients to seek out dementia care. Through knowledge sharing with formal and informal care providers, healthcare providers better understand client needs, severity of symptoms, and care plans. Sharing knowledge, as indicated by the arrow caption in Figure 1, thus transports one from a state of ‘not knowing’ to a state of ‘knowing.’ In turn, occupying this state of knowing positively contributes to providing dementia care.

The second way in which the importance of knowledge sharing becomes evident is when it fails to occur. Two major instances of withholding knowledge are noted by participants: failing to collaborate among healthcare providers and institutions, and PWD withholding information about their symptoms. The former can represent a frustrating and time-consuming issue for healthcare providers, as they must spend significant resources to investigate changes in care and fill gaps in knowledge. In addition to wasting resources, this withholding of knowledge may also lead to serious safety concerns regarding medication changes or medical equipment needs. Clients withholding information about symptoms is also contributing negatively to providing care, as their needs cannot be properly met. Further, they typically access the healthcare system when in a crisis, which leads to healthcare providers needing to spend more time ‘putting out (preventable) fires’ and thus using resources inefficiently. Knowledge withholding, as indicated by the arrow caption in Figure 1, thus prevents healthcare workers from transitioning from a state of ‘not knowing’ to a state of ‘knowing,’ which in turn detracts from their ability to provide care.

The outermost circle of Figure 1 denotes the four elements of the dementia care ‘system’ within the First Nations community: healthcare providers, PWD, informal care providers, and the community. All four of these elements hold and need access to equally important knowledge regarding dementia care, and all occupy equally important roles in the process of providing effective dementia care. The double-headed arrows between these elements in the figure are meant to represent that all elements of the circle (not just those directly connected to each other) influence each other and are inter-related. Thus, the arrows denote that these elements occupy a relationship that is similar to that of the four quarters of a circle that all touch in the middle.

It is important to note that while the two frameworks presented here intersect at multiple points, the knowledge framework does not underlie all barriers and strategies to providing care. For example, although lacking resources is a significant barrier to care, in most instances (with the exception of dementia care literature) a lack of knowledge does not underlie this issue. Rather, it is mainly a function of not having enough funding, personnel, and time. Similarly, strategies such as spending time, maximizing resources through arranging transportation, and filling the role of other healthcare providers do not directly relate to having or sharing knowledge.

2.4.1 Limitations

There were several limitations to this study. First, there were limitations to the participant sample, as only dementia healthcare providers were included in this study. As such, the perspectives of First Nations PWD and their informal care providers are not represented, except as second-hand information from the experiences of healthcare providers. Similarly, while healthcare providers discussed their relationships and interactions with hospitals, CCACs, and physicians, representatives from these healthcare institutions or fields were not included in the participant pool. Gaining the perspective of physicians, in particular, would be significant as they control the diagnostic and medical management processes. Second, because an operational definition was used for dementia, it is possible that some of the experiences described were not true cases of dementia, as without a diagnosis symptoms could potentially have been the result of other conditions including depression, mismanagement of blood sugar levels or medications, or delirium. Finally, participants were only drawn from one urban centre and reserve community, and the experiences of healthcare providers in providing dementia care in other parts of the province or country may differ. Thus, results may only be transferable to and resonate with healthcare workers who provide care to First Nations communities in southwestern Ontario.

2.5 Conclusion

This study has contributed to the literature by attempting to understand for the first time how dementia care is delivered to First Nations communities. Care delivery is focused on ensuring safety and keeping clients independent (or interdependent). A number of barriers exist with regards to providing dementia care, including a significant lack of culturally appropriate resources. Despite this, healthcare workers have effective strategies for providing care to the First Nations community. Sharing knowledge is an effective way to overcome a number of barriers to care and is instrumental in creating culturally appropriate resources, successfully encouraging clients to seek out dementia care, maximizing available resources, and filling gaps in care. Conversely, withholding knowledge can contribute significantly to barriers. In the future, studies should focus on understanding First Nations dementia care from the perspectives of PWD, informal care providers, physicians, and major healthcare institutions such as hospitals.

2.6 Acknowledgements

This research was funded by the University of Toronto/McMaster University Indigenous Health Research Development Program Graduate Scholarship and Research Support, funded by the Canadian Institutes of Health Research-Institute of Aboriginal Peoples' Health (CIHR-IAPH), and by The University of Western Ontario Western Graduate Research Scholarship.

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3 DISCUSSION

3.1 General Discussion

The aim of this thesis was to understand dementia care in the First Nations population from the perspective of healthcare providers. This was accomplished through conducting in-depth interviews with health practitioners from an urban centre and reserve community in southwestern Ontario, using a qualitative grounded theory approach. In this final chapter, a brief summary of findings is outlined, followed by a reflexive dialogue on how the author's beliefs and perceptions contributed to and influenced the study. The chapter ends with a discussion on future directions of research, and how this study contributes to the fields of dementia care and First Nations health with regards to theory, methods, and policy.

Findings for this study were divided into two frameworks: a care delivery framework and knowledge framework. The care delivery model described the elements of care that are being provided and two inter-related goals: ensuring safety and keeping clients in the community (Table 2). Several significant barriers to providing this care were identified. However, healthcare providers had a number of care delivery strategies and solutions to barriers that they employed in order to deliver effective dementia care to the First Nations community.

Table 2

Summary of Care Delivery Framework

Elements of Care	Barriers	Solutions
• Ensuring safety	• Lacking resources	• Maximizing available resources
• Keeping clients in the community	• Failing to collaborate	• Creating culturally appropriate care
• Assessing	• Burning out	• Involving/relying on family
• Managing symptoms	• Encountering mistrust	• Investigating
• Dealing with crises	• PWD not accessing care	• Developing relationships
• Coordinating care		• Encouraging action
• Healing		• Using coping strategies
• Educating		• Being there/spending time

The knowledge framework described how having or lacking knowledge and sharing or withholding knowledge can alternatively contribute positively or negatively to First Nations dementia care. Healthcare providers, PWD, informal care providers, and First Nations community members were all seen as important holders of knowledge – knowledge that they could choose to share or withhold. Gaps in knowledge were often filled through effective knowledge sharing and this process led to higher quality care. Conversely, withholding knowledge detracted from care.

Although not overlapping entirely, the care delivery and knowledge frameworks merged to a significant degree. Sharing knowledge formed the basis of many care delivery strategies and solutions and led healthcare providers, PWD, informal care providers, and community members to occupy a state of 'knowing.' This, in turn, facilitated the delivery of elements of care and the achievement of care goals noted within the care delivery framework. Withholding knowledge and being in a state of 'not knowing' were the foundation of several barriers to care. Withholding knowledge actively prevented healthcare providers from moving from a state of 'not knowing' to 'knowing.' In turn, lacking relevant knowledge prevented dementia care from being delivered effectively.

3.2 Discussion of Reflexivity

While conducting this research, I was constantly aware of the fact that I am a non-Aboriginal researcher trying to carve a space in First Nations health research. Knowing I could never fully understand the lived experience of being First Nations, made me self-conscious and my initial interactions with participants more tentative than they might otherwise have been. I was frequently concerned that I would inadvertently show my ignorance and in the process offend somebody, undermining any relationship I was trying to build. I was also concerned that I would be treated differently by participants. I was particularly cognizant of this feeling while interviewing Alfred, a traditional healer, and at times I caught myself neglecting to follow up on themes raised because I did not want to give the impression that I 'didn't understand.' As it turned out, Alfred was very understanding of our diverging experiences and knowledge, and truly wanted to share his stories with me. He would often give me the opportunity to ask questions (e.g. by asking after responding to a question, “Does that make sense?”), which I began following up on as I became more comfortable throughout the interview.

This awareness of being an outsider was also brought up with one participant who openly acknowledged that she was holding back when speaking with me because she did not entirely trust that I would handle the knowledge she was giving me with appropriate sensitivity. As she put it, “where is this gonna go?” Given the small size of the First Nations community in the area, of particular concern to her was ensuring the anonymity of both healthcare providers and clients that were discussed during the interview. Returning home from this interview, I experienced my greatest moment of doubt during the project and questioned whether the First Nations community approved of my participation in this research. This interview prompted several discussions with members of my thesis committee regarding ways in which confidentiality could be ensured. Ultimately, this unsettling interview led to a more well-defined idea of how results would be presented, and strengthened the research.

Although deep down I felt a desire to conceal my non-Aboriginal status, I recognized that the best method of dealing with being an outsider was to embrace it, and to present myself as a unique person. For this reason, prior to the interview beginning, I told participants ‘my story,’ which included discussing my Jewish upbringing and a brief family and personal history. I also began volunteering with a First Nations after-school youth program, in order to gain a better understanding of the community and as a ‘sign of good faith’ that I was committed to contributing positively to First Nations health.

Underlying this research were also my own family’s experiences with dementia. Having had several close relatives diagnosed with this disease, I have a strong emotional connection to the research. In several instances, participants told stories that reminded me of these painful experiences. For the few minutes following these stories, I often had trouble concentrating fully on what the participant was saying. Once again, my approach to this pre-formed relationship to my research was to embrace it. The second half of ‘my story’ focused on my personal connection to dementia. By embracing and sharing these parts of me, I was able to use it as a building block in developing relationships with participants, and I believe it made many of them disclose more about their own lives and experiences than they otherwise would have had if I just remained “the researcher.”

I struggled at times during this research with my inner quantitative researcher. Because this was my first introduction to conducting qualitative research, and I have been trained in the hard sciences, I would at times find myself slipping into a 'quantitative state of mind.' I would start to conceptualize problems I was encountering from a quantitative, positivist perspective, for example by worrying that I did not have 'proof' of a theme existing. It took constant re-framing on my part to recognize that these problems had to be approached from a different perspective (and in some cases, these were not truly problems). In the case of 'proving' that my themes existed, I eventually realized that by going back and re-interviewing participants, I was able to ensure that my themes represented the stories and experiences of participants, and blended their voices and my own into the co-construction of emerging theory.

3.3 Future Directions and Contributions to the Field

3.3.1 Theory

Two frameworks have been presented in the previous chapter as a way to understand dementia care in a First Nations community. It was useful to conceptualize dementia care from two perspectives as it allowed for a more nuanced understanding of the dementia care process. In examining the interface between the two frameworks, we were able to see how knowledge directly influenced barriers and strategies to care, and thus the effectiveness and ease of care delivery.

3.3.1.1 Care delivery framework.

The care delivery framework has for the first time mapped out a descriptive analysis of how First Nations dementia care is delivered. With regards to the elements of care being provided, two care goals were identified: ensuring safety and keeping clients living at home. While assessing clients and managing symptoms are typical elements of dementia care (Feldman et al., 2008; Hogan et al., 2008), further essential care features were additionally identified. Crisis management and coordination of care both took up a significant amount of dementia care time and resources in the First Nations community, for example. Traditional healing services were important in ensuring that dementia care was culturally appropriate and dementia education services helped to fill gaps in dementia knowledge that exist within the First Nations community.

The current body of dementia care literature often focuses on barriers to providing care, as opposed to effective strategies that are being utilized. Barriers identified through the study in the previous chapter tended to echo the dementia care and First Nations health literatures; failing to communicate symptoms, access care, and trust healthcare providers have all previously been recognized as barriers to providing healthcare in a First Nations community (Adelson, 2005; Elliott & de Leeuw, 2009; Hendrix & Fee, 2004; Kelly & Brown, 2002). Non-First Nations healthcare workers may have a hard time communicating with First Nations clients for a variety of reasons, including differing understanding of disease/wellness, language barriers, differing social cues, differing historical contexts regarding contact with Western medicine, and lack of belief in the ability of Western medicine to help on the part of the clients (Adelson, 2005; Elliott & de Leeuw, 2009). Kelly and Brown (2002) noted that there may be initial distrust on the part of First Nations clients, causing them to hold back personal information regarding their health. Furthermore, as Hendrix and Fee (2004) noted, Aboriginal persons with cognitive impairment may not present with complaints of loss of cognitive function due to different cultural understandings of disease. It is only when these patients/clients enter the healthcare system for another reason, such as help controlling diabetes, hypertension, or arthritis, that healthcare providers are able to recognize the signs of cognitive decline and make an appropriate diagnosis (Hendrix & Fee, 2004).

Lacking resources, particularly having to travel to access care, lacking culturally appropriate care resources, and lacking home care services, has been noted in both First Nations healthcare and dementia care literatures as a barrier to care (Assembly of First Nations, 2007; Forbes, et al., 2008; Hotson, Macdonald, & Martin, 2004; Jansen et al., 2009). The finding that available healthcare resources were fragmented, such that continuity of care was lacking, similarly echoed the literature (Jansen, et al., 2009; Kirby & LeBreton, 2002).

Burning out was identified in the findings as a barrier to care. The concept of caregiver burnout and subsequent coping strategies such as seeking social support, have been well-documented in the literature (Almberg, Grafstrom, & Winblad, 1997; Di Mattei et al., 2008; Galvin et al., 2010); however, this is generally with regards to informal care providers. The finding in this study thus adds to the literature and echoes a recent finding by Duffy, Oyebode, and Allen (2009) by demonstrating that formal dementia care providers also experience burnout due to emotional strain. Further, the findings in this study show that formal caregiver burnout is also a result of a lack of personnel, which creates over-heavy case loads.

The strategies to providing dementia care in the First Nations community that were noted in the previous chapter are an important addition to theory, as the current literature on care strategies tends to focus solely on symptoms management. The findings noted here, including maximizing resources, creating culturally appropriate care, relying on family, investigating, encouraging action, and spending time, for the first time elucidate practical and effective strategies to providing care and overcoming barriers in the context of First Nations dementia care. From the above discussion, it is clear that overall, the care delivery framework has added to the literature by filling the gap regarding where First Nations healthcare and dementia care converge.

3.3.1.2 Knowledge framework.

The knowledge framework presented in the previous chapter draws from many aspects of the literature regarding knowledge management in healthcare. Findings noted that having relevant knowledge – including an understanding of dementia, client care, and First Nations culture – contributes positively to providing dementia care. This is in keeping with the literature, as both explicit (written) and tacit (beliefs, understandings, skills, practices) forms of knowledge have been recognized in healthcare fields as contributing to intellectual capital (Anderson & Willson, 2009; Weston, Estrada, & Carrington, 2007). The framework presented here notes that there are two processes happening with respect to the potential for knowledge movement: sharing and withholding. The concept of knowledge sharing between healthcare providers and their clients (or 'users') is akin to the concepts of knowledge translation and transfer noted in the literature. Knowledge translation encompasses identifying and synthesizing relevant knowledge and then sharing and applying that knowledge with the aim of improving health (Canadian Institutes of Health Research, 2009; Graham et al., 2006; National Center for Dissemination of Disability Research, 2005). Knowledge transfer involves a bidirectional sharing of tacit and explicit knowledge between individuals and organizations, such that knowledge which was previously known to only a few can be more widely used (Graham et al., 2006). Knowledge translation and transfer models are based upon evidence that failing to share knowledge results in poorer healthcare (Graham et al., 2006), and the framework presented here adds to this by explicitly noting how withholding knowledge is impacting dementia care.

The framework presented here envisions a dementia care 'system' that encompasses the PWD in the context of numerous healthcare providers, informal care providers, and the entire First Nations community. Each member of this system holds and needs different but equally important forms of knowledge. This idea of a dementia care system builds on the geriatric care triad model presented in the literature. This model conceptualized the healthcare provider, client, and informal care provider as a 'care triad' in which all three participants play an important and active role (Adelman, Greene, & Charon, 1987). Adams and Gardiner (2005) later fit this model specifically to dementia care, and highlighted the importance of clients and informal care providers in communicating the thoughts, feelings, and wishes of the client with regards to care. In expanding this idea of a dementia care triad to the level of a system of care that encompasses multiple formal care providers this framework adds to the literature by taking into account the multidisciplinary and fractured nature of the Canadian healthcare system in general, and First Nations care in particular. Further, it acknowledges the right of self-determination of First Nations communities with respect to healthcare by understanding the First Nations community members as holders of cultural knowledge that needs to be integrated into care.

3.3.1.3 Integration of care delivery and knowledge frameworks.

By integrating the care delivery and knowledge frameworks, we were able to identify how a knowledge system underlies the success of providing dementia care by relating having and sharing knowledge to care strategies, and lacking and withholding knowledge to care barriers (Figure 1).

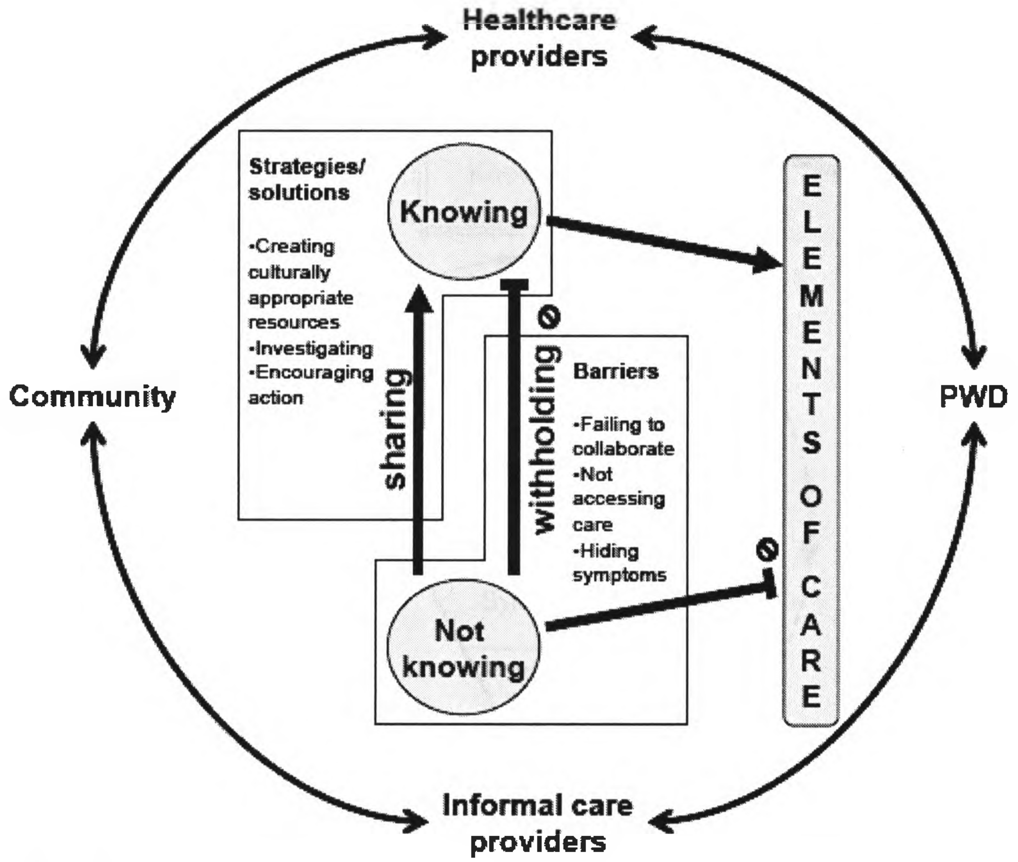

Figure 1. Integration of Care Delivery and Knowledge Frameworks.

↔ Multi-directional relationship; all elements within circle interconnected

→ Uni-directional, constructive relationship

⊣ Uni-directional, inhibitory relationship

This integrated framework is similar to two widely used knowledge translation models: the promoting action on research implementation in health services (PARiHS) framework (Kitson, Harvey, & McCormack, 1998) and the knowledge-to-action (KTA) framework (Graham et al., 2006). These frameworks outline methods in which purposeful knowledge translation and exchange can lead to the implementation of best practices and overcoming of problems in healthcare environments (Graham et al., 2006; Kitson et al., 1998). Briefly, the PARiHS framework considers: (i) the level and nature of knowledge being used, (ii) the context or environment, and (iii) how use of this information is facilitated (Kitson et al., 2008). The KTA model outlines how knowledge creation and application can interlink to solve clinical problems (Figure 2) (Graham et al., 2006).[2]

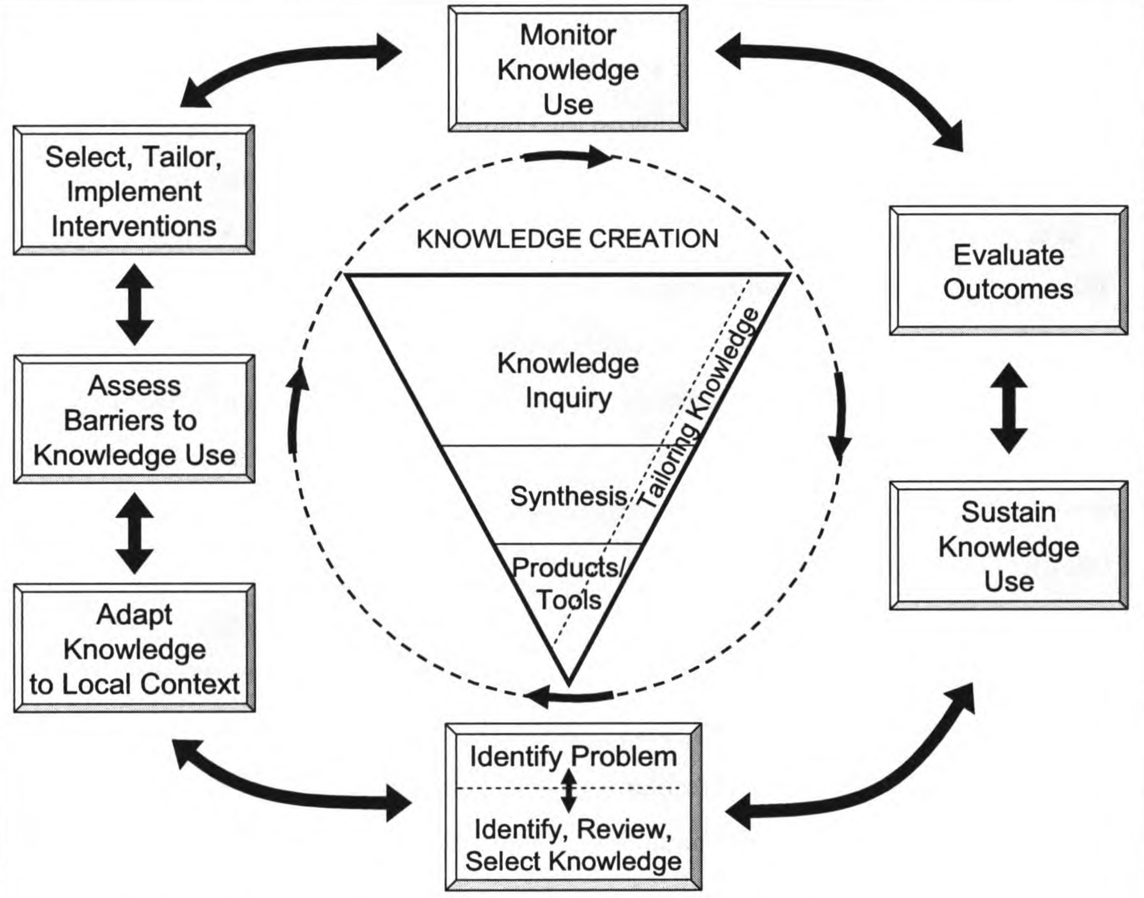

Figure 2. Knowledge to Action Process (Graham, 2006, p.19)

The integrated framework presented here is similar to the established frameworks discussed above as it demonstrates how knowledge sharing can be used to overcome care barriers, thus relating effective care delivery to holding relevant knowledge. However, the framework here departs from the PARiHS and KTA models in several ways. While acknowledging information derived from clinical experience and patient/client preferences has its place in knowledge translation, both the PARiHS and KTA frameworks primarily focus on the implementation of research-based knowledge by healthcare providers (Graham et al., 2006; Kitson et al., 2008). The integrated framework

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[2] See Appendix G for copyright permission.

presented here gives equal weight to multiple types of knowledge, including research-based (or professional) knowledge, knowledge of active care plans (i.e. what care is specifically being provided to a given client), cultural knowledge, and client knowledge regarding health status and needs. The framework presented here also varies from the PARiHS and KTA models in that it is not healthcare provider-centric, as it recognizes that healthcare providers, PWD, informal care providers, and the community all have unique and important interactions with knowledge, and all of these interactions contribute to effective delivery of quality care. First Nations communities frequently struggle to gain more autonomy over their healthcare services, in part because conventional health models may not reflect the First Nations understanding of health or the reality of the health problems First Nations communities face (Adelson, 2005). By acknowledging the important and equal role that community and client play in contributing to and interacting with knowledge, the model presented here contributes to this self-determination process. Thus, it contributes to the literature by creating a knowledge translation framework that is specific and appropriate when considering care in the First Nations community.

It is important to note that while the PARiHS and KTA models represent purposeful methods for knowledge translation to positively impact care and overcome barriers, the model here is more descriptive and incidental in nature. While representative of how healthcare workers provide dementia care to First Nations clients, the model here was by no means a purposeful, comprehensive strategy adopted by care providers. Thus, this model adds to the literature by demonstrating how knowledge translation is being implemented even without the deliberate adoption of a strategy. Further, it provides new knowledge by specifically outlining how knowledge translation is occurring within the context of First Nations dementia care.

In the future, First Nations dementia research should strive to incorporate the direct perspectives of PWD, informal care providers, and First Nations community members, as a more thorough understanding of the needs, barriers, and successes they encounter with respect to dementia care is needed. Similarly, future studies should seek to further understand what knowledge they hold and lack, and how they mediate withholding and sharing of information. In gaining these perspectives, we can further refine our understanding of how knowledge interacts with dementia care barriers and successes in a First Nations context.

3.3.2 Strategies for Enhancing Quality of Study

Regarding methods, several effective strategies were used to collaborate and gain the trust of the local First Nations community. From the inception of this project, the Southwest Ontario Aboriginal Health Access Centre (SOAHAC) was involved as a community partner. The principal researcher attended Board of Directors meetings, professional education events, and cultural events hosted by SOAHAC and volunteered with their after-school youth program in order to establish a good working relationship with the organization. Trust was built with participants by the researcher actively telling 'her story' regarding her personal background and experiences with dementia prior to beginning the participant interview.

Although this was not a participatory action study, community stakeholders were consulted regarding the development of interview themes and questions. This was accomplished by holding two informal focus group meetings with SOAHAC staff members. Using this method ensured that data collection focused on processes that were relevant to First Nations healthcare. SOAHAC staff members, participants, and other community stakeholders were also consulted with regards to knowledge translation and exchange strategies.

In *Constructing Grounded Theory*, Charmaz (2006) notes that participants may be re-interviewed as part of theoretical sampling. Further, Bailey (2007) advocates member checking (described as having participants read over manuscripts detailing study findings) as a method to increase the validity of the study by ensuring that results resonate with participants. In this study, two in-depth interviews, held at one- to two-month intervals, were conducted with the majority of participants. This technique thus had a two-fold advantage: it led to rich data and gave the researcher an opportunity to check that emerging theories reflected the experiences of participants, thus contributing to the trustworthiness of the research.

Assessing the quality of qualitative research can be difficult, as many methods of quality assessment have been put forward by researchers, and no one method of assessment has been unilaterally adopted. Because this study used the methodology and methods of constructivist grounded theory as outlined by Charmaz (2006), her suggested quality criteria of credibility, originality, resonance, and usefulness were used to guide the study. By adhering to these criteria, the researchers ensured that the findings were trustworthy and the study was of high quality. The table below summarizes these quality criteria and how they were achieved throughout the study.

Table 3

Summary and Application of Charmaz's Quality Criteria (Charmaz, 2006)

Criterion	Description	Application to Study
Credibility	• Strongly adhering to constructivist grounded theory methods and methodological guidelines	• Using an iterative process of data collection and analysis, including theoretical sampling • Using a constant comparative method of data analysis • Including persons from multiple health professions and both city and reserve locations in participant sample to achieve depth and breadth of data • Using multiple levels of data analysis • Using extensive quotations in write-up to allow reader to independently assess claims
Originality	• Generating categories and theory that provides new insights and new or refined understanding of process • Creating research that is socially and theoretically relevant	• Using research to fill gaps in knowledge and methodology • Defining for the first time where dementia care and First Nations health intersect • Identifying strategies that can be used to provide effective dementia care in the First Nations community • Refining current ideas by situating findings regarding barriers to care and knowledge in the literature
Resonance	• Creating research that reflects the depth and breadth of the process being studied • Creating research that reflects the experiences of participants	• Continuing data collection until saturation • Using an iterative process of data collection and analysis, in which the majority of participants were interviewed twice to check emerging themes/theories • Keeping data analysis close to lived experience of participants by focusing on day-to-day barriers and strategies to care • Creating interview topics/questions in collaboration with community partner
Usefulness	• Creating research that can be used in a practical way by stakeholders, contribute to knowledge, and spark future research	• Making feasible suggestions with respect to methods and policy improvements • Creating knowledge exchange strategies with community partner and other stakeholders • Identifying areas needing further research • Contributing to dementia care and First Nations health fields of knowledge

3.3.3 Policy and Educational Implications

Based on the findings from this study, this thesis makes several recommendations with respect to First Nations health policy. More culturally appropriate resources are needed for First Nations dementia care. The creation of a First Nations-specific body of dementia education literature would be useful for healthcare providers, First Nations PWD, informal care providers, and First Nations community members. This literature would help to create a more culturally relevant understanding of dementia risk factors, symptoms, progression, and treatments. A significant part of having culturally appropriate resources is having a proportionate number of First Nations healthcare providers. For example, as of 2002 only 0.9% of medical students were members of the Aboriginal community, despite the fact that Aboriginal persons represent 3.3% of the population (Macaulay, 2009). Governments and professional health programs thus need to expand their current efforts in fostering the accreditation of First Nations healthcare providers.

Regarding relationships between healthcare providers and institutions in Ontario, more effort needs to be made to improve the communication and sharing of client information between hospitals, Community Care Access Centres (CCACs), physicians, and First Nations community healthcare providers. This lack of communication represents a significant barrier not just to dementia care, but to First Nations healthcare in general. Repairing this difficulty would lead to a greater continuity of care, more optimal care, and a more effective use of healthcare provider resources.

3.4 Conclusion

This study represents a good first step towards understanding dementia in the First Nations population. In order to continue filling this gap in knowledge, further studies need to be conducted that specifically take the viewpoints of First Nations PWD, their informal caregivers, and community members into account. These studies should take a community-based approach, and researchers should give thought to how trust will be established with the community prior to study inception. Current First Nations dementia care can be improved if policy makers and health educators commit to creating a body of First Nations-specific dementia care literature and other culturally appropriate care resources. Further, health administrators need to work to remove barriers to knowledge by improving communication between healthcare organizations.

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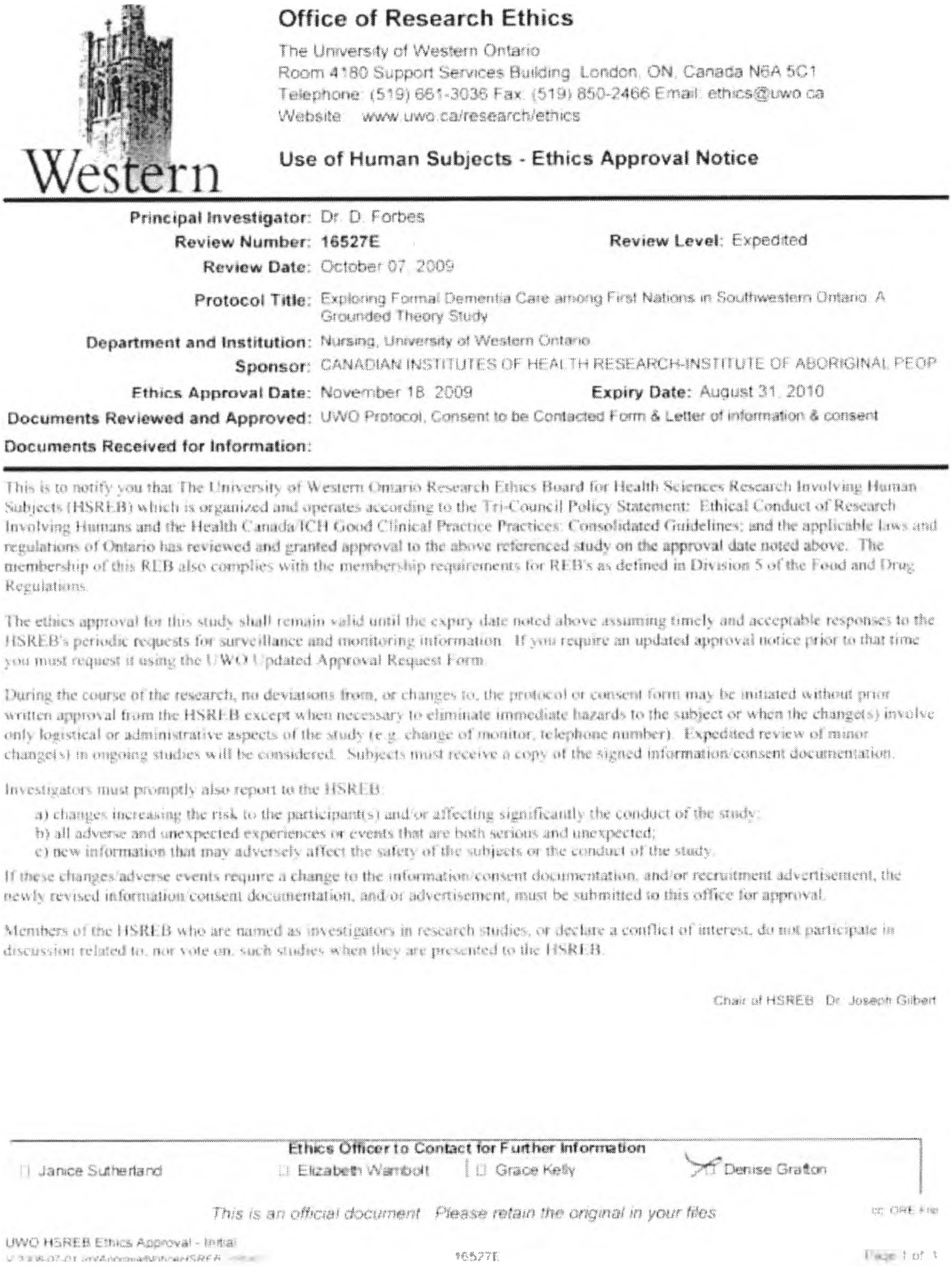
Appendices

APPENDIX A Ethical Approval



Western

Office of Research Ethics

The University of Western Ontario
Room 4180 Support Services Building London, ON, Canada N6A 5C1
Telephone: (519) 661-3036 Fax: (519) 850-2466 Email: ethics@uwo.ca
Website: www.uwo.ca/research/ethics

Use of Human Subjects - Ethics Approval Notice

Principal Investigator: Dr. D. Forbes

Review Number: 16527E **Review Level:** Expedited

Review Date: October 07, 2009

Protocol Title: Exploring Formal Dementia Care among First Nations in Southwestern Ontario: A Grounded Theory Study

Department and Institution: Nursing, University of Western Ontario

Sponsor: CANADIAN INSTITUTES OF HEALTH RESEARCH-INSTITUTE OF ABORIGINAL PEOP

Ethics Approval Date: November 18, 2009 **Expiry Date:** August 31, 2010

Documents Reviewed and Approved: UWO Protocol, Consent to be Contacted Form & Letter of information & consent

Documents Received for Information:

This is to notify you that The University of Western Ontario Research Ethics Board for Health Sciences Research Involving Human Subjects (HSREB) which is organized and operates according to the Tri-Council Policy Statement: Ethical Conduct of Research Involving Humans and the Health Canada/ICH Good Clinical Practice Practices: Consolidated Guidelines; and the applicable laws and regulations of Ontario has reviewed and granted approval to the above referenced study on the approval date noted above. The membership of this REB also complies with the membership requirements for REB's as defined in Division 5 of the Food and Drug Regulations.

The ethics approval for this study shall remain valid until the expiry date noted above assuming timely and acceptable responses to the HSREB's periodic requests for surveillance and monitoring information. If you require an updated approval notice prior to that time you must request it using the UWO Updated Approval Request Form.

During the course of the research, no deviations from, or changes to, the protocol or consent form may be initiated without prior written approval from the HSREB except when necessary to eliminate immediate hazards to the subject or when the change(s) involve only logistical or administrative aspects of the study (e.g. change of monitor, telephone number). Expedited review of minor change(s) in ongoing studies will be considered. Subjects must receive a copy of the signed information/consent documentation.

Investigators must promptly also report to the HSREB:

a) changes increasing the risk to the participant(s) and/or affecting significantly the conduct of the study;
b) all adverse and unexpected experiences or events that are both serious and unexpected;
c) new information that may adversely affect the safety of the subjects or the conduct of the study.

If these changes/adverse events require a change to the information/consent documentation, and/or recruitment advertisement, the newly revised information/consent documentation, and/or advertisement, must be submitted to this office for approval.

Members of the HSREB who are named as investigators in research studies, or declare a conflict of interest, do not participate in discussion related to, nor vote on, such studies when they are presented to the HSREB.

Chair of HSREB: Dr. Joseph Gilbert

Ethics Officer to Contact for Further Information

☐ Janice Sutherland ☐ Elizabeth Wambolt ☐ Grace Kelly ☑ Denise Grafton

This is an official document. Please retain the original in your files.

cc: ORE File

UWO HSREB Ethics Approval - Initial
[illegible]

16527E

Page 1 of 1

APPENDIX B Letter of Information/Participant Consent Form

Western
Health Sciences

Letter of Information/Participant Consent Form

Please read this letter carefully and feel free to ask questions or relay concerns about any aspect of the research study.

Because you have engaged with First Nations patients with dementia, you are invited to participate in a research project titled *Exploring Formal Dementia Care among First Nations in South-western Ontario: A Grounded Theory Study.*

Sponsor: Indigenous Health Research Development Program (IHRDP) Graduate Scholarship and Research Support, funded by the Canadian Institutes of Health Research-Institute of Aboriginal People's Health

Researcher:
Sara Finkelstein, B.Sc., M.Sc. Student
Health & Rehabilitation Sciences, Faculty of Health Sciences
School of Graduate and Postdoctoral Studies
University of Western Ontario

Thesis supervisor and Principal Investigator:
Dorothy A. Forbes, RN, Ph.D.
Associate Professor, Faculty of Health Sciences
University of Western Ontario

Co-investigator:
Chantelle Richmond, Ph.D.
Assistant Professor, Department of Geography and First Nations Studies
University of Western Ontario

Objectives and Procedure:
The goal of this research project is to explore and understand the experiences of health care professionals in assessing, diagnosing, treating, and caring for First Nations dementia patients. In doing so, it is the researcher's hope that this will provide helpful information and insight to health care professionals and community health care programmers in working with and creating programs for First Nations dementia patients in the London community.

You are invited to participate in two interviews, to share your experiences and perspectives on the question above. You may also be invited to participate in a third and even fourth interview to contribute additional depth to information or review findings from the study. The interviews will be held in a private room at the Southwest Ontario Aboriginal Health Access Centre (SOAHAC) in London or at the University of Western Ontario, depending upon room availability and what is most convenient for you. The interviews are each expected to last 1-1.5 hours. Interviews will be recorded and then transcribed. Should you speak of specific patients during the interview, pseudonyms will be used for these individuals and for yourself in the interview transcript.

Number of Participants: While the number of participants for the study cannot be known in advance, it is expected that 10-12 participants will participate.

First Nations Community Involvement: Members of the First Nations community and the Southern Ontario Aboriginal Health Access Centre (SOAHAC) will be consulted in developing and refining the interview questions. To disseminate results to the academic community, results will be published in peer-reviewed journals and presented at conferences focused on Aboriginal health and/or seniors' health. To disseminate results with First Nations community members a Knowledge Exchange Network workshop will be held and all interested community members invited to attend. Persons attending the workshop will be consulted regarding the usefulness of research results, future directions of research, and ideas for further dissemination of results.

Potential Risks: There are no known risks associated with participation in this study.

Potential Benefits: The findings of this research may benefit you directly by providing you with more insight regarding your interactions with First Nations dementia patients. This research may also assist health policy makers in and around London, Ontario in ensuring that the most appropriate services are provided to First Nations dementia patients.

Compensation and Costs to Participants: To thank you for your time and as a token of appreciation, you will be entered into a draw to win a $30.00 gift certificate to HMV in return for your participation in this study. To help defray costs, free transportation to and from the interview location will be provided to you upon request. Should you choose to use your own vehicle to get to and from the interview location, parking fees will be reimbursed.

Storage of Data: The data collected during the interview will be stored in password-protected computer files and in a locked filing cabinet at the University of Western Ontario for a minimum of seven years. Contact information sheets and a master sheet linking your initials with your interview data will be stored in locked filing cabinets at the Principal Investigator's office at the University of Western Ontario and will be destroyed at the end of the data collection period.

Anonymity and Confidentiality: Although the findings from this study will be published and presented at conferences, no reported data will contain any identifying participant information, so that it will not be possible to identify individuals. Although quotations from interviews will be utilized, you will be asked to choose a pseudonym by which to be identified. All of the identifying information that you provide, such as contact information, will be kept confidential.

Right to Withdraw: Participation in this study is voluntary. You may refuse to participate, refuse to answer any questions or withdraw from the study at any time with no effect on your future (care/ academic status/ employment etc). Should you decide for any reason at any point during the study that you wish to withdraw as a participant, you are free to do so. You also have the right to refuse to answer any questions asked during the interviews. Should you choose to withdraw from participation in the study any data that you have contributed during your interviews will be destroyed.

Publication of results: If the results of the study are published, your name will not be used. If you would like to receive a copy of your interview transcript(s) or the overall results of the study, please include your mailing address where indicated at the end of this document.

Questions: If you have any questions concerning the study, please feel free to contact Sara Finkelstein at the number or email address provided above. This study has been approved on ethical grounds by the University of Western Ontario Research Ethics Board on November 18, 2009 and the Board of Directors at the Southwest Ontario Aboriginal Health Access Centre (SOAHAC) on October 27, 2009. If you have any questions about your rights as a research participant or the conduct of the study you may contact the Office of Research Ethics at (519) 661-3036 or email ethics@uwo.ca.

Consent to Participate: I have read the letter of information, have had the nature of the study explained to me and I agree to participate. All questions have been answered to my satisfaction.

(Date) (Name of person obtaining informed consent)

(Name of Participant) (Signature of person obtaining informed consent)

(Signature of Participant)

Do you wish to be forwarded a summary of the results of the study? (Please check box)

☐ **Yes** ☐ **No**

Do you wish to be forwarded a copy of your transcript? (Please check box)

☐ **Yes** ☐ **No**

APPENDIX C Consent To Be Contacted Form

Consent to be Contacted Form

Exploring Formal Dementia Care among First Nations in Southwestern Ontario: A Grounded Theory Study

Principal Investigator:
Dr. Dorothy Forbes, Faculty of Health Sciences, The University of Western Ontario

I agree to provide my name and phone number to Ms. Sara Finkelstein, a research staff member who will contact me to further explain the project and discuss my participation.

Name of potential participant (Print)	Phone number or Email
Signature of potential participant	Date
Name of person obtaining consent (Print)	
Signature of person obtaining consent	Date

APPENDIX D Demographic Questionnaire

Date of Interview: **Interview Pseudonym:**

A. Basic Demographic Information

1) Gender:
[ ] Female
[ ] Male

2) Age range:
[ ] 18-25
[ ] 26-35
[ ] 36-45
[ ] 46-55
[ ] 56-65
[ ] 66-75
[ ] 76+

3) What is your discipline as a healthcare provider (e.g. nurse)?

____

4) Educational background:
List all degrees, diplomas, or certificates currently held:

Degree/Diploma/Certificate	Year Credential Received
______________________	_________
______________________	_________
______________________	_________
______________________	_________

5) How many years have you been practicing as a healthcare provider? _________

B. Employment

1) How long have you held your current employment position? _________________

2) What is your current work setting (e.g. hospital)? __________________________

3) How many years have you worked as a healthcare provider in southwestern Ontario?

____

4) Hours worked in the past year
[ ] Less than 20 hours/week
[ ] Between 20 and 40 hours/week
[ ] More than 40 hours/week

5) What is/are your area(s) of current practice? (Mark *all* that apply)
[ ] Acute care
[ ] Long-term care
[ ] Community health
[ ] Home care
[ ] Primary care
[ ] Administration
[ ] Education
[ ] Research
[ ] Other (please specify) ____________________________

6) In what area of practice do you spend the most time? ______________________

7) What hours of the day do you usually work (e.g. 9 AM – 5 PM)?

____

C. Practice

1) What is the approximate proportion of patients/clients with dementia that you have cared for in the past year?
[ ] Less than 10%
[ ] 10-25%
[ ] 25-50%
[ ] 50-75%
[ ] More than 75%

2) Approximately what number of First Nations persons with dementia have you cared for in the past…
…12 months? ______
…5 years? ______
…10 years? ______

3) Do you ever make use of interpreters (family members/friends or professionals) in your interaction with patients/clients?
[ ] Yes
[ ] No

APPENDIX E Interview Guide

Interview Questions

Tell me about your professional background:

- How long have you been working for…?
- Prior to your current position, where were you working?
- Have you ever worked in or with a First Nations community in the past?

Tell me about your practice:

Probes:

- How prevalent an issue is dementia among your First Nations patients/clients?
- How prepared do you feel in working with First Nations patients/clients with dementia and their family caregivers?
- Tell me about the dementia resources/educational materials that you know of that are available/not available to you?
    - Tell me about culturally appropriate resources that you know of that are available/not available to you?
    - Which of these dementia resources have you accessed?

Tell me about some of your first encounters with First Nations patients/clients with dementia:

Probes:

- Typically, what is the initial reason for your contact with First Nations persons with dementia?
- When you first encounter patients/clients, what is the typical severity of their dementia symptoms (e.g. memory loss)?

Do you screen for dementia?

→ IF YES:

Tell me about the process of diagnosing dementia in First Nations patients/clients:

Probes:

- In your experience, is it typically patients/clients, their families, or you the healthcare provider who suggests the possibility of dementia?
- How do you approach explaining the possibility of dementia to patients/clients?
- What is your approach to diagnosing dementia?
- Once a diagnosis of dementia is made, how do you explain this diagnosis to patients/clients?
- What, if any, are some of the barriers you have encountered to diagnosing dementia? (e.g. geographic, language, cultural, etc.)
- What is your experience like during the process of diagnosing dementia?
- What are some of the perceived responses of patients/clients to a diagnosis of dementia?

→ IF NO:

- If you suspect patients/clients have dementia, do you typically refer them to another healthcare provider for diagnosis?
- Tell me about the process of referring a patient/client to another healthcare provider due to suspected dementia?
- What, if any, are some barriers you encounter in ensuring that your patients/clients are properly referred?
- Once you have referred the patient/client, what is your level of involvement in their care regarding dementia?
- Tell me about some of your experiences liaising with other healthcare providers with regards to a First Nations PWD?

Tell me about the process of treating and caring for First Nations persons with dementia:

- Please tell me about your discussions with patients/clients and/or their families regarding treatment/care options.
- What types of treatment/care do you usually recommend?

- Please describe the treatment/care you typically provide for patients/clients. When you see them, what is your routine?
- What, if any, are some barriers you've encountered to providing treatment/care for your patients/clients with dementia?
- What are some of your experiences with compliance regarding treatment/care?
- In general, how often do your patients/clients express a desire for traditional healing or other treatments/care?
- To your knowledge, how common is it for your patients/clients to receive traditional healing in addition to biomedical treatment/care for dementia?

Tell me about your overall experience of working with First Nations persons with dementia:

Probes:

- Please describe a good experience.
- Please describe an experience that did not go well.
- Tell me about your most significant/meaningful moment working with a PWD.
- Have you learned anything as a result of working with First Nations PWD?
- Has there been any impact on the way you run your practice as a result of working with First Nations persons with dementia?
- In general, do you notice significant differences in your interactions with First Nations and non-First Nations persons with dementia?
- Tell me about the progression of your relationship with your First Nations PWD.
- Are there any special considerations you keep in mind when working with a First Nations person with dementia?

Tell me about some of the typical issues encountered when caring for a First Nations person with dementia:

- How do you typically handle the disclosure of information regarding diagnosis, treatment, and care?
- Do you ever encounter any language barriers when working with First Nations persons with dementia? If so, tell me about some of your experiences.

- Do you ever encounter any nutrition problems with your First Nations PWD? If so, tell me about some of your experiences.
- How do you typically handle legal issues such as driving and medical imperatives with First Nations PWD?
- Do you ever encounter problems with medical transportation for your patients/clients? If so, tell me about some of your experiences.
- Are there any other issues you typically run into when caring for a First Nations person with dementia?

Tell me about your experiences and encounters with the families and friends of your First Nations PWD:

- Who usually accompanies your patients/clients to appointments?
- What contact do you typically have with family members and friends of your patients/clients with dementia? What role do they play in caring for the person with dementia?
- Please describe a good experience interacting with a patient/client's friend or family member.
- Please describe a negative experience interacting with a patient/client's friend or family member.
- Do you ever have to care for family members, as a result of them having a loved one with dementia (i.e. caregiver stress)? If so, tell about some of your experiences.
- Tell me about your most significant moment interacting with a friend or family member of a patient/client.
- Has there been any impact on the way you run your practice as a result of working with friends/family members of patients/clients with dementia?
- In general, do you notice significant differences in your interactions with the family members/friends of First Nations and non-First Nations persons with dementia?
- Tell me about the progression of your relationship with a patient/client's family or friend caregiver.

Others have told me…Has this been your experience?

Is there anything else that you would like to tell me?

APPENDIX F Field Note Guide

Interview Field Notes

Participant Code:

Interview Date:

Starting Time:

Ending Time:

Location of interview:

Technical Problems (e.g., timing of interview, tape recorder):

People present:

Pre - interview goals for interview:

Description of environment:

Researcher's impressions (e.g., discomfort of participant with certain topics, emotional responses to people, events or objects):

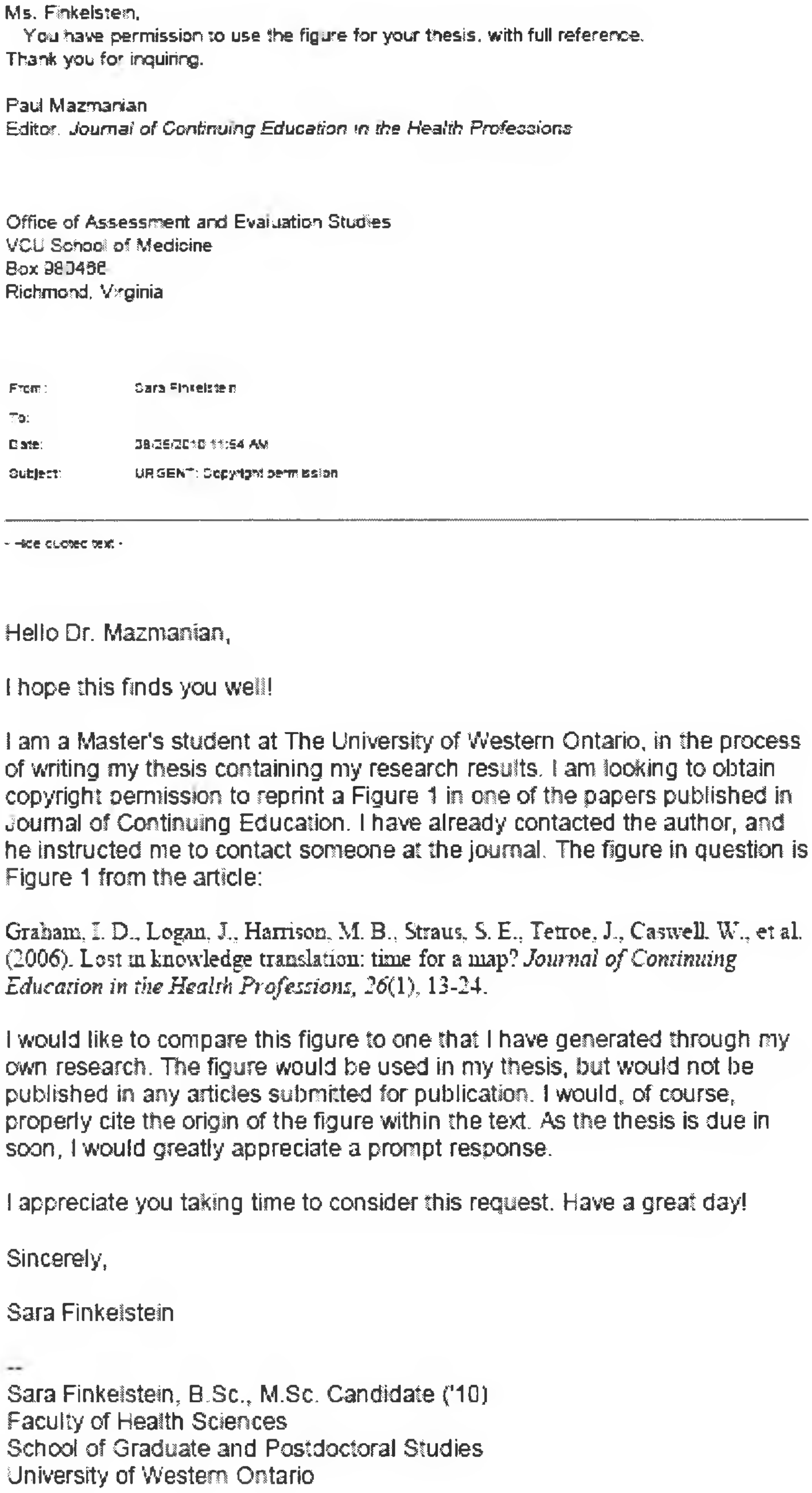
Nonverbal behavior (e.g., tone of voice, posture, facial expression, eye movements, forcefulness of speech, body movements, and hand gestures):

Analysis: (e.g., researcher's questions, tentative hunches, trends in data and emerging patterns, insights, interpretations, beginning analysis, working hypotheses):

Additional Notes:

Adapted from:
Morse, J., & Field, P. (2002). *Nursing Research: The Application of Qualitative Approaches* (2nd ed.). Cheltenham, UK: Nelson Thornes Ltd.

APPENDIX G Copyright Permission: Knowledge to Action Process (Figure 2)



Ms. Finkelstein,
You have permission to use the figure for your thesis, with full reference.
Thank you for inquiring.

Paul Mazmanian
Editor, *Journal of Continuing Education in the Health Professions*

Office of Assessment and Evaluation Studies
VCU School of Medicine
Box 980466
Richmond, Virginia

From: Sara Finkelstein
To:
Date: 03/25/2010 11:54 AM
Subject: URGENT: Copyright permission

- Hide quoted text -

Hello Dr. Mazmanian,

I hope this finds you well!

I am a Master's student at The University of Western Ontario, in the process of writing my thesis containing my research results. I am looking to obtain copyright permission to reprint a Figure 1 in one of the papers published in Journal of Continuing Education. I have already contacted the author, and he instructed me to contact someone at the journal. The figure in question is Figure 1 from the article:

Graham, I. D., Logan, J., Harrison, M. B., Straus, S. E., Tetroe, J., Caswell, W., et al. (2006). Lost in knowledge translation: time for a map? *Journal of Continuing Education in the Health Professions, 26*(1), 13-24.

I would like to compare this figure to one that I have generated through my own research. The figure would be used in my thesis, but would not be published in any articles submitted for publication. I would, of course, properly cite the origin of the figure within the text. As the thesis is due in soon, I would greatly appreciate a prompt response.

I appreciate you taking time to consider this request. Have a great day!

Sincerely,

Sara Finkelstein

--
Sara Finkelstein, B.Sc., M.Sc. Candidate ('10)
Faculty of Health Sciences
School of Graduate and Postdoctoral Studies
University of Western Ontario