

**Negotiating Culturally Incongruent Healthcare Systems: The Process
of Accessing Dementia Care in Northern Saskatchewan**

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for the Degree of Master of Science
in the College of Community Health and Epidemiology
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Abstract

This study is an exploration of the process of accessing dementia care for Aboriginal Older Adults living in Northern Saskatchewan. The research question for this project was, “What is the process of accessing formal healthcare for dementia from the perspective of Northern Saskatchewan Aboriginal communities, and what factors specifically impede or encourage accessing formal care?”

Grounded theory methodology informed the research process. Theoretical sampling resulted in a sample of thirty participants. Data were generated through eighteen in-person, semi-structured interviews; two in-person, semi-structured group interviews; and three focus group discussions including a directed activity led by participants. Analysis of data using the grounded theory constant comparison method led to an emergent theory that was verified by research participants.

The theory that emerged explains the basic social process at the heart of the research question. The grounded theory, “The process of negotiating culturally incongruent healthcare systems” explains the access to and use of formal healthcare from the perspective of those living in Northern Saskatchewan. Specific attention to the social context of healthcare access helped to illuminate the challenges faced by Aboriginal Older Adults when accessing healthcare services. The findings indicate a need for enhancing the cultural competence of healthcare provision to Older Adults with dementia in Northern

Saskatchewan while providing formal support for those persons with dementia as well as for their informal caregivers.

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Chapter One: Introduction

Relevance

With approximately 38% of Canadian and 62% of Saskatchewan residents living in rural and remote areas, delivery of healthcare services in rural and remote areas is a very pertinent area of investigation (1).

Estimates from the Canadian Study of Health and Aging indicate that as of 2005, there are 420,600 persons living with dementia in Canada, a number that is predicted to double in the next thirty years (2). These demographics point to a clear need for exploring new approaches to diagnosing and treating persons with dementia in rural and remote Saskatchewan, particularly for Northern Saskatchewan, an area that is often overlooked.

Previous research has identified barriers to the use of healthcare services for dementia by those in rural areas of southern and central Saskatchewan including stigma, lack of privacy, beliefs and attitudes concerning dependence and care, travel difficulties, lack of awareness of services, financial restraints, and problems of accessibility and acceptability of existing services (3). However, these issues have not been explored in Northern Saskatchewan, nor specifically with Aboriginal Older Adults. Currently, very little is known about Aboriginal Peoples' experiences with accessing healthcare specific to dementia, especially in Northern Saskatchewan. This population demographic is growing and a

need for healthcare specific to dementia has been noted by Northern Saskatchewan healthcare providers (4).

This research sought to investigate the factors that influence the process of accessing dementia care by residents in Northern Saskatchewan, with a specific focus on Aboriginal Older Adults. Sociocultural, political, and historical contexts that emerged prior to and during the research process, as well as logistic issues, are examined in light of their effects on healthcare access. By studying factors that impede as well as factors that promote dementia healthcare access, service provision can be improved to incorporate the needs of Northern Saskatchewan residents while enhancing the capacity of local communities.

Background to the Research Project

The idea for this proposed research grew out of my experience with the New Emerging Team (NET) project “Strategies to Improve the Care of Persons with Dementia in Rural and Remote Areas” (Principal Investigator: Debra Morgan, Institute of Agricultural, Rural, and Environmental Health). This five year project was awarded funding by Canadian Institutes of Health Research (CIHR) and partners in 2003. The primary project within the NET study involves the development, implementation, and evaluation of a Rural and Remote Memory Clinic. The clinic involves a one-day, streamlined multidisciplinary assessment in Saskatoon and pre-clinic assessment and follow-up using telehealth

videoconferencing in the patient's home community or nearest telehealth site, thereby minimizing travel burden. The project brings together a diverse mix of highly skilled and experienced individuals to address the diagnosis, treatment, and supportive care of patients and families living with dementia in rural and remote Saskatchewan.

During the initial development phase of the NET projects in 2003-2004, I traveled with the team to each of the fourteen rural and remote communities serviced by the Saskatchewan Telehealth Network to discuss the research and clinic plans. Valuable information and insight was given by local formal and informal care providers at each of the visits, particularly those in Northern Saskatchewan. Previously, Drs. Kirk and Crossley, the clinic neurologist and neuropsychologist with longtime practices in Saskatoon, have received very few referrals for Northern Saskatchewan residents, particularly for Aboriginal Older Adults. Very little is reported in literature regarding dementia in this population. Though awareness of the challenge of providing dementia care to rural populations is increasing, this is an area that has typically been overlooked for remote and Northern populations.

During the Northern community visits, the team learned of a number of factors that may affect use of healthcare services for dementia, including cost, lack of public transportation, difficulty in traveling long distances, language barriers, cultural barriers, and varying attitudes towards dementia (4). Community care providers indicated a

need for dementia care services within Northern communities and reported numerous cases of probable dementia, both past and present. This research project developed out of the community visits; community care provider input pointed to a need for a directed study examining the specific barriers and challenges to accessing diagnosis and care for dementia by those living in Northern Saskatchewan. The discussions with community members and healthcare providers indicated a need for a postcolonial examination of not only the barriers to access but of the underlying structural inequities that create and perpetuate these barriers. By respectfully privileging the voices and opinions of those who are affected by dementia in Northern Saskatchewan this research contributes to the body of knowledge from a unique perspective.

Purpose Statement

The aim of this research was to explore the systemic and personal characteristics that influence the access to and experience of formal dementia care for Northern Saskatchewan residents with a particular focus on Aboriginal Older Adults. Using grounded theory methodology, the purpose of this research was to examine the factors that influence accessing and using formal healthcare systems for dementia. The research question for this study was: “what is the process of accessing formal healthcare for dementia from the perspective of Northern Saskatchewan residents, and what factors specifically impede or facilitate accessing formal care?” For this study, formal healthcare is

broadly defined as any feature of healthcare systems involved in diagnosing, supporting, or providing care.

Chapter Two: Literature Review

Rural and Remote Healthcare

“If there is a two-tiered medicine in Canada, it’s not rich and poor, it’s urban versus rural.”(5, p.193) There is a growing body of evidence that, in terms of health, those from rural and remote areas are at a disadvantage compared with those from urban centers. With approximately 38% of Canada’s and 62% of Saskatchewan’s population living in rural and remote areas, this is of extreme concern to those interested in healthcare and equitable access. (1) Congdon and Rosswurm state that rural-dwelling people are challenged by “difficult access and distance to health care, acceptability and cultural congruency of care, inadequate transportation, inclement weather, shortages and poor quality of health resources, and poverty.” (6, p.266)

Both the 2002 Kirby report (7) and the 2002 Romanow commission (8) note that access to healthcare is the largest challenge facing rural residents. Indeed,

rural and remote area residents can have access only to a small range of service providers, and if they have to seek more specialized care they must travel long distances and incur additional expenses, which are not fully reimbursed. During some parts of the year, travel may be impossible due to weather conditions, leading to poor health outcomes. (9, p.246)

As well, the report, *Rural Health in Rural Hands*, notes that:

Canadians who live in rural, remote, northern and Aboriginal communities face significantly greater health challenges than those living in urban centers for reasons directly related to where they live, risks associated with their

occupations and the level of access to timely health care. (10, p.7)

The Romanow commission illuminates a troubling fact: “the health of the community also appears to be inversely related to the remoteness of its location.” (8, p.162) That is, the further a community is from an urban center, the more disparity is experienced in terms of health outcomes. “Compared to urban residents, people living in rural, remote and northern communities have shorter life expectancies, higher death rates and higher infant mortality rates.” (10, p.11) Adequate, accessible healthcare is an important factor contributing to this disparity in health status.

This dilemma is not specific to Canada; researchers from the United States echo the plight of rural residents regarding healthcare inequities:

Rural populations and American Indians in particular experience various access barriers to health care services. These include lack of transportation, distance, and lack of comfort in dealing with unfamiliar environments. (11, p.8)

Jervis and colleagues note that the barriers to healthcare access experienced by rural Older Adults are also experienced by rural Older American Indians, but that “these problems are often magnified by extreme poverty and rurality, as well as unique cultural orientations.” (12, p.299)

Slifkin suggests that a discussion of rural healthcare can not be limited to availability of services. Rather, rural health care is

influenced by community perceptions of need and comfort in using a service:

Relative underutilization of certain health care services by rural populations may be attributable to lack of availability but may also stem, in some instances, from a perception that the services are not necessary, even though by some medical standard they are considered needed. (13, p.234)

She further describes three key features that must be understood when evaluating the barriers to care that exist for rural and remote populations:

a) people's perception of what they need or want, b) whether they have the personal resources to obtain those services, and c) whether the services are available in a reasonable distance. Before there is attempted entry into the health care system, individuals make a decision as to whether they need care (on the basis of symptoms and the perception that the condition is serious, or . . . the perception that the services have value) and whether it is felt that there will be a benefit from seeking help. (13, p.234)

With this in mind, the specific needs and wants, as well as the unique features that characterize a rural or remote community must be thoroughly understood in order to accurately assess the access to and use of healthcare services.

While many groups work to combat the disparity between rural and urban healthcare access and use, little is understood with respect to the specific barriers regarding dementia care and Northern Saskatchewan populations. The issues of access and utilization for Northern residents are complex and multi-faceted and warrant specific attention and examination.

Dementia

Alzheimer Disease (AD) is a devastating illness. Over time, the person with the disease is robbed of his or her identity, independence and dignity. He or she eventually becomes incapable of performing the simple tasks of daily living, of remembering recent events, relating to others or controlling thoughts and emotions. For family, friends and caregivers of the person with AD, the burden can be unbearable as they try to cope with the challenges and adjust to the changes in their own lives and that of the patient as the disease progresses. (14, p.2)

Dementia is a chronic progressive syndrome that includes several neurological diseases marked by cognitive decline. Overall prevalence of dementia cases in Canada in 2005 is estimated to be 420,220. (2) The most common form of dementia is Alzheimer's Disease with an estimated prevalence of 279,030 for Canadians in 2005. (2) Dementia can be characterized by progressive memory loss, impaired judgment, and a decreased capacity for abstract reasoning. (15) According to the Diagnostic and Statistical Manual of Mental Disorders, a diagnosis of dementia is warranted when a person exhibits demonstrable evidence of short- and long-term memory impairment accompanied by at least one of the following: impairment in abstract thinking, impaired judgment, disturbances of higher cortical functions (e.g., aphasia, apraxia), or personality change. (16) The major known risk factor for dementia is age, with the risk increasing proportionately with increasing age. (2) Given that Saskatchewan has a large proportion of older adults, there is a clear need to investigate healthcare strategies that address dementia in Saskatchewan.

In 1994, Ostbye and Crosse estimated that \$5.5 billion is spent annually in Canada on dementia health care and caregiving. (17) As well, caregiving for a person who has dementia can be a tremendous mental and emotional burden. (18) Without the use of supportive care services such as homecare, adult day care, dementia support groups and respite, the burden of care can be overwhelming.

Early differential diagnosis is key for treating dementia. Treatments involve pharmaceutical interventions such as anti-dementia drugs (cholinesterase inhibitors, etc) which can help to treat initial symptoms and slow the progression of the disease, and behaviour management strategies for the affected person and his or her caregivers which can reduce stress and burden. The Saskatchewan Alzheimer Strategy purports “early diagnosis provides individuals and their families with the opportunity to plan for the future, to understand the disease and its progression, to receive treatments, to seek support and to promote the potential for a healthy quality of life.” (18, p.7) According to Hinton,

With early detection, reversible causes of cognitive impairment can be identified and treated earlier, improving functioning. The person who is in the early stages of dementia can participate more fully in his or her future. Dementia interventions, both pharmacological and non-pharmacological, are likely to be more effective if begun earlier in the course of the illness. Such interventions contribute to the quality of life for both the person with dementia and the family caregiver, reduce burden in the family, and are likely to delay institutionalization. (19, p.134)

While early diagnosis is recognized as crucial to treatment and management of dementia, it is not a simple or easy process. Current

research indicates “many either ignore or fail to acknowledge early symptoms, coming to services at a much later stage when treatment is limited and carers’ quality of life is reduced.” (20, p.23) The blame does not lie solely with caregivers; attaining a diagnosis of dementia is a complicated process. Teel and Carson investigated the process of seeking a diagnosis of dementia among families living in rural and urban Kansas and report that it often took multiple visits to many types of health practitioners over an extended period of time to achieve a diagnosis and treatment plan. (21) They note that this process is more difficult for those families living in rural areas and having to travel to services, and reported that

... consulting with multiple caregivers over a period of years had significant consequences for family caregivers. They were continually uncertain about the situation and many eventually developed concerns that doctors might be withholding information. [This] left caregivers with feelings of mistrust toward the medical community. (21, p.47)

As well, a diagnosis of dementia may not be sought due to various barriers to healthcare service and specialist care, and to a perception that no treatments for dementia exist. Boneham et al. describe that for elderly people from ethnic minority populations “reasons for under-utilization [of healthcare services] are likely to include the perception among providers and carers that nothing can be done to cure their illness.” (22, p.173)

Aboriginal Health and Dementia

Research has shown that Aboriginal groups have poorer health on average than the non-Aboriginal Canadian population, with a higher

death rate and significantly higher prevalence of many chronic diseases.

(23) While these indicators have shown improvement over time, Aboriginal Canadians still “bear a disproportionate burden of illness.”

(24, p.59) Adelson asserts that the health disparities experienced by Aboriginal people in Canada stem from direct and indirect social and structural inequities. (25) She defines health disparities as “indicators of a relative disproportionate burden of disease on a particular population” and says that to improve health, research must look beyond the disparities to the health inequities which “point to the underlying causes of disparities, many if not most of which sit largely outside the typically constituted domain of ‘health’.” (25, p.S45)

In terms of literature describing the prevalence and experience of dementia in Aboriginal populations, an extensive search revealed very little information on the topic. One exception is an epidemiological study by Hendrie in 1993 that concluded that Native Americans have the lowest prevalence of dementia of all groups in the United States. (26) However, this study investigated a very small homogenous sample and with fewer than 192 people studied, it is problematic to draw strong conclusions.

Jervis and Manson contest Hendrie’s sampling method and argue that early mortality within the American Indian population “may remove individuals from the population who would otherwise be vulnerable to the onset of late-life disorders such as Alzheimer’s disease, and thus contribute to the reduced rates of observation.” (27, p.S91) They state

that health statistics in the United States are a poor gauge of the prevalence of dementia in the American Indian population, noting:

discharge diagnoses and mortality statistics are not precise vehicles for determining [dementia] disease prevalence ... The former are subject to significant selection biases in help-seeking behaviour, reflecting differential availability, accessibility, and acceptability of the offered care. The latter are plagued by well-documented problems of racial misclassification error that typically lead to undercounts of causes of death. (27, p.S90)

A 1998 report from the Care Needs of Ethnic Older Persons with Alzheimer's Project, *Dementia and Minority Ethnic Elders*, concluded "the problem of dementia among [Black and minority ethnic] elders is *hidden* rather than *absent*." (28) This may also be the case for Aboriginal populations in Saskatchewan. In 1996, Kramer noted that the extremely low reported prevalence of Alzheimer's disease "raises questions about possible barriers to diagnosis and limitations of standard screening and diagnostic criteria." (29, p.177) Possibly, a cultural bias inherent in current assessment protocols could serve to misdiagnose Older Adult Aboriginals. It was noted in NET group-community meetings with Northern Saskatchewan healthcare providers in 2003 that dementia is an issue that is under-recognized and under-addressed in northern and Aboriginal populations. (4)

Without understanding the cultural beliefs that shape understandings of dementia among Aboriginal people living in northern Saskatchewan, it is difficult to examine the experience of accessing care

for dementia. That is, culture is a very important aspect of the experience of any disease. “Cultural values, norms, and beliefs are a framework that guides individuals’ interpretation of their sense of well-being and direction in life.” (30) The Assistant Deputy Minister of the First Nations and Inuit Health Branch of Health Canada, Ian Potter states:

To be effective in restoring or maintaining health, services need to embrace the culture of the people they serve. Therefore, culturally appropriate program design and delivery must be a focus for health programs in any community, taking into account local customs, priorities, language, foods, resources, and sensitivities. (31, p.4)

Culture can be defined as “the meanings that develop when individuals or groups interact in [social] relationships.” (32) Agar notes, “culture becomes visible only when differences appear with reference to a newcomer, an outsider who comes into contact with it.” (33, p.5) Culture is not then a static concept, but a dynamic set of principles that is relational and translated between individuals or groups.

Culture isn’t a property of *them*, nor is it a property of *us*. It is an artificial construction built to enable translation *between* them and us, between source and target. It is *intersubjective*, as the jargon says. It needs to be elaborate enough to get the job done and no more elaborate than that. (33, p.6)

In this way, culture is continually negotiated and mediated across social difference. Any one individual simultaneously belongs to multiple cultural groups that interact with each other --- those of ethnic, gender, geographic, social, and professional identity, for example.

Just as there is not a sole defining 'Culture' that characterizes any one person or group, there is not a singular defining 'pan-Aboriginal' culture. Canadian Aboriginal culture is diverse, with many different tribal affiliations and language bases, as well as different geographic locations and urban versus rural versus reserve occupancy. John et al. indicate that in the United States "the cultural construction of dementia varies within and across American Indian tribes in accordance with individually held health beliefs that are part of larger cultural systems." (34, p.39)

It is imperative that any research on dementia and Aboriginal peoples address the cultural aspects influencing perception of disease, and the resultant treatment sought and care provided. In a 2004 Gerontological Society of America publication, *Closing the Gap: Improving the Health of Minority Elders in the New Millennium*, Allery et al. state

Culture is linked to Alzheimer's Disease through interpretation and perception of the illness; the meanings that are assigned to it; the history within the family; local customs surrounding how people have addressed the disease; community views of the disease; and local healing/medical systems that diagnose and treat disease, as well as care for affected individuals. It can be hypothesized that cultural behaviors may influence biological risk through differences in exposures to different lifestyle factors such as diet. (35, p.83 - 84)

A 1998 study of Asian and Pacific Islander Americans and dementia-care by Braun and Browne found that culturally sensitive outreach services must be developed based on "information gathered directly from these groups, not on assumptions or stereotypes about

elderly people of color.” (36, p.271) Similarly, Spack asserts that any healthcare planning must be culturally relevant and respectful in order to be successful with Aboriginal populations. (37) Dilworth-Anderson and Gibson suggest that cultural factors may be a key feature in the under-representation of ethnic minorities at memory-disorder clinics and programs in the United States. (38)

In terms of ethnic minorities and dementia, much research has been done internationally with Black, Asian, and Latino groups. These studies all point to a need for cultural relevance and an incorporation of cultural values into assessment and treatment in order for access barriers to be reduced. (39 - 50) A review by Means, et al. concludes that services for those with dementia are limited in comparison to other health issues and that ethnic minority groups are even more vulnerable as a subset of the already marginalized situation of dementia care. (51) Patel suggests that cultural needs are often addressed only superficially and that a “strategic response to an emerging but an increasingly important issue is urgently needed.” (39, p.24) The lip-service paid to cultural distinction is not enough; Innes argues:

Culturally appropriate services cannot be developed without the willingness of service providers to become culturally competent, which includes the flexibility to address wider issues of culture, ethnicity, and racism. Not only do service providers need to be aware of differences in cultures but also systems and procedures in place that contribute to dissatisfaction among service users. (40, p.28)

Services for dementia care are not only sparse, but often inaccessible due to cultural incongruence between service users and providers. In a study of Asian elders with dementia living in the United Kingdom, St. John notes “the lack of awareness among professionals about lifestyles, health, religious and cultural needs of minority communities can deter people from approaching services” (20, p.23)

Both the 2002 Kirby report and 2002 Romanow commission pay specific attention to the situation faced by Aboriginal populations with regard to health care in general. (7,8) The Kirby report recommends that the federal government increase funding to support research in the area of Aboriginal health, and include Aboriginal people in the process to strengthen community capacity, in order to improve the health of Aboriginal Canadians. (7) With regard to the specific needs of culturally sensitive and appropriate services for ethnic minority groups with dementia, a project examining Northern Saskatchewan Aboriginal health and dementia is both timely and purposeful.

Chapter Three: Methodology

The purpose of this study was best addressed using the methodologies of qualitative inquiry. Qualitative methods are “inductive, holistic, emic, subjective, and process-oriented research methods used to understand, interpret, describe and develop theory pertaining to a phenomenon or setting.” (52, p.243) The methodology that informs this project is grounded theory. Grounded theory, originally developed by Barney Glaser and Anselm Strauss, allows the researcher to “discover what is going on, rather than assuming what should be going on.” (53, p.159) Grounded theory is an inductive form of inquiry where a detailed exploration can identify theoretical explanations of phenomena rooted or grounded in social context. Grounded theory methods “provide a set of inductive steps that successfully lead the researchers from studying concrete realities to rendering a conceptual understanding of them.” (54, p.311)

This project follows the methodology of grounded theory advocated by Kathy Charmaz. Charmaz espouses a constructivist grounded theory, acknowledging the researcher’s involvement in shaping the research and co-constructing the data. (55) Constructivist grounded theory is rooted in symbolic interactionism, “a perspective that places great emphasis on the importance of meaning and interpretation as essential human processes.” (56, p.75) Blumer, known for his contributions to the

development of symbolic interactionism theory, has identified three premises requisite of a symbolic interactionist stance:

First, human beings act toward the physical objects and other beings in their environment on the basis of the meanings that these have for them. Second, these meanings derive from the social interaction (communication, broadly understood) between and among individuals... Third, these meanings are established and modified through an interpretive process. (57, p.233)

Denzin argues that the concept of symbolic interactionism must be expanded to incorporate perspectives from feminist and cultural studies in which “interacting individuals connect their lived experiences to the cultural representations of those experiences.” (58, p.74) Strickland notes that grounded theory is a culturally appropriate method for “. . . advancing understanding and meeting health needs of American Indian communities.” (59, p. 524) A postcolonial feminist lens compliments the symbolic interactionist underpinnings of grounded theory.

Charmaz’s constructivist grounded theory accounts for postcolonial feminist epistemological considerations of cultural and contextual influences of multiple realities. Central to grounded theory are the tenets: “participants are the experts about their experience and subjective experience is valid data.” (60, p.128) Wuest argues that this contextual and relational nature of knowledge, central to feminist praxis, is a “characteristic inherent in grounded theory that discovers social process within social structure.” (60, p.128) This research is feminist in the examination of inequalities and gender as legitimate factors shaping

participants' realities and in the attention to the potentially devaluing and oppressive nature of research. It is postcolonial in the attention to:

a) issues of partnership and “voice” in the research process, b) a commitment to redressing inequities through praxis-oriented inquiry, c) understanding how continuities from the past shape the present context of health and health care, and d) the colonizing potential of research to perpetuate unequal relations of power and control. (61, p.19)

Postcolonial research strives to “locate health and social conditions in the domain of the historical and structural disadvantages that shape them.” (61, p.31) Throughout the research process I attended to the underlying systemic and historical conditions that influence current access and use of healthcare services for dementia. Without a postcolonial lens, an examination of the barriers to dementia services in Northern Saskatchewan would be cursory at best.

This grounded theory research study took place with 30 participants within four Northern Saskatchewan Aboriginal communities. Data were generated through individual interviews, group interviews, and focus group discussions.

Setting

Research that is inherently feminist “contends that an understanding of ... social and environmental contexts, as well as those of the researcher ...is essential.” (62, p.428) Grounded theory research requires an adequate framing of the research setting “to describe the social world studied so vividly that the reader can almost literally see and

hear its people.” (63, p.56) With this in mind, a description of the communities where the research participants live and work is warranted.

Field visits were made to engage in research with participants. For the purpose of this project I traveled to four communities within the Keéwatin Yatthe Regional Health Authority (RHA) of the province of Saskatchewan: Île-à-la-Crosse, Beauval, Buffalo Narrows, and English River First Nation. Maps illustrating the locations of these communities are included in Appendix A. The population of these Northern Saskatchewan communities is predominantly Aboriginal.

The term Aboriginal includes three distinct groups, with unique heritages, languages, cultural practices and spiritual beliefs: 1) Indians, now commonly referred to as First Nations, Status, and non-Status as determined by the *Indian Act*, living on reserve and off reserve; 2) Inuit people; and 3) Métis people. (10, p.48)

The four communities included in this study are mainly First Nations and Métis, with Métis defined as those “of mixed First Nations and European ancestry”. (10, p.48)

Population characteristics according to the Statistics Canada 2001 census data (64) and the 2001 Aboriginal Peoples Survey (65) are summarized in the following table (with the exception of English River First Nation as census data was not available for the categories of interest):

	Île-à-la-Crosse	Beauval	Buffalo Narrows	Total Saskatchewan
Population in 2001	1268.0	843.0	1137.0	978,933.0
Total private dwellings	421.0	278.0	452.0	431,628.0
Population density per square kilometer	53.2	125.6	33.3	1.7
Land area (square kilometers)	23.8	6.7	34.1	651,036
Total population Age 65 and older	90.0 (7.1%)	45.0 (5.3%)	60.0 (5.3%)	147,565.0 (15.0%)
Median age of total population	22.0	21.7	25.7	36.7
Population identifying as Aboriginal	1215.0 (95.8%)	790.0 (93.7%)	1010.0 (88.8%)	130,190.0 (13.3%)
Population identifying as non-Aboriginal	40.0 (3.1%)	50.0 (5.9%)	130.0 (11.4%)	832,960.0 (85.1%)
Employment rate	36.3%	45.3%	52.6%	58.0%
Unemployment rate	29.6%	18.6%	19.8%	5.7%
Median household income of all households	\$25,920.0	\$30,656.0	\$31,680.0	\$40,251.0
Population reporting unpaid care to seniors	315.0 (24.8%)	160.0 (18.9%)	325.0 (28.6%)	165,260.0 (0.17%)

Table 1: Population Demographics by Community

Île-à-la-Crosse is a community of primarily Métis people in northwestern Saskatchewan, approximately a five-hour drive from Saskatoon. The community includes a 46 bed hospital with 12 level two long-term care beds, a medical clinic, public health offices, two churches, a community centre, a public library and a school. In terms of population demographics, approximately 5% of the Aboriginal population

of Île-à-la-Crosse is over the age of 65, compared with the Saskatchewan provincial Aboriginal population average of 3%. (64, 65)

Beauval is located approximately 400km north of Saskatoon. The town has a health center, school, library, church, and community centre. Approximately 4.0% of the Aboriginal population of Beauval is over the age of 65 in comparison to the Saskatchewan provincial Aboriginal population average of 3.0%. (64, 65)

Buffalo Narrows is located approximately a one-and-a-half hour drive northwest of Île-à-la-Crosse. The community has a health center, the Keéwatin Yatthe RHA offices, school, library, churches, and community centre. Approximately 4% of the Aboriginal population of Buffalo Narrows is over the age of 65, in comparison to the Saskatchewan provincial Aboriginal population average of 3.0%. (64, 65)

English River First Nation is located alongside the township of Patuanak, approximately a one-and-a-half hour drive north of Beauval. According to 2001 census data, there are approximately 435 people living in English River and of those, 94% are Registered Indians. The community has a health center, band offices, school, library, church, and recreation complex. Seven percent of the Aboriginal population of English River is over the age of 65 compared to the Saskatchewan provincial Aboriginal population average of 3.0%. (64, 65)

The following table summarizes community demographic information from the 2001 Aboriginal Peoples Survey. (65) Again,

information specific to English River First Nation is not available as the community did not participate in the survey.

	Île-à-la-Crosse	Beauval	Buffalo Narrows
Total Aboriginal population	1210	790	1010
Total Aboriginal population >15 years old	740	480	660
Persons identifying as North American Indian	70	60	100
Persons identifying as Métis	680	430	560
Adult population that did not complete highschool	55.9%	55.2%	42.2%
Adult population that attended a Federal Residential School	18.0%	10.0%	10.0%
Adult population with family members who attended a Federal Residential School	60.0%	50.0%	70.0%
Adult population that speaks or understands an Aboriginal language	92.0%	79.0%	55.0%
Adult population that use Aboriginal language at home most of the time	57.0%	53.0%	25.0%
Unemployment rate	32.4%	21.2%	23.2%
Adult population that has always lived in the same city, town, or community	79.0%	73.0%	73.0%
Adult population with a long-term health condition as diagnosed by a professional	39.4%	36.4%	37.1%

Table 2: Aboriginal Population Demographics by Community

Approval and Consent Process

The research was limited to a specific geographic location bounded by the Keéwatin Yatthe Regional Health Authority. A written overview of the project was provided to the CEO of the Keéwatin Yatthe RHA which she then presented at a RHA Board meeting. The RHA Board approved the project and gave permission to conduct research within the healthcare organizations of the RHA. The RHA's letter of support for the

project is appended (Appendix B). Ethical and operational approval was also sought from Meadow Lake Tribal Council (MLTC) prior to beginning the project, as English River First Nation falls under MLTC jurisdiction. Oral approval from the Tribal Council was granted and a statement attesting to that was faxed to the researcher and supervisor. After discussion of the project via telephone, oral approval and support was given by the Health Director for the English River Health Center. Ethical approval of the research project was granted by the University of Saskatchewan's Office of Research Services, Behavioural Research Ethics Committee (Appendix C).

Informed consent was obtained prior to conducting research with each of the participants. At each point of contact during data collection, written consent was provided by the participant prior to engaging with the researcher. The consent forms were read by the researcher and participant and then discussed before authorizing. Different consent forms for individual interviews and group interviews or focus group discussions were used. For group interviews and focus group discussions, the consent form emphasized my relative inability to control the security of information provided within a group setting. Copies of the consent forms are appended (Appendix D and E).

Research Participants

Because of the difficulty in identifying informal caregivers of someone with dementia in advance of visiting communities, participants

were identified as those who had experience with dementia care formally within the healthcare system. The scope of the research eventually grew to include participants with experience caring for those with dementia in a personal capacity as well as professionally. Research participants were initially recruited from the key informant contact list developed at the NET Rural and Remote Memory Clinic community planning meetings held in Île-à-la-Crosse on October 23, 2003 and September 1, 2004, and in Beauval on October 23, 2003 and September 2, 2004. At those meetings, attendees were given the option to provide contact information for further involvement with the project. For the communities which the NET had not previously visited, specifically Buffalo Narrows and English River, discussions with Community Health workers took place to initially find participants. During field visits to each community, research participants volunteered or were referred by other participants. I identified specific questions and subjects of interest and, based on these, participants with experience in the particular area were suggested by community contacts or by other participants.

Theoretical sampling method was employed to seek participants who had experience with dementia care, either formally as a healthcare professional or informally. Theoretical sampling refers to the process of “seeking and collecting pertinent data to elaborate and refine categories.” (55, p.96) Charmaz, 2000, notes “the aim of this sampling is to refine ideas, not to increase the size of the original sample. Theoretical

sampling helps us identify conceptual boundaries and pinpoint the fit and relevance of ...categories.” (66, p.519) Rather than seeking a representative sample of formal and informal caregivers of Aboriginal Older Adults with dementia, this type of sampling is used to develop an emerging theory and clarify gaps in the data.

Theoretical sampling continued to the point of theoretical saturation, defined as the point at which “gathering fresh data no longer sparks new theoretical insights, nor reveals new properties of your core theoretical categories.” (55, p.113) “Saturation tends to be an elastic category that contracts and expands to suit the researcher’s definitions rather than any consensual standard.” (54, p.325) Originally, saturation was anticipated at between 15 and 25 participants. This estimate was based on the approximate number of participants sampled in other grounded theory studies. In this study, theoretical saturation was reached with 30 participants and was defined as the point at which the grounded theory was fully developed and no new information, no further depth, and no clarification of emergent properties was gained through contacting other participants. Saturation likely occurred prior to 30 participants being sampled but, since this was my first independent grounded theory investigation, I intentionally sampled more participants than theoretically necessary in order to enhance my confidence with the analysis and the emergent theory.

In the interests of protecting the privacy of research participants, information will be presented only in a delimited, non-identifiable manner. That is, identifying information such as specific profession cannot be listed alongside participants from each community as it could lead to identification of the individual. Instead, generic descriptions with little identifying information are provided.

Participants included informal care providers and formal healthcare workers including nurses, homecare workers, mental health workers, travel coordinators, physicians, and community health representatives. Of the thirty participants, eight were from Île-à-la-Crosse, thirteen from Buffalo Narrows, four from Beauval, and five from English River. In terms of ethnicity, twenty-two participants were Aboriginal (fourteen identified as First Nations and eight as Métis) and eight were non-Aboriginal. Of the non-Aboriginal participants, all but one had worked in Northern Saskatchewan for more than five years. Twenty-nine of the thirty participants were women.

The multiple roles occupied by Northern healthcare providers are illustrated in the fact that five of the twenty-eight formal care provider participants had personal experience caring for a loved one with dementia. Two participants were informal caregivers who did not work within the formal healthcare system. Formal care providers occupy a good vantage as they are professionally familiar with the issues faced when accessing dementia care through the formal system. Informal

caregivers attested to the personal experience of interacting in the formal care system, while those who were both formal and informal caregivers informed the interplay of personal and system, insider and outsider. The following is a table that summarizes the characteristics of participants and delineates the overlapping roles of the participants:

Participant Characteristic	N	%
Participants who are women	29	96.7%
Participants identifying as Aboriginal	22	73.3%
Participants identifying as First Nations	14	46.7%
Participants identifying as Métis	8	26.7%
Participants who work in healthcare	28	93.3%
Participants with personal experience caring for a loved one with dementia	7	23.3%

Table 3: Summary of Participant Characteristics

Each participant was given a satin sachet handmade by Dr. Crossley from the NET team, her student, and myself. The sachet was filled with flavoured tea as a gift to express gratitude for the time spent reflecting on and sharing experiences for the purpose of this project.

Researcher as Instrument

In qualitative research the researcher serves as an instrument of data collection and interpretation. Positionality or situatedness are important factors to consider in such a study; Lincoln argues that “a text that displays honesty or authenticity ‘comes clean’ about its own stance and about the position of the author. Detachment and author objectivity

are barriers to quality, not insurance of having achieved it.” (67, p.280)
It is then crucial to consider the qualifications and background of the researcher undertaking this project.

I am a registered dietitian with a Bachelor of Science degree in Nutrition and a Bachelor of Arts degree in Women’s and Gender Studies. As such, I have a strong foundation in health science and social science allowing me to undertake a project that bridges aspects of health, healthcare and socio-political conditions. I possess a working knowledge of rurality and healthcare as I was raised on a farm in southwest Saskatchewan. I have a diverse healthcare background including two years of employment in rural Saskatchewan where my responsibilities included care at a long-term care facility for dementia residents. I have worked as a Research Assistant collecting and analyzing data for four other qualitative studies and have completed my coursework toward a Master of Science degree in Community Health and Epidemiology.

The fact that I am non-Aboriginal may be a limitation, although this may have been reduced by my past involvement in these communities through the NET project. However, it is a factor that cannot be overlooked. I learned about cultural sensitivity and appropriate communication with Aboriginal Older Adults through work with an Aboriginal Grandmother’s Group at the Saskatoon Community Clinic prior to beginning the research project. Trust and rapport were facilitated by spending time with participants within the communities

and sharing personal experiences of having family members with dementia.

Any gaps in my background and training have been filled by my committee membership: researchers with considerable experience in the field of dementia and qualitative inquiry, and a committee member who lives and works in Northern Saskatchewan.

Data Generation

Data were generated through in-person semi-structured individual interviews, group interviews, and focus group discussions. A total of eighteen in-person interviews were conducted, each lasting between one and two hours. Two group interviews of two and four participants respectively, and taking approximately one and a half hours each, were conducted. Group interviews were conducted when the participants requested it, some indicating that they did not feel like they were 'experts' or had the authority to speak to the situation by themselves. Focus group discussions were planned to give participants a chance to interact and explore the issues collaboratively. Three focus group discussions, each including a directed group activity, were held including eight, four, and five participants. Overlap of participants in the individual interviews, group interviews and focus group discussion did occur.

Individual and group interviews followed the same format: background of the research project was provided followed by some semi-

structured questions to open up the discussion. Examples of questions included, “What is your experience with dementia care?”, “Tell me about older Aboriginal Adults and dementia”, “What do you see as barriers to accessing dementia care in Northern Saskatchewan?”, and “What supports exist to accessing formal care? ...Informal care?”. As data generation progressed, areas of exploration were added and more specific information was sought in accordance with emerging concepts.

“Throughout the research process, grounded theorists develop analytic interpretations of their data to focus further data collection, which they use in turn to inform and refine their developing theoretical analyses.”

(66, p.509)

In all but three cases, the individual interviews were conducted prior to the focus group discussion. Although the intention was to gain each individual’s perception of the issues prior to group interaction and discussion, three individual interviews were conducted subsequent to a focus group discussion. The focus group discussions began with a short background and informal discussion lasting approximately twenty minutes followed by a group activity. This activity was modified from an activity described by Lori Hanson, a professor in the Department of Community Health and Epidemiology, during a presentation in 2004 at the University of Saskatchewan. The group activity could be called “Swimming the River of Care”. I asked participants to envision accessing care as a river and gave them coloured paper cut-out shapes of fish,

waves, and rocks. The fish represent those who must swim the river, the people who are accessing or affected by accessing care. The waves represent things that help to move the fish along the river, that is, items that facilitate or support accessing care. The rocks represent things that impede the travel of fish in the river, barriers or limitations to accessing care.

After I explained the activity, participants worked as an independent group, discussing and listing items that could be considered fish, waves, and rocks. Names of specific barriers, supports, and people were written on the paper cut-outs and then assembled on a table-top or piece of bristol board that represented the river. I encouraged participants to discuss the relationship of fish, waves, and rocks and place them accordingly in the river. I did not intervene in the activity after the initial description was given, except to ask for clarification of items that I did not understand. Participants asked me for confirmation that items were correct; instead I answered that I did not know, as they were the experts. Working as an observer put the control in the hands of the participants; each volunteered information and debated choices freely from their point of view. Appendix F contains photos of the finished product of each of the three focus group activities.

Tape recording of discussions was planned but executed in only two individual interviews with formal healthcare workers of non-Aboriginal background. The option for tape recording was identified in

the original consent form as a voluntary activity that participants could refuse. Initial responses to the question of whether tape recording could occur were not positive, including body language to suggest that the very question made participants uncomfortable. The question of allowing tape recording was posed to only three Aboriginal participants before I decided to discontinue the option and instead ask if I could take notes and record responses on paper. Participants allowed me time to hand-record statements; the pauses while I wrote encouraged further thought and often led to follow-up statements by the participants. As well, participants allowed me to read them quotations if I was unclear or felt I had missed something while writing. I have experience in transcribing data for focus groups, interviews, and research retreats and find that this is a challenging pursuit but not altogether impossible. However, to facilitate the process of group interviews and focus group discussions, a Research Assistant attended and aided in transcribing.

Data Analysis

Central to grounded theory research is the analysis of data occurring in tandem with data collection. (66) That is, analysis of data begins immediately from the first interview and is performed continuously throughout data generation. Initial analysis guides further data collection and participant involvement. Analysis begins with coding of the data.

Coding is the pivotal link between collecting data and developing an emergent theory to explain these data.

Through coding you define what is happening in the data and begin to grapple with what it means ... By coding ... you begin weaving two major threads in the fabric of grounded theory: generalizable theoretical statements that transcend specific times and places and contextual analyses of actions and events. (55, p.46)

After each interview the data was transcribed, notes were made, and initial or open coding was performed. Data was gathered in clusters then analyzed. That is, data collection took place in concentrated periods during field visits to Northern Saskatchewan communities. Initial notes and memos were recorded immediately after each interview or focus group in order to reflect and forecast needs to be addressed in the following interview. This was followed by detailed field notes and journaling each night. Detailed coding of the cluster of data was performed once each field visit was completed. Charmaz, 2000, states that open coding:

keeps us studying our data. In addition to starting to build ideas inductively, we are deterred by line-by-line coding from imposing extant theories or our own beliefs on the data. This form of coding helps us to remain attuned to our subjects' views of their realities, rather than assume that we share the same views and worlds. ...Line by line coding keeps us thinking about what meanings we make of our data, asking ourselves questions of it, and pinpointing gaps and leads in to focus on during subsequent data collection. (66, p.514 - 515)

Next, focused or selective coding was conducted. This type of coding creates categories from the initial or open codes and develops conceptual relationships between the categories. Through this, causal connections and contextual processes were explored and core categories

began to develop in the data. Selective codes “cut across multiple interviews and thus represents recurrent themes. In making decisions about which codes to adopt, the researcher checks the fit between emerging theoretical frameworks and their respective empirical realities.” (54, p.322)

Core categories emerged through the selective coding process, at which point theoretical coding began. Core categories are those categories that develop through the research process that explain what is going on; they account for the basic social problem at the heart of the emergent grounded theory. Charmaz describes theoretical coding as building “an analytic diagram that maps the range of conditions and consequences related to the phenomenon or category.” (66, p.516) Glaser indicates that theoretical coding is where the researcher “weaves the fractured story back together.” (53, p.516) Through theoretical coding, the emergent grounded theory was created and evaluated in terms of context, relationship to the entirety of data, and explanation of the major social processes at the root of the study.

Throughout each type of coding, the constant-comparison method of analysis was employed to “establish analytic distinctions and thus make comparisons at each level of analytic work.” (55, p.54) In this way, data were compared line by line, incident with incident, and interview with interview. Sequential comparison of later interviews with earlier data was also conducted.

Memos were written during data generation and analysis. Morse and Field, 1995, define four functions of memos:

1) They help the researcher obtain insight into tacit, guiding assumptions. 2) They increase the conceptual level of the research by encouraging the researcher to think beyond single incidents and look for themes and patterns in the data. 3) They capture speculations about the properties of the categories, relationships between categories, or possible criteria for selection of additional participants to enrich the data. 4) They enable the researcher to keep track of and preserve ideas. (52, p.159 - 160)

According to Glaser memos “are the theorizing write-up of ideas about codes and their relationships as they strike the analyst while coding. Memos lead naturally to abstraction or ideation.” (53, p.83)

Data Quality

Data quality was assessed according to Charmaz’s 2005 criteria for grounded theory studies (68) and according to Lincoln and Guba’s 1985 model to ensure the quality and trustworthiness of data. (69)

According to Charmaz a grounded theory can be evaluated based on its credibility, originality, resonance, and usefulness. (68)

Credibility: Credibility exists when the theory contains “strong, logical links between the gathered data and your argument and analysis.” (55, p.182) This theory is credible because it is based on information given by participants and all theoretical claims are illustrated and supported by participants’ statements. As well, current literature supports the theory.

Originality: A work can be judged original when it offers new insights or “provides a new conceptual rendering of the data.” (55, p.182) This research is original in that until now, the topic of accessing formal healthcare for dementia had not been explored in Northern Saskatchewan and understanding of the situation was limited.

Resonance: The resonance of the theory can be assessed by its “portrayal of the fullness of the studied experience” (55, p.182) and by determining whether the theory “makes sense to . . . participants or people who share their experiences.” (55) This theory represents an understanding that is contextual and evolving, not simply an examination of static surface effects. The emergent theory was presented to and evaluated by participants and community members on field visits during the summer and fall of 2006.

Usefulness: To evaluate grounded theory research on its usefulness, Charmaz suggests asking “How does [the research] contribute to a better world, Does your analysis offer interpretations that people can use in their everyday worlds?” (55, p.183) This research is useful in that it will have short-term effects on the development of the NET Memory Clinic processes and procedures and potential long-term effects on future healthcare planning and policy. It provides impetus for further inquiry into appropriate dementia care and support for Northern Saskatchewan Aboriginal communities.

Lincoln and Guba's 1985 model to ensure the quality and trustworthiness of the research process and findings contains four elements: credibility, dependability, confirmability, and transferability. (69)

Credibility: Credibility refers to the process of conducting research in a way that increases the believability of findings. (69) Credibility was achieved through regular peer debriefing with supervisors to review and evaluate research findings. Credibility was demonstrated through triangulation of methods: individual interviews, group interviews, and focus group discussions. As well, presenting the theory to research participants and community members enhanced credibility.

Dependability: Dependability was addressed by developing an audit trail "that provides documentation (through critical incidents, documents, and interview notes) and a running account of the process (such as the investigator's daily journal) of the inquiry." (70, p.34) The audit trail for this study includes transcripts of interviews and focus group discussions, field notes, written memos and diagrams, and a field journal of research experiences.

Confirmability: Confirmability refers to the ability of multiple researchers to agree on the decisions and conclusions made. (69) The audit trail developed to document the dependability of the research will also be used to assure confirmability. That is, the audit trail "enables the auditor to determine if the conclusions, interpretations, and

recommendations can be traced to their sources and if they are supported by the inquiry.” (70, p.35) My research supervisors reviewed coding and category formation in order to determine that conclusions were firmly rooted in the data.

Transferability: Transferability refers to the generalizability of the research findings, or the extent to which results can be applied to other settings or populations. (69) Thorough description was sought in order to facilitate transferability. According to Erlandson, researchers must “collect sufficiently detailed descriptions of data in context and report them with sufficient detail and precision to allow judgments about transferability.” (70, p.33) Transferability was increased through sampling from multiple communities in Northern Saskatchewan but is limited in the fact that the research was conducted in one geographic area and may not transfer to all Northern or Aboriginal groups.

Chapter Four: Findings

While the original intent of the research project was to examine barriers and supports to accessing formal care for those with dementia living in Northern Saskatchewan, it soon became clear that this approach was limited and problematic. By characterizing experiences as either supportive or limiting, a 'black and white' picture of reality would be represented when a more liminal, fluid understanding is needed. That is, variables which in one instance would be construed as barriers would in another case appear to be supportive. A striking example of this is the concept of funding travel to healthcare appointments for Status First Nations persons. This is quite supportive but is also limiting in the sense that there is a perception that all travel is covered for Northern residents. This perception serves as a barrier in the case of non-Status and Métis persons who are ineligible for travel benefit, yet the preconception within many urban care providers is that travel coverage for Aboriginal peoples is universal.

In light of this, the research question evolved to examine the process of accessing formal care, with the understanding that factors and experiences can function as both barriers and supports to accessing formal care and that negative preconceptions and stereotypes could be reinforced by a crude, dichotomous representation. Because life in Northern Aboriginal communities is complex and nuanced, so too should

an examination of the social context and circumstances of a part of that life.

Introduction to the Theory

The theory developed from the interviews, focus group activities, and field notes is called *The Process of Negotiating Culturally Incongruent Healthcare Systems*. The theory is represented in a visual model (Figure 1). Overall, participants described accessing dementia care in terms of cultural contrast – that of specialist care or urban healthcare and that of Northern healthcare. At some points, the systems were seen in opposition, at others as congruous, and sometimes as complicit. Throughout each description and interview was a thread of cultural focus, be it lack of cultural awareness, clashing of cultures within and around healthcare, or the struggle to maintain cultural identity while benefiting from formal healthcare.

Four categories emerged to form the resultant theory. These are social context, managing in spite of healthcare systems, submitting to culturally insensitive healthcare systems, and participating in and affecting healthcare systems. In this theory the social context informs the use or non-use of dementia care services. The decision to use or not use healthcare is based on the social context within which choices are made. This category includes socio-cultural environment as well as practical considerations. The category, ‘managing in spite of healthcare systems’, stems directly from the ‘social context’ category. Indeed, a

causal connection can be established between the social context and the resultant process of 'managing in spite of'. The category 'managing in spite of healthcare systems' leads to either or both categories, 'submitting to culturally insensitive healthcare systems' and/or 'participating and affecting healthcare systems'; the former creates negative experience to reinforce the negative aspects of the 'social context' category, and the latter creates positive experience to inform the 'social context' category. This chapter is devoted to explicating the categories of the theory and providing examples from the data and analysis to support the dimensions of the theory.

Figure One: Visual representation of the grounded theory, 'The Process of Negotiating Culturally Incongruent Healthcare Systems'

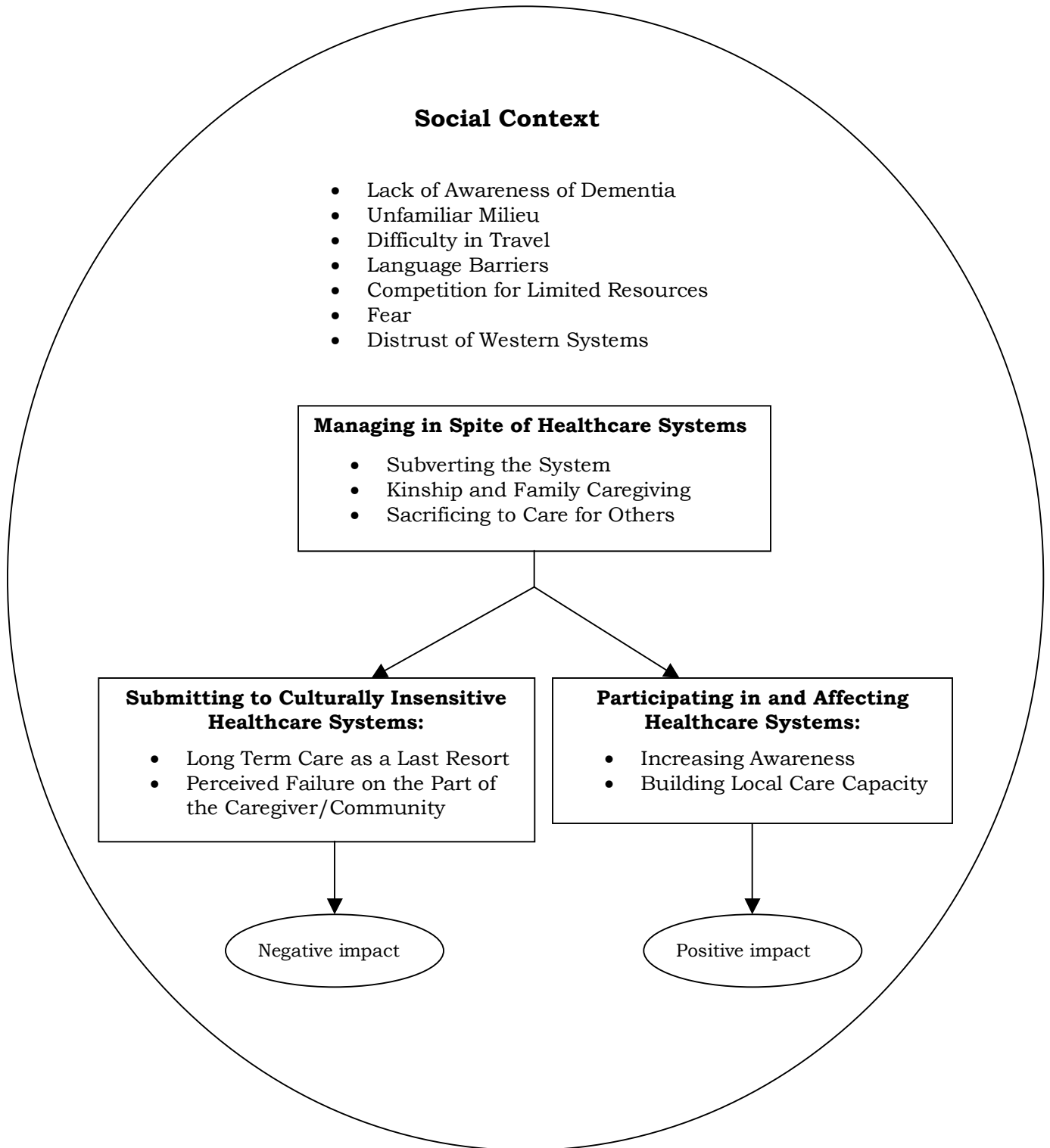
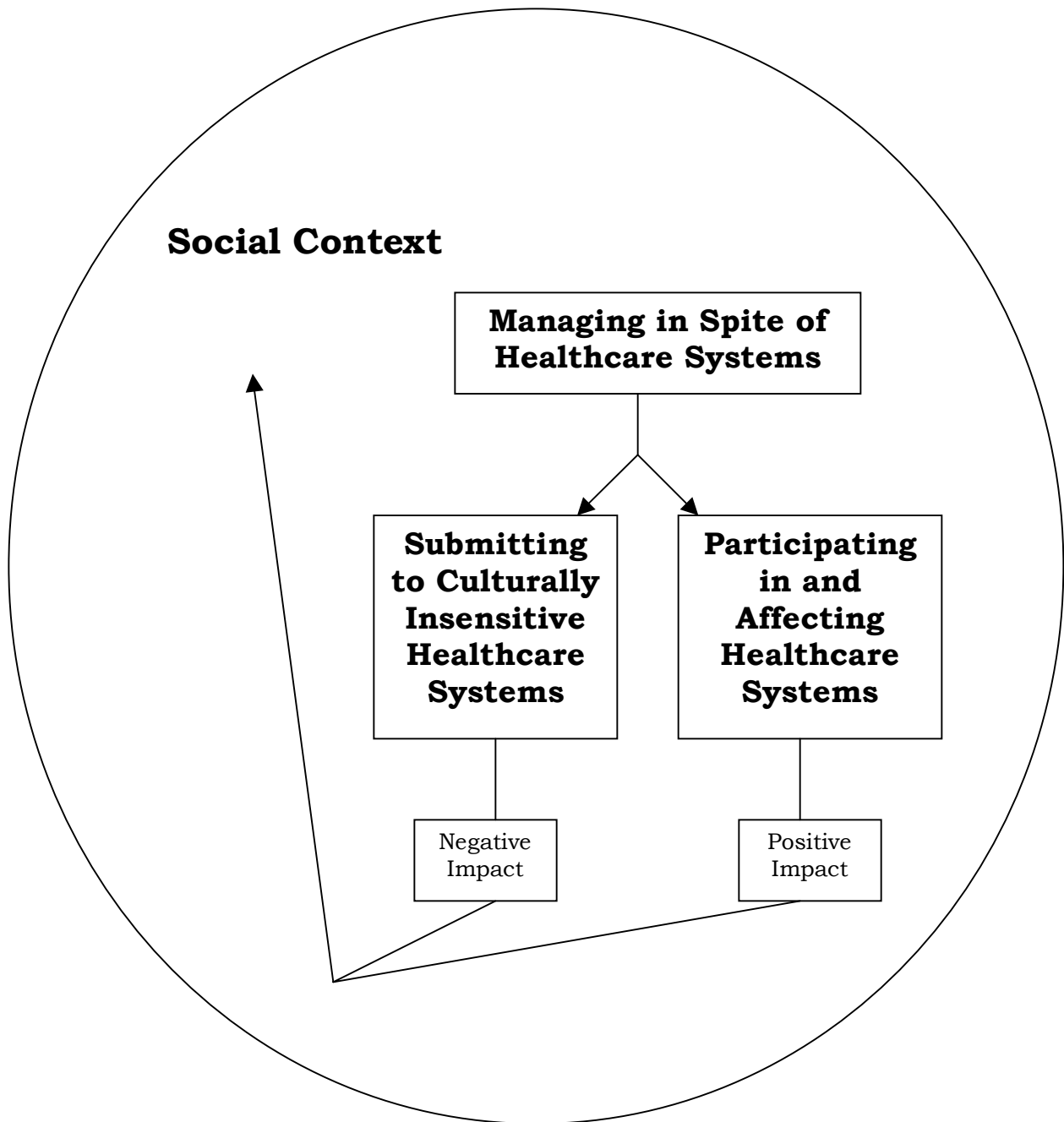


Figure Two: Truncated representation of the grounded theory, 'The Process of Negotiating Culturally Incongruent Healthcare Systems'



Social Context

At the root of the theory lies the social context in which dementia care access is negotiated. This category contains seven sub-categories or dimensions: 'lack of awareness of dementia', 'unfamiliar milieu', 'difficulty in travel', 'language barriers', 'competition for limited resources', 'fear', and 'distrust of Western systems'. Each sub-category contributes to the overall picture of Northern communities and constitutes the framework that dementia care access is built around.

Lack of Awareness of Dementia

Participants spoke to a lack of general awareness of dementia as a medical health problem. In some interviews it was explained that dementia is sometimes misunderstood to be a normal part of aging, or that the impetus to characterize dementia as a problem does not exist to the same degree in Northern communities.

It's almost expected for grandmas to be a bit more forgetful. One lady who lives with her son and daughter, but they decided that it was hard, they wanted their privacy. And before you know it, the poor little darlin' catches her housecoat on fire on the burner and burnt her arm. So, she probably shouldn't have lived by herself. Eventually, they did bring her back in with them, they sold her home, and moved her back in with them and that's where she is now.

Often we know about someone, but it's like "who cares", "he's fine", "his granddaughter looks after him". There's no problem. Because for many people it's just one of those things that happens. It's not really regarded as pathology.

People have more of an attitude of "that's just the way it is". So I don't think it's a bad attitude. We still look for value in [elders with dementia]. And it's not seen as something bad, not as traumatic a thing. It's not something to be embarrassed of, more of a "how do we live with it attitude?", and not panicked about it.

Some participants who had experience in more remote Northern communities described that awareness of dementia might be lower there than in the middle-North of the Keéwatin Yatthe RHA jurisdiction. These participants reflected positively on their home communities and speculated that awareness may be worse in more remote areas.

Here people are more aware of dementia, but in other communities there might not be awareness and they might think it's just normal part of aging – you know if they're unfamiliar with what dementias are. Or, they could keep them hidden. Because we know it's there. Maybe some people follow traditional healing. Because some just never see a doctor or nurse their whole life.

Participants also indicated people within their communities were aware of a problem or observed defining features of dementia but may not necessarily apply a medical label to the condition:

We look at dementia differently in the north somewhat. It has to be explained in the north because people aren't as aware of it, like many people don't know what it is so they know what's going on - like the person's memory isn't good and they think someone is someone else, but they don't have a name for it so they don't know what to call it – but everybody knows about it.

Awareness of healthcare services for dementia and knowing what to do when a person has dementia were raised as salient concerns that impact access to formal care. Being aware of services and resources was described as a necessary step to accessing services.

A big thing is that we don't know what's out there. We don't know where to find out information even. We don't have someone in the district who's focused on older adults so there's no specialization there. In terms of support, I mean, where do you call for help? We don't know. In cities you have seniors daycare but here, nope. We have nothing like that, no programs for elderly at all.

I think it's a lack of knowing what to do. Because people want to take care of their parents but don't know what to do and why it's happening.

Once you understand what's happening you can cope because you aren't worried that they're 'crazy' or perverted but maybe it's dementia, and understanding that would help everything. So knowledge and understanding is the biggest thing then resources. Because if you don't understand, you can't use resources. And having programs that have things like lower light and low music and quiet. But we don't have those nearby. Waiting lists are huge problem too. Knowing how to deal, what are techniques to use with someone with Alzheimer's – very important. Huge barrier is lack of knowledge and understanding.

If I had a patient that I wondered about, I would have to do a little research to figure out where do I send them. Well...I'm kind of ignorant about the processes. I think the biggest barrier is not knowing what's available. We don't know who to ask and where to go to ask it.

Unfamiliar Milieu

The lack of familiarity that Aboriginal Older Adults have with tertiary care systems was brought up by many participants. The foreign environment of cities, paired with unfamiliar milieu of urban clinics and hospitals makes accessing formal care outside of Northern communities more difficult.

The comfort zone with anything, no matter who we are, is so important. People go into places, in particular services where you are getting help by a specialist – just how cold it can be, how left out and uncomfortable it can be. Then add on barriers of language and cultural differences and you really wonder how it is for that patient. Or if you're struggling, worried about your health – and your mental health at that, and you're in a completely foreign environment, foreign culture and everyone's a stranger – well just imagine how stressful that is. Maybe we need to do more work on just that – making people more comfortable beforehand. That would help. And for the caregiver maybe even more – they're in both places.

Some people find it scary to go to the city hospitals - it's intimidating. And the fact that they don't want to go alone and they don't just have to pay the taxi which is at least \$500 – then there's a place to stay and food – it all adds up. The cultural difference is shocking for some people. It depends on how much they went out and have been to the city already. I've heard from some that they're terrified to go to the city. I know my mom would not deal with it well because she hasn't been out of this town for over thirteen years and she doesn't like to leave.

I grew up with my elderly grandma and when I was twelve I went in a taxi to Saskatoon to a specialist and I had never been to the city – I was terrified – all alone – and staying in a hotel, not knowing where to go and how to get to the specialist. But I could read and write so at least I had that – and I spoke English . So for older people, how would they cope? It was terrifying. Travel is hard, for sure but there's a lot to it – if you get dropped off, that's just the start. If you've never phoned for a taxi or taken a bus and you barely speak English, well, you can see why they don't want to go. It's just totally unfamiliar and if all you speak is Cree, well, coping in the hospitals and the city and restaurants and hotels – it's too much.

The lack of cultural familiarity was reported not only with regard to the medical care environments but in terms of the methods of assessing dementia as well.

There's difficulty with assessment questionnaires and then culture relates to that. Dignity is so important and it doesn't make sense to them. They ask some things people have never known; it's disrespectful, makes people ashamed. And comfort; they're with strangers who are sometimes abrupt and they're intimidated and can't do the tests and get upset and it makes it a lot worse.

Difficulty in Travel

The burden of travel to formal care treatment was described by most participants. Travel burden was noted in terms of distance, the physical challenge associated with travel for elderly people, the high cost and financial burden of travel, and the stress associated with planning travel.

It's a real financial burden too because most have to stay overnight. Have to pay for gas, food, hotels. So people who have family to take them...well then they worry about if they [the family members] have to leave work or their kids – stress – it creates a lot of worry. It's not as easy as just getting there. There's the financial burden plus worry about burdening others. And you really have to plan in advance with work and family. That's harder for older people to do. I had experience with this in taking my mom in to Saskatoon at the end of her life – it's challenging. It's difficult in many aspects and then it was so

uncomfortable for her with her other medical conditions like osteoporosis and arthritis, and being stuck in a car for hours at a time.

Older adults are tired. And it's much harder for them to make the trip. Harder physically - they get tired out from the car ride – and also harder emotionally. So maybe younger people like to make the trip in to go shopping or visit but not the older adult on a fixed income who can't even afford it. And then they have to deal with the city, the parking, all the environmental stuff. And I think that puts extra stress on family members because they have to make all the arrangements – family, work, travel – so it just adds to the stress on that whole family. Which is exactly what the older adult is afraid of. Lot of organizing. Just another thing added on. It all adds up.

Others expressed that it is not as simple as getting to the healthcare. Travel is complicated by the process of arranging appointments which in turn creates frustration and 'giving up' on accessing formal care. The idea that perhaps what is received in terms of care is not worth the challenge of travel was voiced by a few participants.

It's a long, drawn-out process too. You see the doctor here and then wait for a referral, get on a list and it can take six months to a year, and it just takes so long. And if you can't accommodate travel and arrange for it, you lose your appointment and go back to the bottom of the list again. By then you've given up or are living with it or it's too far gone. Or you just give up.

Even if people could go south, can they be seen by someone? Well, because what would they do? I mean, what can they provide? How can they help? Waitlists are huge too, a huge problem.

One participant voiced strong frustration with what was perceived as an expectation for Northern residents to travel long distances for all healthcare with little appreciation of the difficulty involved.

We always have to leave to get services. Nothing comes here you know. We always have to leave. It's hard, frustrating. [long sigh] That's how I feel. Been talking about it so long and nothing's being done. Tired. Tired of it all. People in the cities need to understand how we live and how few services we have and how much effort it is to travel. It's a six hour drive to go see a specialist then you see a doctor for 15 minutes then it's a whole other day to come back. And it's tiring

for me – imagine how it is for elders, especially if there’s something else wrong with them like arthritis or if they don’t understand English or are afraid.

Language Barriers

Participants listed language as a challenge to accessing formal care as most healthcare services are provided in English while not all Aboriginal Older Adults communicate well in English. Direct translation of words relating to dementia and dementia care from English into local Aboriginal languages was described as problematic. Participants indicated that the language barrier provokes non-use of services.

Language is a barrier because of the actual language and then all the other things that go along with language and communicating with people not in your voice. If I only spoke Cree and very little English, I’d feel pretty uncomfortable, like anyone.

Others indicated that, as a part of the disease process, Aboriginal Older Adults will often lose the understanding of English they once had and revert solely to their original language. The impossibility of functioning in a English-based healthcare setting for these people was described.

We had one sent to the nursing home in [other community] and got reports saying she was violent and they couldn’t keep her. But it was a language barrier; no one understood her and she was speaking Cree – so it wasn’t violence, it was frustration. Older adults – most of them slowly forget any English they had and revert back to Dene or Cree, especially with dementia.

She doesn’t say too much. Brought up to not complain – not make a fuss. So the family just made the appointments and took time off of work and drove her. She didn’t complain. And we could take her. I mean, she doesn’t read and write. So we have always took care of that end of things – business end and such. But no way she could have managed appointments in town without family. And she only speaks Cree – understands some English but she’s not comfortable with it. That’s common for older people losing any English they did know.

As well, a participant spoke of what she considered the two levels of language barriers functioning to limit access to dementia healthcare; that of English versus patient's language and that of specialized medical jargon which is often not well understood, even by healthcare workers.

I think there are two language barriers: people who don't speak English, or they do but then they revert back to their first language due to their diagnosis, but also, I have communication problems with specialists, with the health care professionals because they talk up here [gestures above head] and I'm down here [gestures shoulder level]. So imagine the family who isn't used to medical-speak. So ya, there's these two levels of language barriers and medical people speak so quickly, they're so busy and there's no time to explain.

Competition for Limited Resources

In nearly every interview frustration was expressed with the fact that there are not enough resources to provide adequate healthcare within communities for those with dementia in the North. Personnel and financial resources are often directed to necessary health concerns and conditions other than dementia. Though participants could appreciate the practical aspect of the resource allocation, they voiced concern that some are not receiving care because of the competition for resources.

You know, we're so busy trying to get prenatal classes and stuff like that and parenting classes, that maybe dementia education has been sort of put on the back burner, maybe not as much of a priority. We're just scrambling to get less pregnancies, less fetal alcohol syndrome, so I think a lot of our focus is that way more than educating families about dementia. We did put together a little elders day last fall, but with our work load we don't have those chances to do those things.

Frankly, the long-term care [here] is inadequate. People are almost shelved away there – seen by a doctor once a week, if they see them at all. It's really not adequate. They don't have nice rooms or a garden. They don't have a good surrounding. And what else can we offer them? Nothing. That's the sad thing about chronic development things like dementia in the North. There's not really much we can offer them.

Often the domestic situation is not really ideal to have them there. The community doesn't have the resources to cover that. We have an old folks home here in town. But that's really for independent elderly people who can look after themselves. The moment there is pathology involved, then where do they go to? They either come here and we have a long waiting list and can only take 12 people. Or they have to move out of the community to go to something down south which is often completely out of the way for the family or very far removed. And for many things we simply don't have the programs or the resources for people to help. And dementia is never high on the list of priorities. It's really not high on the list.

There's a financial aspect because this is a small community. Not getting their 'bang for their buck' to invest in older adults because there's just too few people; they're overlooked. And they're not going to set up a whole day-program for one person... but why is that one person ignored? Why are they not important? They shouldn't just be ignored, shouldn't just say, "Oh well, what can you do?" It's not right...

Participants said that the need for formal dementia care services is not captured or measured by the current healthcare systems and so it is difficult to justify a need for or investment in local dementia care.

I mean, technically, it doesn't show up that we have any cases because it could be tracked through medications – but most people don't get medications because they're so expensive. And to see the doctor, they bill for the primary or 'most' condition – and it's usually not dementia. So we know there's people here in community, I can name off four right now, but is that tracked anywhere? No. We don't have any statistical way of tracking. And without that, we don't really know exactly how many and what the real need. Or we can't prove it anyway.

However, it was noted that this situation would likely change in the future as the Northern population ages:

Probably in a few years more programs for older adults will be needed because there will be more people that age and then there'll be a big push and the region will do more. There's generally a lack of programming for older adults; the focus is kids and parents right now.

Still, another participant located the competition for care resources in the history of the *Indian Act*, describing the current situation as a deviation from traditional values.

It goes back to the *Indian Act*. If one family got eleven apples in their ration and the next family got ten, they'd go back and ask for another. There you have it: it made people compete for resources instead of meeting everyone's needs.

Fear

The fear of healthcare services described by participants is based on personal experience with healthcare, and the experiences of others which are then communicated within the Northern communities. Fear was described in terms of travel, of unfamiliar care settings, of the healthcare personnel, and of diagnosis. As well, Aboriginal Older Adults fear what is understood to be the unavoidable trajectory of formal care: that they will be removed from their home community and be forced to stay in a long-term care facility or hospital.

Going away has a bearing – leaving a familiar setting and going to a completely different place. So fear: fear of unknown, fear of being in a completely different, well foreign environment. Fear is big. And it's real fear because they maybe won't have access to family. I mean – scary.

There's fear – not wanting to admit that it's happening and then not wanting people to know. Fear of being diagnosed with it and then knowing that certain things are going to happen, like moving away from family and community.

Transportation is also a huge barrier because a lot of older adults have never driven a vehicle in their whole life. And fear of leaving community is huge. I mean, you live in a small community all your life – imagine how hard it would be to manage maneuvering in the city. It's a combination of fear and travel and being old and long time and staying over and language and culture. Put those together and it's huge.

The attitude of the specialist – people, they come back with stories. Sometimes they have a bad experience and then they tell others in the community. But it's the "I'll never go there again" and then someone else comes in and they say "I'm not going to see a specialist"... in a community like this, there is a lot of talk, the story goes very quickly. And it sticks. By the time we send patients out to [tertiary care], they're quite sick. Many of them die. And the older people say "No, I'm not going, because people die there. They don't come back again." They don't understand the whole process; they don't see individual cases...

Distrust of Western Systems

The recent history and socio-political background that informs each aspect of life in Northern Aboriginal communities is that of racism and colonial rule. Several participants described the learned and internalized racism and fear that characterized life for Aboriginal Older Adults and impacts interaction within formal healthcare systems today.

My mom grew up afraid of white people and she says that when they were young and a white man came to the door, they were taught to run and hide. They were raised to be scared and not speak up, not speak their opinion or mind. And they were sent to the convent at Île-à-la-Crosse and the nuns taught them – that has to affect them. I mean, she's not like that with us, but she reverts back to it when she speaks to anyone in authority.

We were taught to be scared of white people, our parents taught it. Well and you can see why – they might demand you go away to school or to a hospital. People were taken away from home, can't blame them for being scared. And the only reason white people came to the door was when there's trouble, when you're in trouble. Sorta still that way. Ha ha. And sometimes we still do it, say, "You be good or I'll send you to live with the white man" – or "I'll send the cops after you".

Participants made direct links between formal healthcare for dementia and colonially imposed attempts at assimilation, such as the formation of reserves and residential schools. In many instances, participants alluded to residential schools and earlier hospitals run by nuns when discussions broached the subject of care for dementia. The

broader socio-political context of colonialism was also often referred to when participants were asked what they considered barriers to dementia care.

Quite a few people went to residential school and were already taken away from home so they are always just scared. And the nuns were just so bad and strict and kind of mean. And the hospital is the nuns' hospital so there's the association. The nuns were here still in the 80s and they ran the hospital. They were strict but not that bad I guess. And the nuns worked as aides up here until they were too old; they lived over in the residences connected to the hospital. So there's still the connection; it's recent.

The people are the ones affected by the residential schools so could be a big barrier to coming to the hospitals because they're 'the institution'.

I think it has to do with other issues – like going to residential schools and being looked down on and trying to change how you are. There's a lot of shame with that loss of self-esteem and identity. And I went to residential schools so I know ... I know... We would watch movies with cowboys and Indians with the nuns and we'd cheer for the cowboys – not the bad Indians. We thought that was normal. There's a lot of shame. Shame. So sad. It's going to affect generations. Take its toll. They always told you, "You're not right, you're not good enough". And, you know, I still feel that way. I try to fight it but I still do. I know it was the government. But it's *people* in the government. People just lack compassion. I still sometimes feel that 'I'm not smart enough, I'm not good enough.' And that's because they told us that. Never a kind word. No kindness. You just went and that's how it was. But it was wrong, so wrong. They never said a kind word – no kindness. Hard way to grow up. I learned things, yes, but I also learned that I wasn't good enough. Try to unlearn that. We give people what we can as healthcare, but I think it all boils down to self esteem. It all comes back to the *Indian Act*, being put on reserves, being put in residential schools. So I think that's the main thing. That affects everything. It's all connected to that and you need to know that.

As well, an undercurrent of colonial paternalism was described in one focus group when discussing the challenge of developing culturally appropriate services within Northern Saskatchewan. Participants described culture as an asset (wave) and also as a barrier (rock):

Culture's a boulder because organized systems are planned by people outside of the culture and don't understand Northern communities. And we are multicultural, not just one culture. Plus the racism and stigma. Not recognizing our needs, saying that, "This is how it is" and leaving no room for negotiating or having a say.

Managing in Spite of Healthcare Systems

This category accounts for the processes people engage in when confronted with potential dementia or a dementia diagnosis personally, within a family kinship network or community. Dementia care is often provided without entry into the formal care system or with minimal reliance. Sub-categories include 'subverting the system', 'kinship and family caregiving', and 'sacrificing to care for others'.

Subverting the System

Participants described relying on mechanisms of care outside of formal healthcare systems to ensure the safety and care of those with dementia. Comfort in working around and outside of formal systems was expressed by many. The ability to address care needs without complete reliance on formal healthcare systems was voiced as a commonplace occurrence. One such example was the use of community radio stations to enlist the help of others in watching out for those with dementia who may wander or become lost.

We put warnings out with the community, talk to people, put it on the radio to try and get everyone aware so can note any problems – like if someone's out wandering and shouldn't be. Family take care and help out as much as they can.

My [relative] had Alzheimer's and our family understands well – because they spoke to the doctor and it was explained well. They went on the radio and explained to the community and asked people to watch

out for her. Lots of people would find her out wandering and bring her home – family can't watch all the time.

We've had radio announcements about people who have dementia – friends and family here take care of each other. And we try to watch out for each other. One woman would always go across the street to the neighbours' and sleep in their bed. And they'd just wait until she woke up and take her back home. Her daughter took care of her until her dying day. If she wandered out, that's the first place they'd check. If she was gone more than an hour they would announce it over the radio station to help find her.

Some participants discussed ways in which they used healthcare services in unique ways or bent rules to provide care when care was not formally mandated or when care would be otherwise ineffective. One formal healthcare provider conveyed that needs are not ignored, even if the person falls outside the formal domain of care. Subverting the restraints of formal systems was articulated as a necessary evil in providing the best care possible while respecting culture.

People have to pay for some services – like some homecare – out of their pockets – we're the lowest money in Saskatchewan and if we know they're in extreme hardship, we find ways – we need to be flexible. Like when you consider pensioners with cost of living up here plus their drug costs. It's a big hardship with older adults, the family often pays bills or we just...well we find a way, let's put it that way. I mean, we never deny services. If they're in hardship we just say we'll deal with the money end at year end.

A lot of times the doctor will admit elderly people [with dementia] to the hospital's long-term care for 'social reasons' and they won't chart Alzheimer's or dementia – or they'll chart 'respite b/c family having trouble coping' or 'family needs break'. Because the hospital is only Level Two care, not set up for dementia.

There's rules about visiting in our long-term care but no one really follows them. Let the families stay overnight, visit.

Sometimes we sneak escorts in [with subsidized travel] because sometimes I can't imagine them managing on their own, but they don't 'qualify' for an escort.

Kinship and Family Caregiving

Possibly the greatest support for those with dementia in Northern Saskatchewan articulated by participants is the family and kinship network. Family members, blood or otherwise, were described as necessary in ensuring that Aboriginal Older Adults receive proper healthcare. Without informal caregivers to assist, participants felt it would be impossible for Elders to navigate the social context and receive formal dementia care at all.

Not many people here who don't have family – some type anyway. Put it this way – everyone's related somehow even if not through blood. Technical terms maybe not, but family extends further than blood. Sometimes you find you get more support from the children who were raised but not blood. Maybe because they're grateful. I think that it's part of the culture: people take care of their own.

We're a close family so we noticed the differences in [my relative] and we got the appointments and we just told her that we're taking her. So we got things done. Otherwise I don't know what a person would do. It wasn't so bad with the appointments – because she had family with her the whole time – she has seven living children and lots of grandkids. But now in the home she's all alone and sometimes she recognizes people and sometimes not. But she gets sad.

There's a lot of community cohesiveness. Which is one of the big advantages up in the north and families stick together and family groups stick together. And whole communities help each other out.

Participants said that the formal healthcare system does try to support informal caregivers but that most often it is informal caregivers and community networks that deliver the care.

Used to be 'what happened in the house stays in the house' but that's changing. When people are sick or get diagnosed with something we have family case conferences with doctor, nurse, home care, you name it – and we all discuss it. No longer thought of as just the family's problem. Used to be all on the family. Like all the burden of illness – any illness – was on the family. But it's opening up – so you still have

the support family network but they don't shoulder the full burden. Healthcare takes on some too – but of course we're limited.

There are more opportunities in the city [for formal care] but also more people who fall through the cracks. Here people don't get missed, there's more support in terms of community coming together.

All participants mentioned the reliance on family caregiving and the need to recognize caregivers as affected by dementia as well. Many did, however, note the difficulty that could be experienced by family assuming the full burden of care while balancing a full and complicated life. Again, participants recognized the dual nature of family, as supports and sometimes the only source of care for someone with dementia and as challenges if the family itself was unable to cope or provide care. The negative side of relying on family caregiving was described in cases where perhaps the family could not provide adequate care or when an Older Adult was without any family or kinship network.

It's very normal for family to care for loved ones – with any diagnosis. But in this case [dementia], it is just too difficult. Just the fact that they can't remember who they are hurts people's feelings and having to watch 24 hrs – and then having to work a job too. And always worrying they'll get in trouble. They could be cooking and forget, start a fire or just walk out of the house and get lost. And they get very violent because they're afraid. And can't remember from one minute to the next so they don't understand how they got there or why you're helping. It's scary when they get violent. And just so sad.

If you don't have family, you're alone. And there's a whole cycle there because maybe the family has other problems that they're dealing with and then trying to take care... and it stresses them so other problems get worse and then they can't care at all. It can be a whole cycle. So, if you've got family support and it's functioning well, you'll be okay. But if it breaks down for whatever reason, you're on your own and that's probably pretty tough. I don't know what people do then. Probably get shipped away.

The only support really is family and if you don't have that because you don't get along or can't because of other things going on, well, you're basically alone.

Family can be a boulder too if they refuse to admit it, are in denial, don't get help, or argue amongst themselves and cause more problems. And it always falls on one person to provide care too, and that's hard on them.

A few elders have been abandoned by their kids – they just don't care. But they have complicated pasts...

Caregiving was described as a task relegated to women and in only one instance was a husband caring for a wife. It was noted though, in that particular instance, daughters were assisting and providing most of the care.

Family members are key. Say I was 65 and I got Alzheimer's, I would know that my kids would take care of me. Right now I live with my daughter and my mom and take care of her. It's what we do in the North.

Families just take turns [providing care]. I've only known of daughters who take care – they either move in or the parents move in with the daughters. There is more of an expectation that the daughters will take care of the parents.

Sacrificing to Care for Others

Participants communicated hardships endured by those providing informal care for a person with dementia in Northern Saskatchewan. The cultural obligation of elder care is expected, as is the responsibility to fulfill other family obligations such as raising children and often working outside the home. Participants described situations where informal caregivers met expectations of care by making personal sacrifices, often without any reliance on the formal healthcare system.

If I hadn't been around, hopefully someone would have helped. Well my niece was teaching and she would've quit and came back because

my [relative] raised her. And she did come home last summer and helped me look after [relative] until she passed away. We are a small family – the only time I felt I didn't have support...well...I didn't because other family members were living too far away. I could've used their help but they were so far away. And working while trying to look after someone with dementia was pretty hard. We didn't have homecare. She had it when she lived on her own but not when she lived with me because I did it – I never even thought to request it. I felt like I needed more support caring for her... because it was so hard. Emotional support for me would have helped. I don't know. I used respite [at local facility] twice but because she was wandering so much they refused to take her they were scared she'd fall downstairs and get hurt.

Another [relative] has Alzheimer's disease and is in long-term care. Found out at age 60 but caught early so it can be a slow progression, they say. She's 65 now. Her daughter quit her job and stayed home with her for three years but couldn't handle it because it's really hard – they get aggressive and she [the daughter] had just got married and wanted to have a family. She was in mid-twenties and taking care of her mom. Hard, really hard for her to put her into a home.

And then the one case, she couldn't go to [Level Two long-term care] because she was wandering too much with her dementia, her young granddaughter took care of her. And I thought bless her heart, she's a young girl herself with a baby and she looked after her [relative]. It got to the point where she was coming in with anxiety stress situations. She was a strong young lady, but collapsing. It was hard for her to put her [relative] in the nursing home, and it turned out that she understood that that was the best situation since she couldn't handle things at home and handle her own family as a single parent. But she tried.

I cared for my an in-law who had Alzheimer's – in his home. And it was difficult because he wandered and we'd lock the door and he'd get angry and violent. He thought I was his wife and would beat me. It was really hard because I was working here and caring for him...He was admitted to long-term care [away from the community] finally because I couldn't handle him anymore...it got dangerous. It was stressful and I felt bad until I found the Alzheimer's support group in Saskatoon when I was going for classes. I thought it was my fault, that I was doing something wrong.

Some participants noted that this situation is perhaps more difficult in the North because of the lack of formal healthcare services to support informal caregivers and the challenge of accessing services

outside the community while maintaining family life and care for someone with dementia.

It's pretty tough. It's hard on family without formal support...because in the south there's support groups for people dealing with this ...and here the person end up having to leave home and the community just for care – well, to be safe even – which is so hard. It's hard on the person and it's hard on the family. Family has to take care of the Alzheimer's patient or they have to live in a Level Four which means moving away. People try to delay it as much as possible, families take care of family members. Or they hide it so they don't have to leave. Fear is big. They figure that they leave and then that's it – not going to get to come home again. They'll be away and not at home to die. They feel like their family is just sending them away. It's a lose-lose situation for everyone.

Submitting to Healthcare Systems

When dementia progresses to a point where formal healthcare is needed, the process continues through either 'submitting to healthcare systems', or 'participating in and affecting healthcare systems' or both simultaneously. The category, 'submitting to healthcare systems' is exactly that: the point at which people submit to culturally insensitive and sometimes oppressive healthcare situations because they are left without other options. The experiences that characterize this category serve as negative feedback that re-informs the first category, 'background and social context'. 'Submitting to healthcare systems' contains two sub-categories, 'long-term care as a last resort', and 'perceived failure on the part of the caregiver/community'.

Long-term Care as a Last Resort

In many interviews the participants equated care for dementia with long-term care, at least as a final outcome of care. Long-term care was

described very negatively as it connotes removal from the family, community, and culture because there are currently no long-term care facilities in these Northern Saskatchewan communities that are equipped to house patients with dementia. In this way, long-term care was discussed by participants as a last resort taken once all other options had been exhausted.

There's nowhere here to stay. Not even a group home and it gets too hard for family members to take care so they have no choice and have to send them away.

Older people don't like living in a nursing home – feel like you're living in a prison. Away from everything. No support. Away from family and culture.

I had two [relatives] who had dementia. They were sent to nursing homes. They felt like they were in a jail – they were incarcerated or might as well be. It is just sad – they're supposed to be in their own home but there's all these rules and restrictions. It's not home.

[My relative] cried all day [in the long term care]. She was very active and independent so to end up there – well, maybe she had lucid moments and thought to herself, “What the hell am I doing here?” She was a strong person who liked to do her own thing – hard to ask permission about every little thing. Their girls took them to live with them and then had to put them in a home. Very hard. People don't like moving. Just don't. And you've lived one way all your life and then you have all these different rules. I wouldn't like it either.

With 'X' I said, “What about going to nursing home” and she said “No way. They put you in and throw away the key” – she just wouldn't even consider. Very adamant. With 'X' her niece asked me to discuss with her to go to nursing home because I was trusted and impartial. Well, it was a two week ordeal. And she *had* to go because she was getting lost all the time and family couldn't take care of her. It was a major process. Really hard on family. For two weeks she packed and it was a two hour ordeal just to get her into the taxi and I went with her in the taxi and tried to get her settled in and she just kept asking to leave. So basically we did exactly what she feared the most. Put her there for good. What pushed the family to long-term care was that she got lost so badly the police had to look for her. She was so confused and didn't recognize anyone anymore. Really devastating for family members.

But if people don't have family – oh my god, they'd die a very lonely death. There is homecare and they're nice, but they are only there a little bit, not all day, and not every day. Other than that, there's long-term care ... but... well, no one wants to be in long-term care. It's lonely and at home everyone visits and stops by all the time, but no one visits in long-term care. Maybe because it's scary and they don't know what to expect and it's death: you go to long-term care because you're going to die. The perception of long-term care is bad; everyone's nice but it's still long-term care.

Perhaps the most challenging moment experienced during an interview occurred when a participant redirected the question to me. She illustrated the factors at the root of negative perceptions of long-term care while illuminating the difference between Aboriginal communities and Western communities. The difference lies not only in the separation from family and community, but in the past negative experiences with colonial systems.

Interviewer: What would you do if your parents had memory problems/dementia?

Participant: We always say we'll never take them to a home. That's how we are. We want our parents with us and near. Want to respect them, care for them. If it got too bad I'd move with them to one of those homes – but I wouldn't send them off and not see them. I wouldn't just *abandon* them. I couldn't abandon them... We would all take care, my sisters and I. We wouldn't be able to see them – we wouldn't be able to visit hardly ever if they went to a long-term care home. We would do whatever we have to. To keep them, I mean. I guess with dementia they might not know where they were and who we are – but we would. What would you do?

Interviewer: Well, my family went through this experience and in the end we did admit my great-grandmother to long-term care. It was really difficult but she needed continual care and no one was able to provide that.

Participant: So you'd leave your parents with strangers? ... I couldn't. I just couldn't.

Interviewer: Why is it that you feel so strongly against nursing homes? It's maybe not the greatest option, but for me it *is* an option whereas for you it doesn't seem to be an option at all.

Participant: Scared, mostly scared ... we know the care that *we* give. It's scary to let strangers take care of a loved one. Scared that maybe they'll be mistreated. You never know. And we wouldn't be able to be there and see a lot ... We call them 'those homes', 'those places'. It's mostly out of fear. You don't know. We have trust issues. [discussion about her residential school experience and that of her father]. But long-term care, it's just scary – there's just lots of trust issues.

A concern was vocalized by one participant who feared that by not investing in culture and tradition, the future for Aboriginal Older Adults could be bleak where the only option would be culturally insensitive long-term care.

We have a lot of middle-aged and young people here, and the middle aged will be old soon and I don't know what the young people will do to look after them – it's getting less and less ... young people won't even sit with their grandparents who are well, so I don't know what will happen when they're sick. We're losing the tradition of care. We'll need a nursing home for sure.

Perceived Failure on the Part of the Caregiver/Community

For participants, a feeling of failure in fulfilling the care needs of the loved one coincided with the view of long-term care as a last resort. Extreme guilt and sometimes shame was described by participants when describing the eventual need to pursue long-term care, sometimes describing this as 'sending away', and 'abandoning'. The removal from family and culture paired with the fact that family cannot visit often creates a sense of failure.

There's a lot of guilt if you have to send person away – usually it's because they're dangerous – like violent or wandering – and it's just how it is and sometimes you have to. But leaving the community is just so hard. Last resort, definitely.

You're studying access – like the fact we don't have any? Ha ha. Like how [my relative] had to move away to live in a Level Four care home because she has dementia? It's really hard because she used to speak some English but with her disease she reverted to entirely Cree and hardly anyone in the care home spoke Cree. Well no one really. She was finally diagnosed because time and again she was at the doctors and my aunts took her and wanted a CT scan. So she went to Saskatoon for it and they diagnosed it then. Then we all tried to take care of her on shifts then we tried to hire someone to stay with her. That didn't work out – was a hard year for us. Then she stayed with [informal caregiver] and had someone come in and help take care of her but then we had to place her in a home... We all have jobs and families so we just couldn't take care of her and she was a totally independent lady and she just went to needing watching 24-7 and then even needed help to use the washroom. It's very sad because she used to take care of everyone and was so independent. Hard for her, hard for everyone. It's just really sad and really hard on family. Everyone tries to take care as long as they can but sometimes you just can't and then there's guilt. We all just can't wait for the new hospital so we can have [relative] closer. They can't build it fast enough.

It's not so good in the [long-term care] home. It's hard to see [loved one] like that. She walked everywhere, was really active and well known in community, and now she just lays in bed. Doesn't know anyone there, doesn't do anything. She broke her hip a few months ago because she had a seizure and fell. The doctor said it was due to the dementia. She fell and just broke her hip. And not knowing how to communicate, she didn't know how to tell them that her hip hurt. She was in hospital for four days before they knew that her hip was broken. Once the family got there, we figured it out. She just didn't say a thing – couldn't – just stayed with the pain... It's very stressful for our family with her there and us here. And it's all on [informal caregiver] who is there and she's working. And we'd all like to do more but with the cost of gas and getting a vehicle and time off work. And it's far to go. It's very hard.

One guy [in long-term care] jumps up and tries to pack his clothes to leave when his family visits but they can't take him because they both work and then they feel sad and guilty. It's just so sad. I cry every time he does it. His heart is breaking he's just so sad and wants to go home with them.

And living in the nursing home – they treated [loved one] good but no one spoke Cree – maybe one a bit – so she was very lonely ... all alone. I felt so guilty having to send her to the nursing home but it was just so much stress. And I was arranging to take time off of work and take care of her. It was still getting worked out when she passed away.

One participant stated that the community contributes to the personal sense of guilt on the part of the informal caregiver, albeit unintentionally.

A lot of people have trouble admitting they need help and in such a small community, if you're seen getting mental health services, you're seen as weak or not okay. Torn between family and community: Family needs help but is scared to be seen as weak, the community will say 'go get help' but then, if they have to send them away, people say 'how could you have sent them away? We could have helped.' But then if they're here, they don't help. Really torn. It's sad.

Participating in and Affecting Healthcare Systems

This category represents the positive experiences of engaging with healthcare systems that serve to reshape those systems into more culturally sensitive and appropriate. Experiences captured in this category include building cultural capacity and confronting colonial oppression. This category serves to positively impact the 'background and social context' category, which in turn influences the categories following it. In this way, the process is continuous, not in that experiences will continually repeat, but that future experiences will be continually re-shaped by what precedes them. This category contains two subcategories, 'increasing awareness', and 'building local care capacity'.

Increasing Awareness

Participants communicated the fact that, within Northern Aboriginal communities, dementia is not stigmatized as a personal failure but instead thought of as an unfortunate medical condition. They noted

that this strengthens the process of accessing care because people will not avoid care out of shame.

I think there's less stigma. Well, it's not something you *can* hide. Everyone knows everyone here and knows what's going on.

If people trust you, they're very open about it. I don't know, maybe it's still regarded as one of those natural processes. There's nothing wrong with it; it's a disease. Do something about it. In the cities there's this drive to excellence or perfection or no disease. I just hate it on TV – it shows this perfect world with no disease and no pain. And that's so far from the truth. We live in an imperfect world with a lot of diseases, a lot of pain and suffering. It's all how we deal with it. We shouldn't ever think that we'll get to a point where we'll have no pain and no suffering. That's a part of life. It's how we deal with it. For many of these people, it is a part of life. Suffering and shame and embarrassment, it's nothing to hide. It's there. Deal with it. And how can you hide it in a small community like this? Things that happen, well, it's not the end of the world, it happens. Everyone knows about it, so we might as well join hands together and fix it.

Others noted that awareness of dementia has been increasing within Northern communities, especially for care providers, and that the increased awareness and education will improve the type of care provided and the use of care.

Right now we're trying to educate all the staff in how to recognize signs of Alzheimer's and also how to deal with patients properly. Like don't walk up behind them or be loud, don't take away their 'baby', and don't argue. It's a learning experience for everyone. We try to get speakers come in – like we had a mental health day and a speaker about recognizing illness in elderly.

Many years ago, we used to think it was completely natural. You know, Grandpa 'went to the dilly' and that's normal. But yes, with a difference in pace and some people starting at a very young age we definitely have to realize that it's not just a normal aging process but that it is often pathology involved as well. Sometimes you can do something and sometimes not, and the thing about dementia is it's not like someone having the flu where you can treat him for the flu because dementia often involves more than one person, a small household or larger family group. It's an important disease in the sense that you are not just treating one person, but you are basically treating a community or managing a community.

Additionally, participants noted the importance of making community members more aware through education, especially those providing informal care so that they can better access current services and help to shape future services provided.

Education is so important, especially for family, well, and the whole community because everyone's involved. But especially for family because it's hard to understand. And it must be really hard to take care of them and cope. Maybe counseling for families would help – but it would have to be quite regular because people say “I'm okay” even when they're not. And if they know someone cares and there's continuity, well maybe they'll discuss the everyday problems and open up more.

Building Local Care Capacity

Participants spoke to the need to develop culturally-relevant resources within the communities. They noted that instead of attempting to remedy the difficulties in accessing formal care from outside Northern communities, they should instead circumvent the problem by developing local capacity to deliver formal care for those with dementia and to formally support the informal caregivers. The formal healthcare for dementia should be provided within communities by trained community members, said many participants.

The key is keeping health professionals in community. Because they leave just once they got to know the patients and people just got to know them. Constantly re-learning; meeting new people and getting to trust them and then they leave.

When we recruit people we really place a strong emphasis on “you really need to work at building a relationship with your patients.” This is not a clinic where you just see the next patient and then go home, come back tomorrow. You really need to get involved with people. This is community building as well. And the only way that you can build trust is by really getting your feet into the community, into the patients. It's so important. You really can't build trust in a few days or

a few weeks. It's hard work to do that. You need someone who has the time and the patience and the correct attitude and the wavelength to deal with it. You really have to find out how the culture works before you start approaching people because if you aren't working on the same cultural wave-length, no matter what you do it's going to be ineffective. That's why the health care workers need good training as well.

We're hoping that the new hospital they are building will help things out because they say they'll have a better Long-term care and people don't have to leave so far away from family and friends and be alone. Stay with their community. And hope that more specialists and services will come to new hospital because people really don't like traveling to Prince Albert or to Saskatoon, especially to the hospitals which are scary – totally foreign to them. Like with the language and it's just so big and intimidating. I mean, can't blame them – especially when they're older, they don't leave as much.

Local assessment would be better. Having somebody from the community trained would help because maybe early diagnoses would be made, or they'd be diagnosed without going to Saskatoon. And they'd be more comfortable talking to one of us and aren't as threatened.

Three out of four nurses are from here – they just went out [of the community] to train. The nurses are very caring too. Really good. They go above and beyond; order and deliver meds, teach people, visit them, do home visits. Do lots of outreach. They see everyone, know people so know when things are going on.

Participants articulated that the focus cannot rest completely on the formal care system, that the community must be developed as well. Some participants expressed interest in new directions such as providing formal training for informal caregivers.

We need to make it better for the elders, more like their traditional ways. We need to have programs and things for them to do and have some volunteers from town and the community come and take them out so they're not just locked away. They need more security and comfort; they're usually afraid of everyone, especially if they've never met the workers. Strangers helping with personal things when no trust has been built up – if they don't know you and don't trust you, you can't have a good caring relationship.

It all boils down to money on programming – maybe an increase in homecare would help, maybe make funds available – like if you need a

person to stay and sit with an Alzheimer's patient, so be it. Increase the number of visits and monitoring. Maybe we ought to be sending families out to get educated about Alzheimer's, maybe that would be a better investment because it's brand new to them. Once they understand what's going on it's less stressful, less scary. They wouldn't feel like failures, and it could decrease elder abuse or negative coping behaviours.

Support is an area that needs to be developed ... support has to come from within community. An outsider can come in and be a vehicle to get it going but it has to be taken up by community, they have to run it and direct it.

Because family is the biggest support we need to focus on helping them. Maybe educational videos or something for them to learn about disease and what to do. And respite just to get a break, because it can be quite taxing.

Summary of the Theory

The theory that emerged through this project, Negotiating Culturally Incongruent Healthcare Systems, accounts for the activity taking place at each point during the process of accessing formal healthcare for dementia. Participants described the many challenges faced by informal and formal caregivers living in Northern Saskatchewan in terms of accessing dementia care and demonstrated the larger socio-political connections of how and why the process is challenging. 'Social Context' underscores the awareness, desire, and ability to access formal dementia care service. 'Managing in Spite of Healthcare Systems' was described by participants as the common action taken when caring for a person with dementia, formally or informally. Finally, when care can no longer be maintained within the community the process of 'submitting to culturally insensitive healthcare systems' and/or 'participating in and affecting healthcare systems' begins. The experience of submitting or

participating re-feeds the 'social context' in a negative or positive manner. The process is then continuous; it can be affected and modified by new encounters with formal healthcare for dementia.

Chapter 5: Discussion

The theory generated through the research process, *The Process of Negotiating Culturally Incongruent Healthcare Systems*, encompasses both the historical and social context informing the current experience of accessing care, and the implications that result from choices and actions thus re-informing the social context. Any discussion regarding the health of Aboriginal peoples requires a thorough understanding of the subtext of racism and colonialism that underscores the social experience of health; "...analyses of issues pertinent to Aboriginal health are incomplete if they fail to consider the social conditions that have resulted from our colonial heritage and their effect on the context in which health is experienced and health care is delivered." (61, p.25) Several of the sub-categories of the theory directly address the roots of colonialism whereas others involve more practical or logistical issues. Each sub-category, however, contributes to an understanding of the process of negotiating care and the theory would be incomplete without both day-to-day experiences and the deeper rooted context informing experience.

Social Context

Lack of Awareness

Participants characterized awareness as a barrier to accessing formal healthcare for dementia in that many people do not recognize dementia as a disease or they are unaware of healthcare options available for dementia. This contributes to the context in which care is negotiated in that it limits help-seeking behaviour; if something is not

understood as a medical condition, healthcare will not be sought and if healthcare is thought not to exist it will likely not be accessed.

Henderson and Henderson state

In the American Indian population, dementing disease is “new”. This is because they are only now approaching the life expectancy of the majority population and, consequently, greater risk for dementia. In order for American Indian populations to make sense of the new phenomenon of long term, progressive dementia, they may turn to culturally determined explanations of illness to aid them in either accepting or coping with an illness, especially when faced with an illness of “unknown” cause. (71, p.199)

In the American Geriatrics Society publication, *Doorway*

Thoughts: Cross-cultural Health Care for Older Adults, American

Indian Elders “with dementia are often not identified by family as ‘ill’ or ‘lost’, but rather, changed in capacity and function.” (72, p.20)

The fact that the majority of participants spoke mainly of long-term care placement when discussing formal healthcare treatment options also speaks to awareness. Many mentioned home care as a formal healthcare service used by those with dementia, but only in terms of homemaking or to manage other illnesses. Few mentioned behaviour therapies and even fewer mentioned pharmaceutical interventions, possibly due to a lack of awareness.

Unfamiliar Milieu

A lack of familiarity with tertiary care systems, specialist services, the geographic urban locales where most care is provided, and the

culturally unfamiliar methods of assessing dementia was presented as a challenge to be negotiated in terms of care access for dementia.

Potentially, this sub-category will decrease in terms of impact on the access to healthcare outside the community as younger generations are more familiar with cities and medical culture. Participants mainly characterized the challenge of unfamiliarity in terms of the older generations and spoke of the necessity of younger family members to mediate this.

Difficulty in Travel

Because much of formal healthcare, especially diagnostic and assessment services for dementia, lies outside of Northern communities, it is not surprising that the difficulty in travel would emerge as a salient barrier to negotiating care. The lack of public transportation and extreme cost of travel alone function to limit participation in healthcare outside one's community in the North. The difficulty in travel is exacerbated by the physical aspects of aging, by presence of comorbidities, and by the disease process of dementia. Anything problematic including cost, distance, stress, and discomfort is heightened due to age. In the United States, the National Indian Council on Aging reports that:

lower rates of service use may result from barriers to care such as less availability, inaccessible services, different cultural attitudes, different health beliefs and practices, lack of telephones to arrange services, lack of transportation, turnover of medical staff, crowded health care facilities, and long waits for care." (73, p.74)

It is worth noting that initially no participants discussed road conditions or weather as a concern with regard to travel. I however, experienced this as a great concern when conducting field visits. During a wintertime visit, a trip between communities that should have taken roughly two hours stretched to over three due to inclement weather. Good weather was encountered on the day prior but the road conditions were not optimal; I lost control of my vehicle on a rough section then hit a patch of ice and crashed into a snow bank. The danger of winter travel must be a limiting factor when deciding to pursue treatment and care options outside of the home community.

Language Barriers

It is not simply the act of translation that must be undertaken that serves as the barrier between Aboriginal languages and English spoken at most formal healthcare services. While translation in itself is a challenge, it is complicated by the fact that many words, especially those relating to dementia and healthcare, do not directly translate. That language barriers were constructed as having two levels is interesting as much attention is devoted to the spoken language barrier but little to the factor of medical jargon that impedes and deters some from participating in formal dementia care.

Competition for Limited Resources

Participants were able to describe the many deficits requiring funding and development within communities, and then located dementia as lower on the list of priorities for communities due to the

relatively small proportion of the population that is affected. However, participants also engaged in discussions of inequity and indicated that those with dementia and their caregivers are marginalized within an already disadvantaged group. That is, their care warrants attention despite the challenge in providing it. This lack of resource allocation may change as the population demographics change. Within this sub-category the complexity of health in Northern Aboriginal communities is illuminated. The formal healthcare resources, financial, structural and personnel, are stretched in addressing the myriad other health concerns and conditions that grow out of social inequity.

Fear

Though somewhat based on present personal experiences, much of the fear described by participants regarding the healthcare systems, specialists, and particularly long-term care is a result of the institutional impositions on Canadian Aboriginal society, particularly the formation and control of reservations and structure imposed by *The Indian Act*. Removal of children and division of families by residential schooling that continued until the early 1990s and the forced removals from community due to tuberculosis during the 1950s has also contributed to current fears.

The generation of Aboriginal Older Adults currently at greatest risk of dementia is also the generation that experienced residential schools, limited freedoms and virtual imprisonment on reserves, and attempts at cultural assimilation. (74) For people who have experienced these

oppressions, distrust of Western healthcare systems is not an unrealistic or pessimistic outlook. Fears of being moved from family and friends to be placed in a nursing home take on a heightened meaning as this may have been experienced earlier in life or experienced when children were taken. The separation from socio-cultural norms and everyday securities such as language, custom, and food may be more threatening to someone from an ethnic minority than from the majority culture.

Participants' descriptions of their experiences at residential schools were compelling and heart-breaking. Though some were able to give examples of benefits experienced through residential schooling, such as Western education, residential school experience described in this study was typified by abuse and cultural assimilation. In 1998, the Canadian government issued a Statement of Reconciliation in its effort to address the experience of residential schooling. It states:

Sadly, our history with respect to the treatment of Aboriginal people is not something in which we can take pride. Attitudes of racial and cultural superiority led to a suppression of Aboriginal culture and values. As a country, we are burdened by our past actions that resulted in weakening the identity of Aboriginal peoples, suppressing their language and cultures and outlawing spiritual practices. We must recognize the impact of these actions on the once self-sustaining nations that were disaggregated, disrupted, limited, or even destroyed by the dispossession of traditional territory, by the relocation of Aboriginal people, and by some provisions of the Indian Act.

One aspect of our relationship with Aboriginal people over this period that requires particular attention is the Residential School system. This system separated many children from their families and communities and prevented them from speaking their own languages and

from learning about their heritage and cultures. In the worst cases, it left legacies of personal pain and distress that continue to reverberate in Aboriginal communities to this day. Tragically, some children were the victims of physical and sexual abuse. (75)

Though the statement is fraught with paternalism and positions Aboriginal people as outsiders or subjects of the government rather than equal citizens, it does represent a desire to heal the trauma inflicted by residential schooling.

The fear and distrust expressed by participants is not limited to systems outside of healthcare but on current and past experiences within healthcare systems, again often imposed on Aboriginal peoples and not motivated by the best interests or needs of Aboriginal people. Adelson refers to research conducted on the development of healthcare throughout Northern Canada by Hodgson in 1982 when she states:

Anyone testing positive for [tuberculosis] was physically removed from the reserve or residential school to a sanatorium far away from home. ...The long-term effects of the disruption to family life from the long-term removal of family members had a profound impact across the country. To this day, for many Aboriginal peoples, there is a lingering fear of institutions that can be traced back to the insensitive treatment of those with tuberculosis.” (25, p.S57)

Distrust of Western Systems

The previous sub-category, ‘fear’, is intimately linked to the sub-category, ‘distrust of Western systems’, in that the experiences that motivate fears about healthcare also motivate distrust of Western systems, including Western healthcare systems. Reservations and

residential schooling were borne out of agreements made between Aboriginal groups and government in the form of treaties. These grievous actions on the part of government have resulted in an erosion of trust, as expressed by participants. Much of the social context underscoring the process of negotiating care is based in the history of colonialism. The distrust of Western systems is a direct consequence of this rather recent history, and all aspects of accessing dementia care are, at least in part, affected by this. Adelson, 2005, indicates that to understand present circumstances of Aboriginal peoples we must engage in the discourse of colonialism:

The context of this inequality emerges with and through a distressing legacy of colonialism and is sustained by ineffective, inappropriate, or under-funded programs or services for First Nations peoples in Canada. Thus, it is firmly believed that ills and illnesses ... must be seen, at least in part, as the direct and indirect present-day symptoms of a history of loss of lands and autonomy and the results of the political, cultural, economic and social disenfranchisement that ensued. (25, p.S59)

Managing in Spite of Healthcare Systems

Subverting the System

The attention paid to the social context of colonialism is not meant to depict Aboriginal peoples as hopeless victims. According to Waldram,

Any approach which fails to consider Aboriginal people as active in response to their colonial situation, rather than simply as passive victims, will fail to comprehend not only the past changes in health status and health care, but more importantly the future direction that will be taken in those areas. (76, p.270)

Rather than viewing Aboriginal peoples living in Northern Saskatchewan as passive recipients of care, healthcare practitioners and policy makers best heed the resilience and perseverance among Aboriginal Communities. The ways in which participants were able to subvert or transcend formal healthcare to ensure the needs of community members with dementia were met is a clear indication that they are active agents shaping and determining their own well-being.

Kinship and Family Caregiving

Participants characterized family caregiving and kinship as the greatest source of support throughout the process of negotiating healthcare. Kin or family members facilitate the use of formal healthcare for Aboriginal Older Adults with dementia. Without the assistance of these caregivers the Older Adult would often be unable to access formal healthcare. The family plays a central role in maintaining the well-being of the person with dementia outside of formal healthcare systems and is often the sole factor allowing the Aboriginal Older Adult with dementia to remain within his or her community. However, reliance on family caregiving can create barriers to the development of healthcare services as it obscures the need for formal care.

Research conducted by Chapleski et al. with Great Lakes American Indian families indicates that family caregiving is preferred to formal care but should not be a justification for lack of investment in formal service provision.

[People] in all residential communities maintain strong beliefs about caring for patients in non-institutionalized, home settings. It is critical to recognize that despite family support of taking care of elders, they may need help doing so. (77, p.99)

The complexity of care required by a person with dementia is challenging and could be experienced as quite a burden by the women providing care, especially in light of the multiple caregiving and work roles assumed by women:

...many people of color are finding themselves taking on the role of caregiver to an older family member with dementia. Substantially more find themselves in multi-generational caregiving positions where they are caring for a parent as well as their children and possibly grandchildren. (78, p.S46)

Caregiving by family and management outside of formal healthcare supports was described as being negative when the family was not available or able to give the care expected due to other demands or complicated circumstances. Researchers in Australia note, “decades of domination and maltreatment have left many Aboriginal families bereft of the emotional endurance needed to provide quality long-term care to a member with high support needs.” (79, p.11)

Sacrificing to Care for Others

‘Sacrificing to care for others’ relates in part to ‘kinship and family caregiving’, but it goes beyond the positive attributes of family care to account for the experiences participants shared when they or others were expected to resign from jobs or relocate to provide care for an Elder with dementia rather than use formal healthcare. Certainly the lack of formal

care that would enable those with dementia to remain within their communities plays a large role in necessitating the reliance on informal care by family.

However, it is this point that warrants further reflection: Who is sacrificing to provide care and why is it expected of them? In the case of Northern Aboriginal communities in this research project, the sacrifices made to provide care were expected of women. In some circumstances, the women sacrificed their careers, their mental health, and their personal safety by tolerating abuse in order to provide care. Armstrong argues that “when care moves home, it usually means care by women because of assumptions made about who should care.” (80, p.26) Indeed, Spitzer affirms, “cross-culturally, women are presumed to be the most appropriate caregivers for children, the infirm, and the elderly.” (81, p.S80)

Truly, the role of caregiver is complicated; it is sometimes a source of power, pride, and honour not easily relinquished, but it can also intensify the oppressions experienced by Aboriginal women by making unfair demands of them and limiting their independence and agency. Healthcare policy and planning that relies on the informal care provided by women can serve to institutionalize women’s oppression. (82) While family caregiving is characterized as the greatest strength in coping with dementia in Aboriginal communities, it cannot be the solution unless the nature of informal care is restructured in a way that does not conscript women into unpaid and sometimes unsafe environments. As well, formal

healthcare must be provided to support both the caregiver and person with dementia. Indeed,

Sending care and responsibility closer to home has been presented as a means of responding to local needs. But sending care closer to home without public service support simply means ...more work for women and less control over their lives when they provide care. (80, p.41 – 42)

The point is not to reverse the claims arguing that institutions are better than communities. Instead of setting these up as good/bad alternatives, we should be asking how we can make both better, injecting what is good about each into the other and thinking about the impacts on both providers and recipients. (80, p.35)

When there are no other options, when the healthcare systems can no longer be subverted, and when the informal care network has been exhausted or has broken down, people are forced to submit to healthcare systems that are culturally inappropriate and insensitive. Negative experiences within the formal care system perpetuate oppression by reinforcing the social context of barriers that limit participation in and ability to negotiate formal healthcare.

Submitting to Healthcare Systems

Long-term Care as a Last Resort

Participants described strong feelings of preference that care for their loved ones be provided by family. Research by John et al. indicates that American Indians would prefer that dementia care be provided in the home rather than in an institutional setting. (34) Research in Canada among Aboriginal groups echoes this, detailing some of the

practical considerations that make long-term care a less than desirable option for Aboriginal Older Adults:

Most reserves and many communities do not have nursing homes. Thus, elderly people who need continuing care must enter a nursing home away from their familiar life of their home community. There, they seldom receive the kind of food they prefer, and their family and friends are unable to visit frequently. (32, p.68)

The use of long-term care was characterized as an option only when all other options for care within the community were exhausted. Culturally insensitive long-term care, far from family and community guides the reluctance to send family members to a facility. However, a discussion of the negative associations of long-term care on the part of Aboriginal peoples would be remiss if it did not address the historical context. The perception of long-term care as negative is in part due to the lack of culturally sensitive care facilities but also inextricably linked to the experiences of forced removals for healthcare and for residential schooling. This renders removal from community and culture far more profound than that experienced by one without a historical connection to prior removal and attempted cultural assimilation. This accounts for the burden of care that will be assumed, regardless of the personal cost, to maintain care outside of the formal healthcare system.

Congdon and Rosswurn note that many rural residents “tolerate significant health problems to remain in their own homes.” (6, p.266) Similarly, the 2001 study of American Pueblo Indians by John et al. found that nursing home placement of an elder with dementia would

have a financial cost for the family but “the cultural cost (removing the elder from Pueblo culture and violating a cultural norm to provide care within the family) would be the salient consideration.” (34, p.218)

Perceived Failure on the Part of Caregiver/ Community

It is only when informal care options are exhausted and care can no longer be provided within the community that the Aboriginal Older Adult with dementia is sent to a long-term care facility. Within this project, the experience of sending a loved one to long-term care was always described as sad and painful. Participants reflected on how difficult it would be for others to admit a loved one to long-term care or spoke militantly of their intent to not allow it to happen to their families. Sending a family member to long-term care for dementia was viewed as a failure on the part of the caregiver and the community.

Also reflected in this sub-category is the unintentional contribution to feelings of guilt that comes about when a person seeks culturally insensitive formal healthcare to cope with caring for someone with dementia. A participant paraphrased a familiar statement heard in this situation, “How could you send them away? We could have helped.” The blame is placed on the individual who made the decision to seek formal care rather than constructing it as a condition that left no other option. Similarly, in a 2006 study in which she examined stigma as it relates to dementia, McKenzie notes that conflict is created “when a carer’s desire for health and social care support to maximize and sustain independence and inner pride cannot be taken up because they fear condemnation

from people in their own community.” (83, p.236) She goes on to say that this conflict can cause stress for caregivers and that it impacts how and when services are used. (83)

Participating In and Affecting Healthcare Systems

Increasing Awareness

Participants spoke of the growing awareness of the disease process of dementia and possible healthcare options on the part of practitioners in the North and noted that the increase in awareness of dementia as a disease can help to aid families in coping with the challenging behaviours that occur due to dementia. Formal training for family caregivers to enhance the care they provide was noted as a possible strategy.

The fact that dementia is not stigmatized as a personal failure is an important aspect of dementia in Northern Aboriginal communities.

Hinton and Levkoff indicate that

Whether dementia-related symptoms and disabilities are viewed as part of normal aging or as part of a disease process, they evoke behavioral and meaning-making responses from those in the afflicted person’s social network. ... From this perspective, family responses to dementia-related symptoms and disabilities are culturally and socially patterned. (84, p.455)

It appears that the cultural acceptance of illness and disease precludes the barriers that would otherwise be experienced if dementia was understood as stigmatizing, as something to warrant personal shame and hiding. Though participants indicated that it rarely occurs, hiding dementia or the severity the symptoms experienced due to dementia, is

not due to stigma but, again, relates instead to fear of long-term care and removal from community.

Building Local Care Capacity

Participants indicated that culturally appropriate and responsive formal healthcare for dementia would be better provided within Northern communities by Northern community members with formal training. Findings from Chapleski's 2003 research indicate that there is a need for local long-term care facilities that are "community-based and intergenerational involving entire families ... that represent traditions, beliefs, and spirituality of Native people." (77, p.99) Further, "long-term care systems should reflect and capitalize on the strengths of the culture in both planning and delivery, involve Native elders in planning, and involve families in delivery." (77, p.99)

Participants noted that both the formal care system and the informal care networks need investment and development. Examples of successful care provision by local Aboriginal community members that were described by participants echo the position of the Royal Commission on Aboriginal Peoples as summarized by Smith et al.:

Aboriginal people have pointed out that new health and healing systems must embody equitable access to services as well as health status outcomes, holistic approaches to interventions, Aboriginal authority over health systems, responsiveness to differences in cultures and community realities, and, where feasible, community control over services. (85, p.42)

This will serve to positively inform the background and social context that informs the process of negotiating care. If awareness of

dementia care can be increased and local care capacity enhanced, increased trust of formal healthcare will be established, leading to less reliance and exploitation of informal care and less hardship experienced by communities in Northern Saskatchewan.

Research Strengths

A major strength of this research is its innovation. To date, no studies have been published examining the experience of accessing healthcare for Aboriginal Older Adults with dementia in Northern Saskatchewan. The potential exists for this research to shape future healthcare policy, enhancing both the care provided and the access to that care for Northern residents.

By privileging the voices of those from Northern Saskatchewan, this research seeks to overcome the paternalistic pattern of much health research. That is, the aim of this project was to conduct research *with* Northern communities, not *on* them. In this way the grounded theory methodology is a strength of the research. Grounded theory methodology allowed the concerns and experiences of the participants to emerge, by guiding the data generation and keeping the emergent theory rooted in the voices of the participants.

The attention to cultural context strengthens this research. By visiting each community and interacting with participants in-person, within settings comfortable to them, richer data were generated. At one point, telephone interviews were considered as a method of efficient data

collection. However, body language, facial expression and tone of voice proved to be important factors that would not have been observed via telephone. As well, the effort of traveling to and staying within each Northern community was appreciated by participants and helped to build rapport while giving me firsthand experience of the Northern context. Rapport was also facilitated by relationships developed on prior NET research visits to two communities.

The variety of data collection methods strengthened the research in that it enabled participants to share information privately and to relate experiences within a group setting. Each method provided a different 'piece of the puzzle'. Participants commented that they enjoyed the structured activity within the focus group, saying that it helped them to better conceptualize issues and the role these issues play within the larger picture of dementia care. They also reported that the activity enhanced team building as sometimes personal insights were shared between co-workers that otherwise might not have been. The fact that the research process was considered useful to participants is important and should not be overlooked when discussing strengths.

Research Limitations

It is important to address the extent to which this research is limited in application. First, the research took place in a geographically specific location and as such, the findings may not be applicable in other geographic areas with other Aboriginal groups. As well, within the health

region where the research took place, it is important to note that the majority of participants were of Cree or Métis descent; only one spoke of being 'half- Dené'. The Keéwatin Yatthe RHA catchement area includes a large population who are Dené and, unfortunately, this research may not represent their experience of accessing dementia care. As Adelson asserts, "We cannot presume an unchanged, single, or uniform 'Aboriginal' culture." (25, p.S59)

As well, those who participated in the research project live in communities that have formal healthcare services, and the majority of participants possessed formal training within healthcare. The research may not adequately represent the experience of those who live in the far remote north, away from formal health services, or those who have had little to no contact with formal healthcare.

Originally, an exploration of traditional healing practices for dementia was contemplated as a part of this research. However, no participants discussed knowledge of or experience with traditional healing and dementia. This represents a limitation as traditional medicine may be an important facet warranting investigation.

Related to this is the possible limitation of the researcher's ethnicity. I am non-Aboriginal and disclosed this with research participants. Possibly, this impacted the amount or depth of information provided.

Research and Practice Implications

The theory that emerged through this study indicates that much work in the area of cultural sensitivity is needed. Culturally sensitive assessment tools and protocols should be developed that are readily adaptable for various cultural orientations. Healthcare workers should be encouraged to develop understandings of culture that allow for fluidity and flexibility. Finally, avenues of care that do not involve leaving community, culture, and social support should be increased and developed.

Though much was learned about why the prevalence of dementia is not accurately measured through formal healthcare channels, a gap remains as to how many Aboriginal people are affected by dementia. Also necessary are investigations of the depth of burden experienced by family caregivers and the social reality of providing care outside the formal healthcare system. Most notably, more work with other tribal affiliations and remote Northern communities is needed to provide a fuller understanding of dementia within Aboriginal peoples.

Perhaps most importantly, this research provides insight into the experience of leaving the community to receive institutional care for many Aboriginal Older Adults, particularly those with dementia. If nothing else, further work must be done to improve this situation. Future research should focus on finding the 'middle ground' described by Armstrong where the best aspects of long-term care and the best features

of care within the home and community are combined to re-envision formal care for Aboriginal Older Adults with dementia.

Concluding Statement

The findings of this research project indicate a need for enhanced formal healthcare services for treatment of dementia within Northern Aboriginal communities. “Services alone, however, do not ensure health and what services are available remain largely inadequate and underestimate the link between local control of health services and practices, meanings of health, and health disparities.” (25, p.S57) Indeed, developing formal healthcare services without simultaneously addressing the historical background and social context would render those services useless. Any effort made to improve the negotiation of culturally incongruent healthcare systems must attend to the factors that lie at the root of service non-use. To avoid perpetuating paternalistic systems of colonial oppression, dementia care must be directed from within communities and not provided *to* those communities.

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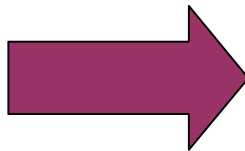
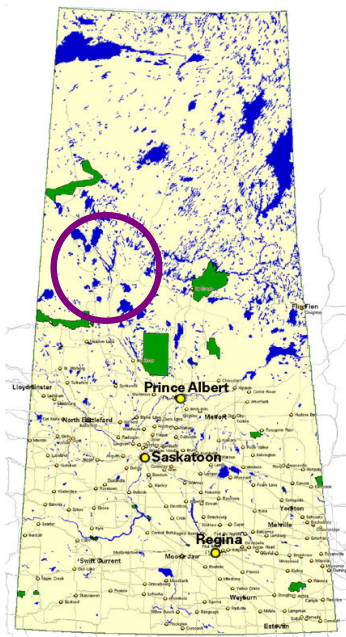
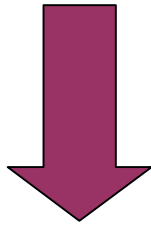
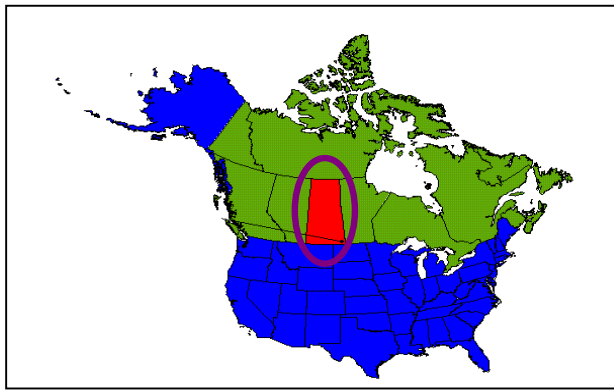
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Appendix A:
Maps Illustrating Geographic Research Area



Appendix B:
Approval to Conduct Research in
Keéwatin Yatthe Regional Health Authority



**“Wholistic
Health
of
Keewatin
Yatthe
Health
Region
Residents”**

May 2, 2005

Allison Cammer, BSc, BA, RD
C/O Debra Morgan, PhD
Associate Professor
Institute of Agricultural Rural & Environmental Health
Wing 3E, Royal University Hospital
103 Hospital Drive, University of Saskatchewan
Saskatoon, SK S7N 0W8

Dear Allison:

RE: Research Project titled: Exploring Issues of Access in Utilization of Dementia Care Services by Older Adults in Northern Saskatchewan

At the April 28, 2005 meeting of the Keewatin Yatthe Regional Health Authority (KYRHA) Board reviewed the research study titled “Exploring Issues of Access in Utilization of Dementia Care Services by Older Adults in Northern Saskatchewan” and made a motion in support of your project.

The board passed a motion for your research study contingent upon receiving documentation of ethical approval for your project. In addition, we cannot speak on services that are not directly provided by the region and would strongly encourage contact with First Nations and Municipal communities involved.

If you require further information or assistance, please feel free to contact me at (306) 832-6250.

Sincerely,

Carol Gillis
Chief Executive Officer

Cc: Keewatin Yatthe Regional Health Authority Board Members

P.O. Box 40
Buffalo Narrows, SK
S0M 0J0

Phone: (306) 235-2220
Fax: (306) 235-2229

Appendix C:
Ethical Approval of the Research Project by the
Behavioural Research Ethics Committee, Office of Research
Services, University of Saskatchewan

**UNIVERSITY OF SASKATCHEWAN
BEHAVIOURAL RESEARCH ETHICS BOARD**

<http://www.usask.ca/research/ethics.shtml>

NAME: Debra Morgan (Allison Cammer)
Centre for Agriculture Medicine

Beh #05-140

DATE: June 24, 2005

The University of Saskatchewan Behavioural Research Ethics Board has reviewed the Application for Ethics Approval for your study "Exploring Issues of Access to Dementia Care Services by Older Adults in Northern Saskatchewan" (05-140).

1. Your study has been **APPROVED SUBJECT TO THE FOLLOWING MINOR MODIFICATION(S)**:

- Please revise the consent form to include:
 - The name, affiliation and contact information of the research supervisor.
 - Statements pertaining to the purpose, objectives, and benefits of the research project.
 - A statement acknowledging that the participants may call the Office of Research Services (306.966-2084) if they have any questions about their rights as participants. It should also be stated that the participants may call collect.
 - A statement acknowledging that the research has been approved by the University of Saskatchewan Behavioural Research Ethics Board (include approval date).
 - A revised withdrawal statement that acknowledges that if a participant withdraws his/her data will be deleted.
 - Participants who are interviewed by telephone should be told they may request a written copy of the consent document; this document should be similar to the one presented to the "in-person" interviews.

2. Please send one copy of your revisions to the Ethics Office for our records. **Please highlight or underline any changes made when resubmitting.**

3. The term of this approval is for 5 years.

4. This letter serves as your certificate of approval, **effective as of the time that the requested modifications are received by the Ethics Office**. If you require a letter of unconditional approval, please so indicate on your reply, and one will be issued to you.

5. Any significant changes to your proposed study should be reported to the Chair for Research Ethics Board consideration in advance of its implementation.

6. **This approval is valid for five years on the condition that a status report form is submitted annually to the Chair of the Research Ethics Board**. This certificate will automatically be invalidated if a status report form is not received within one month of the anniversary date. Please refer to the website for further instructions:
<http://www.usask.ca/research/behavrsc.shtml>

I wish you a successful and informative study.

Dr. Valerie Thompson, Chair University of Saskatchewan Behavioural Research Ethics Board
VT/cc

Appendix D:
Written Consent Form for Individual Interviews



Consent form for Interviews (In-person)

Project Title: *Exploring Issues of Accessing Dementia Care Services by Older Adults in Northern Saskatchewan*

I, (please print name) _____, **agree to participate in this study** which will look at the issues surrounding accessing care for dementia in northern Saskatchewan. This study is being done by Allison Cammer, a graduate student in the Department of Community Health and Epidemiology in the College of Medicine at the University of Saskatchewan.

Participation in this study will involve an informal interview that will be approximately one hour long. I will be asked about my experience as a formal care-provider and community member (or as an informal caregiver and community member) regarding northern seniors accessing dementia care.

There are no anticipated risks to me due to participating in this project. All information discussed will be anonymous; my name will not be connected to any of the information I provide. Any information included in the final report will be described in a manner such that individuals will not be identifiable. The information collected through these interviews will be published in a thesis and may be summarized in professional journals or in conference presentations.

All information collected will be stored and safeguarded by Dr. Debra Morgan at the University of Saskatchewan for at least five years. Upon completion of this study I will receive a summary of the results from the researcher.

My participation in this study is voluntary and I will receive no financial compensation for participating in this study. I understand that I may withdraw from this study at any point with no fear of penalty or loss of service of any kind.

I am aware that this interview will be tape recorded for the purpose of transcribing the discussion. I understand that at any time I may ask the researcher to turn off the tape recorder without explanation or fear of penalty.

If I have any questions I may contact Ms. Allison Cammer at (306) 966-6075 or her supervisor at (306) 966-7905 by calling collect. If I have any questions about my rights as a participant I may call the Office of Research Services at (306) 966-4053.

I have read and understand this consent form and I agree to participate in this study.

I have received a copy of this consent form for my records.

Participant's Signature

Date

Researcher (Allison Cammer, BSc, BA)

Date

Appendix E:
Written Consent Form for Group Interviews
and Focus Group Discussions



Consent Form for Group Interviews and Focus Groups

Project Title: *Exploring Issues of Accessing Dementia Care Services by Older Adults in Northern Saskatchewan*

I, (please print name) _____, **agree to participate in this study** which will look at the issues surrounding accessing care for dementia in northern Saskatchewan. This study is being done by Allison Cammer, a graduate student in the Department of Community Health and Epidemiology in the College of Medicine at the University of Saskatchewan.

Participation in this study will involve a focus group discussion that will be approximately 1 to 2 hours long. I will be asked about my experience as a formal care-provider and community member regarding northern seniors accessing dementia care.

There are no anticipated risks to me due to participating in this project. All information discussed will be anonymous; my name will not be connected to any of the information I provide. Any information included in the final report will be described in a manner such that individuals will not be identifiable. The information collected through these interviews will be published in a thesis and may be summarized in professional journals or in conference presentations.

I understand that the researcher's ability to ensure confidentiality is limited due to the nature of group involvement during this focus group discussion. As a group member I will maintain the privacy and confidentiality of other group members but am aware that it is beyond the control of the researcher to ensure that all information I provide will be completely private.

All information collected will be stored and safeguarded by Dr. Debra Morgan at the University of Saskatchewan for at least five years. Upon completion of this study I will receive a summary of the results from the researcher.

My participation in this study is voluntary and I will receive no financial compensation for participating in this study. I understand that I may withdraw from this study at any point with no fear of penalty or loss of service of any kind.

I am aware that the focus group discussion will be tape recorded for the purpose of transcribing the discussion. I understand that at any time I may ask the researcher to turn off the tape recorder without explanation or fear of penalty.

If I have any questions I may contact Ms. Allison Cammer at (306) 966-6075 or her supervisor at (306) 966-7905 by calling collect. If I have any questions about my rights as a participant I may call the Office of Research Services at (306) 966-4053.

I have read and understand this consent form and I agree to participate in this study.

I have received a copy of this consent form for my records.

Participant's Signature

Date

Researcher (Allison Cammer, BSc, BA)

Date

Appendix F:
Photos of Focus Group Activity Products



Photo of focus group #1, finished product of group activity



Photo of focus group #2, finished product of group activity



Photo of focus group #3, finished product of group activity