

STORIES ABOUT CANCER FROM THE WOODLAND CREE
OF NORTHERN SASKATCHEWAN

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By

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ABSTRACT

Background: Cancer incidence is increasing among Aboriginal peoples in Canada. The semi-isolated conditions of Northern Saskatchewan provide challenges for both health care workers and patients receiving cancer care. Since limited information exists on the way cancer is perceived and experienced, the purpose of this study was to explore the views of cancer, health and illness among the Woodland Cree in Northern Saskatchewan.

Methodology: Woodland Cree participants from the Lac La Ronge Band included 6 Elders, 8 cancer survivors, and 12 family members from five northern communities. Being a member of the band and fluent in the traditional language, the principal investigator used a narrative inquiry approach. Perceptions of cancer, health and illness were elicited through 18 personal interviews and two group interviews. Composite story creation and thematic analysis were the two methods used to analyze the data.

Findings: Four broad themes were generated from the data. The concepts of health and illness among the Woodland Cree show that there is a complex intertwining of Western and traditional belief systems. Knowledge systems of the Woodland Cree represent the ways of knowing and being, including the seminal role Elders have within the communities as teachers and knowledge keepers. Cancer as experienced by the Woodland Cree reflects the physical, emotional, intellectual and spiritual aspects of having cancer or having a family member with cancer, including the challenges of receiving timely diagnoses and cancer care in isolated northern communities. Straddling both worlds was a theme that meandered throughout the data. The Woodland Cree have the capacity to pick the best from both the Western and traditional worlds, by accessing their inherent survival mechanisms.

Discussion: Reluctance to talk about cancer seemed to be a deterrent from participating in the study. Family members need specific support mechanisms apart from the cancer patient and this may not be readily available. Challenges and opportunities for more culturally sensitive ways of providing cancer prevention and care are discussed. Further research is needed to investigate if the findings are reflected among other First Nations.

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This dissertation would not have been completed without the support of my family, my friends, my ancestors and the Creator. *Ni Nanaskomon.*

DEDICATION

I dedicate this dissertation to my mother Elizabeth Nancy Roberts (*Machiskwesis*). She is an incredible woman who had the foresight and fortitude to insist that her children receive a Western education so that they would have a greater chance of success in a world that she knew was rapidly changing. *Teniki Nimama*.

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GLOSSARY OF CREE WORDS

The words are organized by location within the text

Ni Nanaskomon – I am grateful; I give thanks

Teniki Nimama – thank you my mother

Munchoosuk - cancer

Induminahisochik – fending for oneself in terms of survival especially relating to obtaining food from the land

Mathithichikee – to not listen to authority figures; to disrespect people and property

Wepaskoputhichikunis – a particular way of setting a snare where a small tree was bent over and held in place, the snare was set near the tip of the tree, when an animal was caught, the natural flexibility of the tree meant the animal would be hanging a distance from the ground.

Seepeethitamowin – having faith (not necessarily referring to the Christian usage); perseverance

Peeyutukeethimowin – a sense of calm and peacefulness; not having to worry

Munitou- among the Woodland Cree, this refers to Jesus Christ

Kitchi Munitou – among the Woodland Cree, this refers to God

Witikowuk – individuals in Woodland Cree stories that are believed to have become cannibals, their heart area encased in ice and they have eaten the flesh around their mouths, they capture their victims by inhaling. Most often referred to as a single entity in the stories i.e. **Witiko**.

Aswithimin – beware of me

Chukutuhokoot – pecked at with respect to a bird; can also be used to describe an unintentional bumping into usually involving some pain

Pukwati – would not like it; would be upset; would be sad/unhappy

Pukwutamun – present tense of **pukwati**; I was upset/sad/unhappy

Nihithow – single person for someone who is Woodland Cree; a Plains Cree would refer to himself/herself as a **Nihiyow**

Nihithowuk – plural for the Woodland Cree

Seemak – right away; right now; immediately

Wah-wah – an exclamation similar to a phrase such as ‘oh my goodness’ or ‘good grief’ depending on the context

Itinoowapiniwin – An illness/disease process described by the Elders in Grandmother’s Bay, one that has not been translated/transposed into a Western medical diagnosis, described to have been always terminal without any significant means of treatment of symptoms

Itinoowapinit – someone who has come down with **itinoowapiniwin**

Mithopimatisiwin – living a good life; living life according to the cultural teachings of the Woodland Cree

Mithoyawin – being in a state of good health; being healthy; can also be used to describe the process one goes through to achieve good health

Kitiaya – a term denoting an elderly person, male or female

Noochookeso – an old lady

Kisiteno – an old man

Poowamowin – the form of spirituality practiced by the Woodland Cree before and after the arrival of the missionaries and Christianity; can be translated to refer to *the dreaming*, a reference to the power of dreams in relation to receiving knowledge, power and speaking with one’s spirit guides

Nihithowi muskikiyu – a pluralized form of referring to Cree medicines

Apitowikosanuk – literal translation is half-sons, referring to those individuals that have parentage from both the Woodland Cree and the White

Chapter 1. Introduction

The Woodland Cree name for cancer is *munchoosuk*, the word as I understand and use it today refers to beetle type bugs. However, the visual image as it refers to cancer is more like a white maggot. There was a medicine man that came to Stanley Mission when I was a teenager; there hadn't been a medicine man there for years and community members flocked to him, my mother included. Her heel was causing her pain when she walked, and if a Western trained physician were to diagnose it today, it would likely be heel spurs. However, she went to the medicine man and he sucked out two small beetle shaped organisms and her heel pain disappeared. She came home that evening regaling us with what she had seen, such as the half bucket of blood that was released from a man without any cuts on his body and the many maggot-like worms that were sucked out of a woman who had cancer. Although I had heard the term *munchoosuk* before, this was the first time I had a visual image of maggot-like worms.

Does the image of cancer referring to maggots (who live by eating dead organisms) indicate that someone with cancer among the Woodland Cree will soon be dead and maggots will be eating their dead body? Where did these terms come from? How long has cancer been referred to as *munchoosuk*? When my mother was diagnosed with cervical cancer in the year 2000, she informed me that '*munchoosuk e moowichik nutuk*' (*maggot-like worms are eating me in my stomach*). Being a Western trained nurse by that time and knowing that cancer is our own cells over-multiplying, I found that the childhood image of maggot-like worms eating my mother still popped into my head. Along with this image was the thought of what had my mother done to deserve this? Further back in my mind was the question of why my mother was telling people she had cancer in her stomach when it was actually part of her womb, for which there is a Cree word? And of course, was my mother going to die because everyone I had known with cancer had died? It is in wanting to find answers to these questions and wanting to get a deeper sense of how cancer is seen and understood among my people, the Woodland Cree of Northern Saskatchewan that propelled my research into this area.

The Woodland Cree are a small pocket of Aboriginal people who live in and around the communities of La Ronge, Stanley Mission, Grandmother's Bay, Hall Lake, Little Red River, Sucker River, Southend, Dechambault, and Pelican Narrows. Most of the communities are

situated on the banks of the Churchill River, with the exception of La Ronge, Hall Lake, Sucker River and Little Red River. We differ from other Algonquin tribes mainly through linguistics; we speak Cree using the 'th' dialect. The Swampy Cree, of which the only community in Saskatchewan is Cumberland House, speak with the 'n' dialect, whereas the Plains Cree, the highest population of Cree in Saskatchewan speak with the 'y' dialect. The communities of Hall Lake, La Ronge, Sucker River, Grandmother's Bay and Stanley Mission are all part of the Lac La Ronge Indian Band. The communities of Southend, Deschambault and Pelican Narrows are part of the Peter Ballantyne Cree Nation. (See Figure 1. Map of Saskatchewan and Figure 2. Lac La Ronge Band Reserves)

I grew up in Stanley Mission, was baptized and confirmed in the Anglican religion. Stanley Mission is the site of the oldest Anglican Church west of the Red River in Manitoba. It was built in 1854, an indication of the length of time since missionaries made contact with the Woodland Cree. We lived off the land and waters for the most part, eating fish, moose meat, duck, beaver and other wildlife, supplementing our diet with berries and roots when they were available. Mom taught us what she knew about traditional medicines, how to gather them, when to gather them, what they were used for and to always pay back what we took with tobacco. I learned the traditional crafts of beading, tanning hides; birch bark biting and making birch bark containers. We watched my grandfather make birch bark canoes meant for museums and I would accompany my grandmother to collect the roots that would be used to sew the pieces of birch bark together.

Mom also insisted that we go to school and get a Western education. She thought it was a failing on her part that she did not know how to speak English. My years of schooling were spent in either the Prince Albert Residential School or the school that was eventually built in Stanley. What she didn't and perhaps still doesn't realize is that Western education taught us to be ashamed of who we were. It is only now, 30 some odd years later that I am becoming proud of who I am, where I came from and how I was raised. I have received the Western education; working on my doctoral dissertation indicates that I am working on the highest level of education available in this paradigm. Smith introduced me to Fanon's process of how 'Native intellectuals' return to their people.¹ There are 3 phases that individuals will/should go through; 1)

assimilation, 2) disturbance and remembering who they are and 3) realigning themselves with their people and producing revolutionary and national literature.¹ I am now at phase 3 and it is time for me to return to my roots and learn from my elders and my people again.

The semi-isolated locations of the Woodland Cree provide challenges for health care workers not only for providing cancer care but also for screening programs for prevention purposes. Cancer patients must travel to Saskatoon or Prince Albert for their treatment and since cancer primarily strikes the elderly, the entire experience can be culturally and socially alienating. Family members often come along to provide emotional support as well as translation services. The *munchoosuk* concept works well for describing the treatment process for those individuals that cannot speak English. For example, ‘they are going to cut the *munchoosuk* out’, or ‘they are going to shine a bright light on the *munchoosuk* to burn them out’, or ‘they are going to inject medicine into the *munchoosuk* to kill them’.

My mom had a complete hysterectomy and the surrounding lymph nodes were also removed. My sister Isabelle had accompanied and translated for her to the pre-surgery check up in Prince Albert. It wasn’t until I was in the pre-operative surgery waiting room with her that I realized what an excellent job Isabelle had done in the translation. Mom had the pen poised over the final consent form; she looked at me and stated, “*Kespin eka musinahamin niwithowin, numwach nikaki matsokwuk.*” (*If I don’t sign my name, they can’t cut me.*) I nodded my head in agreement. She looked at me, looked at my sister Joan, reiterated once again that she was feeling well but once she signed her name she would be helpless and very, very sick and that sooner or later we were all going to die anyway. The ethical implications of informed and voluntary consent I knew from being a nurse and the selfish reasons of still wanting my mother around were warring inside me. Joan had no such compunctions and was telling Mom that she would be sick only for a short while but she’d be able to live longer and see her grandchildren grow up. (Joan was pregnant with her first child at the time.) Eventually Mom signed the consent form and today she continues to be cancer free. She did not require any adjuvant therapies such as chemotherapy or radiation. However, she still adheres to the viewpoint that cancer will eventually kill her, because after each follow-up visit and a clean bill of health, she remarks that she gets to live one more year. My mother’s comments intrigue me. It leads me to wonder if she

is a pessimist by nature, or by religion, or if this is a widely accepted cultural concept of life in general among the Woodland Cree. It is seeking answers to questions such as these that led me to this research study.

The research questions that guided this project were: how do the Woodland Cree define health and illness; how do the Woodland Cree perceive a diagnosis of cancer and how have Woodland Cree cancer survivors integrated their illness into their world view? There is no qualitative data on the perspectives of cancer among the Woodland Cree; in fact there are very few qualitative studies in this area with any First Nations in Canada. One of the few that I found through personal contacts was a 1996 Master's thesis titled *First Nations People's Perspectives and Experiences with Cancer* by Fjola Hart-Wasekeesikaw from the University of Manitoba. Although the title carries the broad implication of First Nations, in actuality it was an ethnographic study of 4 Anishinawbe (Ojibwe) communities in Southern Manitoba. The Anishinawbe and Cree belong to the same linguistic group of Algonquin. This is evident in the Anishinawbe word *manitoch*, which the Elders used to describe cancer and which Hart-Wasekeesikaw translates to cancer-as-worm as being very similar to the maggot-like worm *munchoosuk* among the Woodland Cree.

When it comes to cancer among the Aboriginal population, quantitative data indicates that although the overall incidence and prevalence rates are lower than the general Canadian population, the rates are definitely on the rise. There is no doubt that cancer is a disease that has not reached the epidemic proportions of diabetes nor has the same mortality rates of cardiovascular diseases. However, it is the third leading cause of death in both sexes.² Furthermore, a recently released statistical profile report on First Nations in Canada states that the lifespan has increased among both genders, 68.9 years old for males, 76.6 years old for females. This represents an increase from 1980 of 13.1% for males and 12.6% for females. Since cancer is most commonly found in the older population, the expectation is that cancer incidence will also rise. Cancer trends from 1967 to 1986 in the Northern Saskatchewan population, which includes the Woodland Cree, shows that there has been a 100% increase in cancer incidence, while the provincial rate has increased by only 19%.³ Although quantitative information provides indicators of the severity of diseases, it is a one sided view of life, primarily morbidity and

mortality. I wanted to hear about the life experiences of the Woodland Cree with respect to cancer, health and illness and I knew that I could accomplish this more easily using qualitative methodologies.

The traditional teachings I have received from Plains Cree and Anishinawbe Elders speak of the interconnectedness of all things and the medicine wheel is the most common symbol used to denote this interconnectedness. There are four areas of the medicine wheel; the physical, the emotional, the intellectual and the spiritual. In order for an individual to be healthy, all four areas need to be in balance. When an individual is diagnosed with cancer, all the focus and the treatment of Western medicine is on the physical quadrant. What happens in the other three quadrants? The Woodland Cree have been Christianized for over 150 years; many of their traditional spiritual practices have been lost in time. How then have their views of health and illness changed? Is there still an unspoken connection to the medicine wheel and the teachings of interconnectedness? Documenting the health and illness paradigm of the Woodland Cree would allow me and other health care practitioners to design and implement culturally appropriate health promotion, education and prevention programs.

The qualitative tradition that I feel most comfortable with is that of narrative inquiry. The research area concerning qualitative aspects of cancer among the Woodland Cree is relatively unknown and according to Clandinin and Connelly ⁴ (p.10), “Narrative and life go together and so the principal attraction of narrative as method is its capacity to render life experiences, both personal and social, in relevant and meaningful ways.” Attempting to uncover the broad understanding of health and illness of the Woodland Cree according to teachings from the Elders is a foray into the social fabric of the Woodland Cree. Furthermore, understanding how cancer survivors have incorporated their illness into their world view is personal as well as social. Narrative appeals to me because of the qualities it shares with Aboriginal ways of knowing. All of my Aboriginal teachings I have learned through stories. Many winter nights were spent listening to sounds of my Mother telling us legends as the fire crackled in the woodstove and we were snuggled up in bed. Story telling evokes many childhood memories and strikes a chord within my soul as a way to return to my traditional ways. Narrative inquiry is also a process of

collaboration; the researcher is not separate from the process and both voices need to be heard in the final product.⁴

Being educated in both the Cree and Western traditions has provided me with the knowledge, skills and understanding of both worlds. While finding a balance and trying to live in both worlds has been a struggle, it has provided me with the ability to traverse both worlds. Aboriginal ways of learning and teaching are primarily based on observation and listening, whereas, Western ways of learning are reading and writing. Sitting and listening to the stories of the Woodland Cree, both in Cree and English was an exhilarating and humbling experience. Translating some of the stories first into English and then into a written word document and then analyzing the stories were two bridging mechanisms between the two world views and hopefully the findings will create some change in cancer care protocols.



Figure 1. Map of Saskatchewan

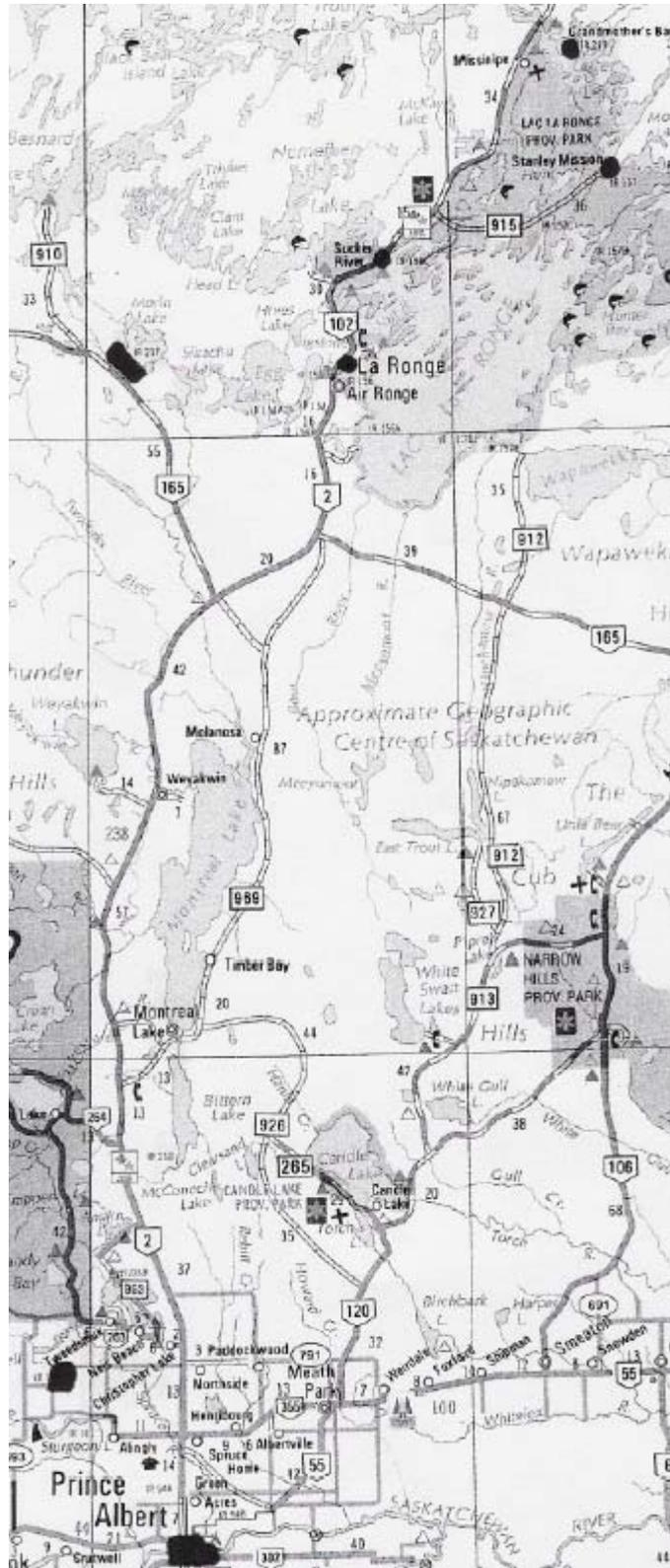


Figure 2. Lac La Ronge Band Reserves

Chapter 2. Overview of the Literature

Clandinin and Connelly suggest that the literature ought to be woven throughout the document so that the distinction between theory and practice of narrative inquiry is seamless.⁵ However, for practical purposes in this dissertation, the literature is presented in its own chapter within the specific categories of Aboriginal cancer epidemiology, Aboriginal cultural perceptions of health and cancer, and Aboriginal cancer screening and prevention programs. The term Aboriginal as I am using it in this chapter is becoming recognized as a catch-all phrase to include First Nations status, First Nations non-status, Métis and Inuit.

Comparing and contrasting between one item and another is one of the well known and commonly used methods in the Western scientific knowledge paradigm. I purposely chose not to compare the cancer literature on Aboriginal peoples with non-Aboriginal peoples, because I did not wish to propagate the view that Aboriginal people are different or less than non-Aboriginal people. I do include reference to other indigenous populations from other countries such as the United States and Australia, because of the cultural similarities between indigenous peoples in other parts of the world in terms of histories, colonization and traditions.

2.1 Aboriginal Cancer Epidemiology

The epidemiology of cancer among the Aboriginal population is the typical description of mortality and morbidity rates compared to the general population or some other population for comparison basis. It was easier to obtain reliable epidemiological data on First Nations due to the treaty number registration system instituted by the Federal governmentⁱ which facilitates tracking through the health system, as opposed to Non-Status First Nations and Métis, who are more difficult to isolate from the general population, and the data presented here reflect this for the most part. The purpose of including this quantitative information within a qualitative research document is to give an overview of the extent cancer has infiltrated the Aboriginal population.

The many negative socioeconomic and health indicators of their peoples often overwhelm Aboriginal communities. The 1991 Aboriginal Peoples' Survey which included

ⁱ Part of the treaty process involved the assigning of treaty numbers to individuals listed in the treaties and to their descendants. The master list is updated and kept in Ottawa with the Department of Indian and Northern Affairs and one aspect is related to tracking health care service utilization by treaty Indians.

respondents who checked off any of the three categories of North American Indian, Métis or Inuit, indicates that the participants listed substance abuse as the perceived number one health threat, with cancer coming in a distant second.⁶ The epidemiology of cancer can give an idea of the severity and extent of cancer as a disease entity, thus providing an indicator within the community health profile, although this does not necessarily correlate with the perceived level of threat at the community level. Cancer incidence and prevalence rates are typically lower than the general population, but the life expectancy rates have been increasing; therefore, the assumption is that the rates of cancer will also increase.

In Canada among First Nations and Inuit, there has been a decreased mortality rate from the 1991-1993 period including cancer, which indicates that there are more survivors within these populations. The life expectancy has also risen, 68.9 years of age for males, 76.6 years of age for females. This represents an increase from 1980 of 13.1% for males and 12.6% for females. This is encouraging news for Aboriginal peoples. However, it also indicates that we can expect to see a rise in chronic illnesses associated with advanced age, including cancer. Cancer was the third leading cause of death for both sexes and the most common cancer sites in males were lung, prostate and colon, while among women it was breast, lung and colon.

Recent improvements in cancer surveillance in the United States indicates that the cancer burden is considerable and increasing.^{7,8} Within the United States, site specific cancers show incidence excesses for American Indians in kidney, liver and gallbladder, for Alaska Natives they were colon, rectum, stomach, kidney, lung and cervical.⁹ Cobb and Paisano state that the patterns are similar to those observed in many developing nations.¹⁰ American Indians also have the poorest survival of any racial group for all cancer sites combined (35% compared to 50% for whites).⁹ Lung cancer is the leading cause of death among American Indians and Alaska Natives, followed by breast, colon and cancer of the cervix.¹¹ It is becoming apparent that the most common cancer sites are beginning to reflect those in the larger population. Risendal et al suggest that the cancer risk is increasing as American Indians adopt the western lifestyle and the ensuing environmental changes.¹¹ Co-morbidity and poorer health status could be factors in the poorer survival rates¹² as well as late stage of diagnosis.¹⁰ The health care system for American Indians in the United States is also a factor. Indian Health Services only provides health care to

those living on or near reservations.¹⁰ American Indians living in urban centers are responsible for their own health care costs. Burhansstipanov and Hollow state that less than one third of American Indian breast cancer survivors have access to insurance.¹³ Kaur¹⁴ (p.1581) states that improving cancer prevention and control programs are very important “because these are small populations, each patient lost is a major loss to the community,” and this is also true for Canadian Aboriginal communities.

Rosenberg and Martel report increases in both incidence (7%) and mortality (50%) from cancer using age-standardized rates for Manitoba First Nations living on-reserve.¹⁵ This trend is consistent with the rising trend in chronic diseases. The crude and standardized rates are lower than the general population but if this present trend continues, the gap will narrow.¹⁵ The rising incidence and mortality of lung cancer, particularly in females, is consistent with the general population. The persistently high rates of cervical cancer are disturbing since pap tests are an effective form of early detection.

The most recent publication by the Saskatchewan Cancer Agency, released in 2004, shows a breakdown of cancer prevalence and incidence by Provincial Health Regions up to 2002. However, due to the small population in Northern Saskatchewan, the statistics were combined for the three northernmost Health Regions and includes First Nations, Métis and others. The report indicates that the North was the only region where lung cancer was the most common site.¹⁶ The second most common site was breast among females, followed closely by colorectal in both males and females and prostate in males.¹⁶ Mortality rates indicate that lung cancer was the leading cause of cancer death in both males and females. Cancer of the breast and primary unknown cancer siteⁱⁱ were the second and third leading causes of cancer deaths among females; while primary unknown site and colorectal were the second and third leading causes of cancer death among males.¹⁶ In an earlier study in Northern Saskatchewan, the trends from 1967 to 1986 showed that there had been a 100% increase in cancer incidence, while the provincial rate had increased by only 19%.³ Lung cancer was the most common at 17.8%, followed by breast (12.6%), prostate (9.5%), colorectal (9.1%) and cervical (6.6%), compared to the southern

ⁱⁱ Most of the time individuals present with a primary site where the cancer has originated from, but in circumstances where the individual has cancer in multiple sites at first contact with the health care system, it is difficult to ascertain where the cancer had started.

population where colorectal (14.1%), breast (12.9%), prostate (12.2%) and lung (11.3%) were the 4 most common cancers.³ Northerners had significantly lower survival rates. Five-year survival was 54% for northerners compared to 60% for total population and females had better survival rates than males. Breast cancer incidence rates increased 350% (24.3 to 86.1/100,000) in northerners, while provincial rates remained fairly stable (78.9 to 83.2/100,000). Cervical cancer incidence rates were generally higher; they decreased by 45% provincially, while the incidence in the north increased by 10%.³ A more recent Saskatchewan-wide study, Alvi separated the population into 4 groups: northern First Nations, northern non-First Nations, southern First Nations and the comparison group of southern non-First Nations.¹⁷ His study which looked specifically at cancers of the breast, cervix, and colorectum found that northern First Nations had significantly lower survival rates for breast and cervical cancer and while the survival rates for colorectal cancer were higher than the other 3 groups, they were not statistically significant.¹⁷

Health Canada issues a yearly report titled *Vital Statistics of the Saskatchewan Registered Indian Population*, which is typically 3 years behind in date and includes First Nations living both on and off reserve. In the three most recent years 1999, 2000 and 2001, neoplasms were the second leading cause of death for males and females combined (n=67, n=63, n=60).^{18,19,20} Starting in the year 1997, Health Canada began reporting the highest incidences of cancers and in 1998 began reporting on chronic diseases as part of the report. Breast cancer, cervical, and prostate have consistently been the three leading sites since 1997. In 1998, there were 265 First Nations people living with cancer²¹; in 1999, there were 275¹⁸; in 2000 there were 277¹⁹ and in 2001 there were 288 individuals.²⁰ The quantitative data indicates that the incidence of cancer is increasing, the survival rates are lower, and the most common cancers are beginning to reflect those of the general population.

2.2 Aboriginal Cultural Perceptions of Health and Cancer

There are multiple definitions of culture found in the various sciences but the common themes often include traditions, norms and symbols. Ting-Toomey states that culture is a complex frame of reference that consists of patterns, traditions, beliefs, values, norms, symbols, and meanings that are shared in varying degrees by interacting members of a community.²² The focus of research in the area of perceptions of health and cancer revolves around different

cultural and social implications among Aboriginal populations in Canada and other parts of the world in relation to cancer, in terms of cause, use of health care services, cultural practices, and traditional healing practices.

I am most interested in how Aboriginal people have incorporated cancer into their world view of health and illness. Aboriginal women of Australia's understanding of health and illness are mediated by personal experiences, culture, social, historical and structural factors.²³ In terms of breast cancer among these women, late presentation is common, with issues such as distrust of medical care, remote location and lack of preventive services or use of them, lack of confidence in breast self examinations (BSE) and hard to find privacy in homes.²³ While these are seen as contributing factors to late presentation, they are not normally viewed through a culture lens. Other issues identified as socio-cultural include being embarrassed to reveal their breasts to someone for examination or screening, and abnormal screening being seen as a death sign.²³ Another example of health beliefs is among the Houma Indians in southern Louisiana who believe that despite such high-risk behaviors of smoking, chewing tobacco, and pipe smoking, that they are less susceptible to cancer as compared with white women because they tend to live in harmony with nature and take less medication.²⁴ Burhansstipanov and Hollow also report that most traditional healers believe cancer is a white man's disease and therefore requires white man's medicine to cure it.¹³ Alternatively, a Canadian study by Hart-Wasekeesikaw among the Anishinawbe in southern Manitoba found that the Anishinawbe felt Western medicine merely slowed down the cancer and only traditional medicine could cure it.²⁵

The following causes of cancer were described by Anishinawbe Elders and community members: environmental pollution affecting the wildlife, high intake of junk food, chemicals in food, canned food, fried foods, tobacco, physical injury, and chemicals in water, infection – contagion, heredity, and bad medicine.²⁵ Some Elders thought cancer has always been in their communities, but it either got cured or the person died without it being diagnosed.²⁵ Another interesting finding in Hart-Wasekeesikaw study was that cancer was seen as being shameful and thus not encouraged to be openly discussed by some of her participants. The psychological response of cancer survivors is often self-blame; this is also shared among Native Americans, feeling that cancer is a punishment.^{25, 26} Other causes of cancer identified by American Indians

and Alaska Natives include: wearing the pain to protect community members, natural part of one's path and lessons to learn, being cursed by someone or breaking a taboo, and cancer as a contagion.⁷

The implication of a cancer diagnosis being a death sentence is fairly common among Aboriginal people. As previously mentioned, an abnormal screening result was seen as a death sign among Australian Aboriginals.²³ Anishinawbe people saw cancer as a death sentence, believing that cancer could never be completely removed from the body.²⁵ "It is a life sentence. There's no cure. Every person that I've known with cancer has died from it" (Hart-Wasekeesikaw²⁵ p.212). Kaur, an American Indian oncologist, encourages that "there is a need to overcome the tendency towards fatalism, because it has delayed diagnosis and treatment of cancer for too many Indian people" (Kaur²⁷ p.452). Poorer survival could indicate later stage of diagnosis, poor access or underutilization of screening services and financial burden, especially for American Indians.²⁸ Logically, if one believes cancer is incurable, one would avoid any tests that may confirm its presence. Long term survivors are virtually invisible in communities, letting no one know of their condition; not surprisingly it is only those that die from the disease that confirms the worst impression.¹⁴

The utilization of health care services in the treatment of cancer is most often presented as either substandard in the case of American Indians¹³, or inaccessible in the outback of Australia²³ and the northern regions of Saskatchewan.¹⁷ Cultural factors that may inhibit cancer screening participation include: norm of not seeking medical care unless sick; present-time orientation; attribution of disease to other factors not lifestyle; reluctance to talk about cancer for fear of bringing it on oneself; modesty; introversion and pragmatism.²⁹ Socioeconomic issues of poverty, rural issues of travel, unavailability of screening equipment and the US health care system as it applies to American Indians, where provision is only applicable on reservations, were also contributing factors.^{28,30}

Hart-Wasekeesikaw reports that all the cancer patients in her study had sought other ways of healing besides the Western cancer treatment modalities, either through healing of traditional Indian medicine and/or Christian prayer.²⁵ Traditional Indian medicine is used by over half of

American Indian cancer patients along with western medicine. “To Native Americans, medicine and religion are inextricably linked” (Burhansstipanov and Hollow ¹³ p.212). Traditional Indian medicine for cancer care is often prayer, herbal beverages, topical ointments and ceremony.¹³ However, among the Hopi in Arizona, Coe et al reported that traditional healers were most often consulted for muscle sprains, aches, dislocations and second opinions.³¹ American Indians are often reluctant to discuss alternative and complimentary health treatments with most western medical providers. This reticence is somewhat due to non-Natives misusing the information or using the information to belittle or criticize the intelligences of the Indian patient, or concerns that traditional Indian medicine practices may not be protected sufficiently.¹³

One Anishinawbe Elder, when asked what does cancer look like, said that there were two types, the first type was a cancer with hair like legs; the other kind has a black head at the center with two projections coming from it, one pointing to the south and the other pointing northward while another Elder described a hair-like creature with long legs coming out of a man’s hip upon removal of a poultice during a doctoring ceremony.²⁵ Other Elders said that medicine people knew how to cure cancer, but this knowledge has not been passed on to the next generation.²⁵

2.3 Aboriginal Cancer Screening and Prevention Programs

Cancer screening and education programs specific to Aboriginal people are becoming more common. An American report states that in 1999 there were over 90 documented programs specific to American Indians, compared to zero in 1990.²⁶ However, American Indian women, along with other racial/ethnic populations were among the lowest users of cancer screening practices, which may be another contributing factor to lower survival rates and later stages at diagnosis.²⁸ Sociocultural barriers are often the most difficult to uncover but they are probably the most important when it comes to screening programs.⁷ It is interesting to note that Foxall et al found that American Indian women were more aware of their bodies and identified an inverse relationship with breast and gynecological screening rates.³² The National Breast and Cervical Cancer Early Detection Program was initiated by the Centers for Disease Control and Prevention with the goal of reducing mortality among underserved women including American Indians.⁸ Tribal associations were provided funding to develop their individualized screening education and awareness programs. Essential elements for planning prevention and support programs

include an awareness and understanding of cultural concepts of cancer and its prevention and sensitivity to cultural barriers.^{29, 33} The widely held cultural values of interdependence, collective responsibility and cooperation could be used to develop strong culturally sensitive cancer education and intervention programs.¹⁴ Brant et al identified factors such as poverty, substance abuse, traditional roles of women as the providers, concern over their health only when it interferes with daily living, and beliefs of a cancer diagnosis meaning death, contributing to the low participation rates in screening programs.³⁰ Therefore, education programs that incorporate one-on-one teaching that accommodate Aboriginal women's sense of privacy, honoring women and their culture, including gifts and incentives that use Native artwork were a few successful strategies.^{8,26,30} Support groups on reserves,²⁶ innovative ways of getting women into screening programs such as posters, advertising in Aboriginal newspapers, community meetings,³⁴ and training female nurses to be examiners^{35, 36} are other examples. Another example is *The Native Sisters*, a support/advocacy program based out of United States focused on improving breast cancer screening participation rates for American Indian women.³⁷ The *Sisters*, who are Native American, educate and encourage women to go for regular screenings; they also help any woman who needs follow-up care to navigate through the healthcare system, accompanying the patient to the healthcare facility for biopsy and /or treatment and assisting her in finding appropriate offices and departments.³⁷ Other examples include distribution of culturally sensitive and low literacy level education material.^{7,30} American Indian women have been reported to have the perception that they are at greater risk for gynecological cancer and have increased rates of breast self examinations.³² So perhaps the educational message is getting out in the American Indian communities.

In Canada, there is a limited amount of literature in the area of screening programs specific to Aboriginal peoples. In British Columbia, First Nations women had lower rates of cervical screening than other women in British Columbia; older women had even lower rates, including some women that had never had a Pap smear.³⁸ In an effort to increase the rates of cervical screening among First Nations women, Hislop et al identified some barriers to cervical screening and initiated recruitment strategies that targeted First Nations women.³⁸ Some of the barriers included health care providers' attitude, ability to understand information being provided, establishing a trusting relationship with health care providers, males performing the

screening procedure, and not integrating the concept of prevention into their views on health.³⁸ Recommendations put forward by the research participants were in three main areas: knowledge, environment, and health care providers. Increasing awareness of the cervical screening process, more visual aids and information that was culturally appropriate, clinics and clinicians receptive to First Nations women, holistic care that includes Western and traditional medicine and practices, were among the specific recommendations.³⁹ An intervention study with a clearly defined population of the Haida Gwaii in British Columbia showed a 15% increase in cervical screening.⁴⁰ Strategies used included: 1) use of the Community Health Representatives as liaisons, 2) scheduling ½ day clinics specifically for pap smears, 3) having female physicians perform the pap smears, 4) contacting women up to three times prior to the clinic and 5) providing refreshments and an opportunity to socialize following the screening procedure.⁴⁰ In Saskatchewan, Northern Medical Services published a pamphlet titled *Take time to care for yourself: Saskatchewan Aboriginal women and cancer* in 1994. It is unknown how widely distributed this pamphlet is but it is heartening to read that in 2000 it had its second publication. Due to the dearth of literature within Canada, it is difficult to establish if Canada is behind the United States in terms of screening and education programs or if it is a lack of publication of such programs. There is no doubt that more programs need to be developed to address this issue among Aboriginal communities.

Chapter 3. Methodology

This chapter outlines the process I went through in traversing philosophical and theoretical perspectives of research ethics, methodologies and paradigms pertaining to the Western world and the Aboriginal world, to the practicalities of researching in Aboriginal communities. I had to find my own path that combined my Aboriginal culture and traditions with Western based research protocols, without either holding sway over the other. Willie Ermine, the Indigenous People's Health Research Center's ethicist and researcher encouraged me by saying, "You are the bridge between Western research and your community."

3.1 Research Objectives

The purpose of this research was to determine the perceptions of cancer, health and illness among the Woodland Cree of Northern Saskatchewan. The population from which participants were chosen was limited to those that were members of the Lac La Ronge Band. This group was chosen specifically because I am a member of the Band and was therefore more likely to gain access and acceptance. I also speak the traditional language and was able to capture the meanings and lived experiences in both languages.

Narrative inquiry is more suited for researching and sorting out 'experience'. Therefore, the basis of my research was to find out the 'experience' of cancer among the Woodland Cree and was guided by the following research questions.

1. How do the Woodland Cree define overall health and illness?

The first step was to find out what the health paradigm is for the Woodland Cree and this was to be accomplished by talking with the Elders. Elders are the keepers of traditional knowledge among Aboriginal communities and if I was going to uncover the traditional health paradigm then these were the individuals that would likely provide the answers. Information was gathered regarding health and illness, such as: what it means to be healthy, what it means to be ill, how people stay healthy, and how people get sick (see Appendix 1). Since the Woodland Cree have been Christianized for over 150 years, I was interested to see if any of the traditional teachings reflect those of more traditional tribes such as the Plains Cree. For example, I was taught to pay for traditional medicine we harvested with tobacco, but my mother could not give me a suitable explanation other than 'because we always have'. Furthermore, I knew the Cree word for sweat

lodge because it was in the legends, but it was only when I came down south that I had a physical image to put with the word. I wanted to find out if there were any Elders that still maintained the traditional knowledge and to what extent it reflected the teachings of the medicine wheel.

2. How do the Woodland Cree perceive a diagnosis of cancer?

Another group of participants were individuals that had or currently have cancer. I surmised that those individuals that have recovered from cancer would be able to give me a more wholistic picture of their healing journey, but the number of survivors is quite small, so I thought I would have to use participants that currently have cancer. My preference was for survivors, and I defined survivors as those individuals that had completed their cancer treatment. Although those that currently have cancer may have been able to provide the steps that one goes through during a life threatening illness, I wanted to obtain as complete a picture of their cancer experience as I could. Fortunately, I was able to get participants that had completed their cancer treatment. Through a series of questions I was able to elicit how the individual progressed through the process of feeling ill, receiving their diagnosis, going through treatment and recovery as well as their personal meanings of health and illness (see Appendix 2).

3. How have Woodland Cree cancer survivors integrated their illness into their world view?

Based on this question I wanted to see if the traditional beliefs of health and illness have been the backbone of the survivors' world view, if they have been assimilated into the Western health paradigm or if they have somehow combined both health paradigms in their healing journey (see Appendix 2). What changes have they made within their psyche, the way they see the world, the way they relate to others, or their day-to-day actions, to continue on with their lives?

3.2 Ethical Research Implications

Research in Aboriginal communities is becoming more complex, especially in relation to ethics, Western versus Aboriginal. Which code takes precedence? This issue can probably be traced back to the history of research in Aboriginal communities where nearly everyone in 'Indian country' has heard of a horror story concerning researchers. This negative image of research has become the driving force behind Aboriginal communities limiting who can come into their community, what types of research can be done and drafting their own ethical protocols for research.

The major difference between Western code of ethics and Indigenous codes of ethics is the amount of importance placed on the individual versus the community. “From Indigenous perspectives ethical codes or conduct serve partly the same purpose as the protocols which govern our relationships with each other and with the environment” (Smith ⁴¹ p.120). In 1994, the major funding research bodies in Canada, the Medical Research Council of Canada (MRC), the National Sciences and Engineering Research Council of Canada (NSERC) and the Social Sciences and Humanities Research Council of Canada (SSHRC) appointed the Tri-Council Working Group to come up with a single unified code of ethics.⁴² O’Neill critiques the proffered code of ethics, specifically referring to the sections regarding collectives in which the Tri-Council stated that collective rights have precedence over individual rights. A collective is defined as a “population with social structures and common customs” (O’Neill, ⁴² p.69). In giving rights to collectives, a researcher would not be able to study the collectivity itself without permission from the leadership, nor could he/she research with a subgroup if the leadership had vetoed the research.⁴² This has strong implications for research in Aboriginal communities where the Chief and Council would be the voice for the collective. If the Chief and Council refuse to admit a researcher into their community, then the researcher has no other option but to try another community. There are, however, no such gatekeepers for urban dwelling Aboriginal peoples. Therefore, the collective versus individual rights would not be an issue in this case and the Tri-Council code would come into play. Is this then another form of forced assimilation for those First Nations who choose to live off-reserve and for Métis and Non-Status First Nations who have never had collective gatekeepers?

Aboriginal people have been the subject of research for years, often with no direct benefit to them personally or collectively. This has angered and frustrated many Aboriginal communities in Canada and around the world. Linda Tuhiwai Smith, a Maori academic and writer notes, “the word itself, ‘research’, is probably one of the dirtiest words in the Indigenous world’s vocabulary” (Smith ⁴³ p.1). Aboriginal peoples in Australia have been critiquing research practices since the 1970s.⁴⁴ Since 1969 Vine Deloria Jr. has been writing about the damage anthropologists have wreaked upon Aboriginal communities in the United States.⁴⁵ “The fundamental thesis of the anthropologist is that people are objects for observation, people are considered objects for experimentation, for manipulation and for eventual extinction” (Deloria ⁴⁵

p.81). Since the middle of the 1980s, Aboriginal people began establishing codes of ethics and research protocols.

There were two workshops in Australia, in 1986 and 1987, where Aboriginal community members met with researchers and health professionals to draw up research guidelines. The “guidelines insisted on Aboriginal control of, and participation in, research, the adoption of non-invasive and culturally sensitive methodologies, the pursuit of research of need and benefit to communities, and full Aboriginal control over the dissemination of findings” (Humphery p.198). The actual guidelines as adopted by the research-funding agencies were a watered down version of the above, only dealing with consultation, community involvement, ownership and publication of data. Criticisms of the guidelines include the retention of a highly Western sense of independent research, and the white institutional dominance over health and medical research funding.

In Canada, the *Tri-Council Policy Statement on Ethical Conduct for Research Involving Humans* is the guideline used by the three major research funding bodies in Canada, including the Canadian Institutes for Health Research (CIHR), Social Sciences and Humanities Research Council of Canada (SSHRC), and the Natural Sciences and Engineering Research Council of Canada (NSERC). The Tri-Council Policy Statement currently has a section (Section 6) that is specific to research involving Aboriginal peoples. The Councils have stated that there has not been enough consultation with the affected peoples or groups; therefore policies have not yet been established. Section 6 is intended to be a starting point for discussions and includes areas such as respect, partnership, benefit, group representatives, and research feedback. The Interagency Advisory Panel on Research Ethics (PRE) has been mandated by CIHR, SSHRC and NSERC to provide independent, multidisciplinary advice on the evolution of the Tri-Council Policy Statement and PRE has deemed section 6 to be a priority and a revision is expected to be complete by the fall of 2006.⁴⁶

In 1998, the National Steering Committee of the First Nations Regional Longitudinal Health Survey formulated a set of research protocols to guide Aboriginal communities and researchers.⁴⁷ This set of protocols is commonly referred to as OCAP, Ownership, Control,

Access and Possession, four key components that researchers should adhere to when they are working within Aboriginal communities. Aboriginal communities are encouraged to maintain ownership of their knowledge systems, which includes controlling any research that happens in their communities, having access to and maintaining possession of all research documents.⁴⁷ The Indigenous Peoples' Health Research Center from Saskatchewan responded to a call from The Interagency Advisory Panel on Research Ethics for a review on current ethical research guidelines involving Aboriginal peoples and produced a document which summarized the literature available, including OCAP and presented recommendations.⁴⁸ The recommendations are heavily focused on Indigenous communities' rights and responsibilities towards research, protection of Indigenous knowledge systems and the Western based research protocols to respect and follow the Indigenous communities' decisions.⁴⁸

SSHRC hosted a national round table in 2002 to discuss research policies and programs in relation to Aboriginal peoples. There was an ongoing listserv discussion with Aboriginal and non-Aboriginal academics and researchers from across Canada to finalize the recommendations that arose from the roundtable discussion. Items of concern were: research priorities, ethical guidelines, Indigenous knowledge, application of research results and support and training of Indigenous scholars. The only addition to the SSHRC website last updated on July 19, 2004 is a one liner stating that "Band approval must be obtained prior to commencing work in an Aboriginal community".⁴⁹ The Canadian Institutes for Health Research (CIHR) has as one of its 13 institutions, the Institute of Aboriginal Peoples' Health (IAPH). Ethical issues relating to research, care strategies and access to care is one of IAPH's identified research areas.⁵⁰ The CIHR Ethics Office has recently released a draft titled *CIHR Guidelines for Health Research Involving Aboriginal Peoples* in September 2005 to select organizations and institutions including the University of Saskatchewan. It appears to be a comprehensive document which looks at what constitutes a community, principles of aboriginal research such as ethical space, cultural issues, community and individual consent, along with procedures and protocols of the research process.⁵¹

Many Aboriginal organizations have formulated their own code of ethics in research. It seems that the ethical implications of research with Aboriginal peoples are becoming more

relevant to the world view of Aboriginal people, rather than the Western view. After all, “whatever benefits may be claimed for their work, community researchers are obligated to establish and maintain good rapport between researchers and the communities in which they seek to work” (O’Neill ⁴² p.76). There has also been an increase in Aboriginal communities and organizations undertaking research themselves and the importance of doing research that will provide a benefit.⁴⁴ Indigenous researchers see Western research traditions as a ‘tool box’ from which they can pick and choose those that fit within their paradigms as well as insisting on a new paradigm of research governed by Aboriginal terms of reference.⁴⁴ However, we have to be aware that “assumptions of interpretations that are derived from Native teachings framed through a Western ‘lens’ can be viewed as a form of assimilation” (Lambe & Swamp ⁵² p.433). Aboriginal academics and students are in a unique position in the present trend towards increased research in Aboriginal communities, especially in the health care field, where research and funding opportunities loom large and provocative; but as Smith⁵³ (p.137) so eloquently puts it, “insiders have to live with the consequences of their processes on a day-to-day basis for ever more, and so do their families and communities.” Indigenous researchers cannot leave the researched as easily as an outsider could and there is also the risk that our communities will not accept us in our double role as researcher and community member. Therefore, Smith recommends that Indigenous researchers have to be good at defining clear research goals, lines of relating, defining closure, skills to say ‘no’ and ‘continue’, to be ethical, respectful, reflexive, critical, and humble.⁵³ We have been trained according to the colonialist tradition to gather Indigenous knowledge for the sake of personal advancement. Or have we? When it comes time to doing research work with Indigenous communities, Smith states that “in many projects the process is far more important than the outcome. Processes are expected to be respectful, to enable people, to heal and to educate. They are expected to lead one small step further towards self-determination” (Smith ⁵³ p.128). Not only do we have the challenge of researching our communities, we also have to convince them of the value of research and in turn develop processes that are not limited or directed by past legacies.⁵⁴

3.3 Researching Across Different Knowledge Systems

Researching across different health paradigms is another area full of contentious issues. In the Western knowledge system, to understand often involves defining, whereas among

Indigenous people, they often begin with the phrase ‘this is how I understand it’ inferring that there are many ways of knowing, and it is also understood that there are others who know more. Alternative knowledge systems about health are becoming more common. Alternative, complementary and traditional medicine are increasingly becoming popular with the general public and therefore researchers are now struggling with how to evaluate the effectiveness of these methods, because the gold standard of the double blind, placebo clinical trial is not entirely appropriate. Protecting the public from unsafe practices and charlatans⁵⁵ is the most often cited reason for wanting to evaluate treatment protocols. Although individuals currently pay for most complementary or alternative medicines with their own money, there is the concern that as certain treatments become more common, they will request that their health insurance provider cover the costs. Therefore, these funding agencies will be looking for research to either support or deny the claims of their customers.

“Worldviews and the values placed on different health outcomes are closely related. Thus the values that underlie medical care shape the scientific questions that researchers ask, the health outcomes they measure, and their interpretations of the results” (Bell et al ⁵⁶ p.136). How then are these alternative health paradigms going to be researched because “the challenge of research methodology is to fuse the philosophical concerns of stakeholders with the highest standards of methodological rigour” (Mason p.832)? Whereas, the underlying ideology of the Western health paradigm comes into play when the research questions are formulated. “When researchers construct questions, they already have a theory in mind which needs testing, and they usually have definite preconceptions that allow them to formulate the questions” (Bensoussan ⁵⁷ p.360).

In the case of acupuncture, Bensoussan maintains that it can fit into the Western paradigm of evaluation as long as the researcher has in-depth knowledge of the relevant field under study. For example, issues such as language differences between the health paradigms need to be considered, not just in terms of spoken or written language such as Chinese and English but also in the way health is spoken about, i.e. Yin and Yang, energies etc. The second concept is methods of diagnosis, where Chinese doctors look at the entire person, not just physical or lab tests as in the Western medical model. Whereas, Bell et al insist that there have to

be new methods developed that will look at the health paradigms as whole systems, because there is no commonly used reductionist method available to study them, no obvious way to incorporate them into conventional medicine, and they don't fit into any Western conceptual framework. Integrative medicine is not the incorporation of Complementary and Alternative Medicine (CAM) as a subsystem of conventional biomedicine but is "a higher-order system of systems of care that emphasizes wellness and healing of the entire person as primary goals" (Bell et al p.133). Integrative medicine believes that an individual can heal spiritually even if physical healing has not taken place and patients choose integrative medicine because of the philosophical orientation to the whole person. Systems theory, which involves 'the study of the whole as a whole'; is a suitable method of researching integrative medicine and qualitative methods need to be included as a source of evaluation. The root of effective cross-cultural dialogue is respect for differences that exist between people and this includes alternative health paradigms such as traditional Indigenous healing systems.

Some First Nations organizations are already covering the cost of patients to access traditional healers partly because "Western explanations are adopted and adapted when they are compatible with local cultural understandings" (O'Neill ⁵⁸ p.549). Yearly gatherings of traditional healers have been occurring in Saskatchewan for the past four years and aboriginal and non-aboriginal people flock to these gatherings. The interest in traditional healing systems is increasing exponentially and Indigenous communities, including researchers, have to be extremely careful in protecting their healing knowledge systems. Other issues for traditional healing include to what extent will traditional healers become part of the mainstream health system? Will they need to go through the same regulation structures as Western-trained physicians? If traditional healers are paid a salary, are they still maintaining their unwritten code about not taking money for payment of services or is this another example of bridging cultures? These are some questions that may appear more frequently as alternative health paradigms such as traditional medicine become more accepted in the general population.

3.4 Narrative Inquiry in the Health Sciences

Narrative Inquiry is a qualitative research method that focuses on stories or narratives. It is through stories that we share our lives and the use of narrative inquiry as a method of research

allows the participants to share their lives and their perceptions of life. The strength in the method lies in the way in which a certain experience is drawn out and the meaning conveyed.⁵⁹ Narrative inquiry is intended to enlarge the vision of a particular experience,⁶⁵ in this case it is the experience of cancer among the Woodland Cree. Clandinin and Connelly, who are well known in the teacher education field, have written a book, *Narrative Inquiry: Experience and Story in Qualitative Research*, published in 2000 which explains the theoretical and practical applications of using this method in qualitative research. A working definition of narrative inquiry as described by Clandinin and Connelly⁶⁰ (p.20) includes the following:

[N]arrative inquiry is a way of understanding experiences. It is a collaboration between researcher and participants, over time, in a place or series of places, and in social interaction with milieus. An inquirer enters this matrix in the midst and progresses in this same spirit, concluding the inquiry still in the midst of living and telling, reliving and retelling, the stories of the experiences that make up people's lives, both individual and social.

Narrative inquiry as a qualitative research tradition has been more commonly found within the field of teacher education. In the field of medical anthropology, well known researchers such as Kleinman and Frank have been using illness narratives since the seventies.^{61,62,63} However, the narrative inquiry method has been gaining in popularity in the health field even though "many healthcare professionals are suspicious of personal narrative accounts which they often dismiss as mere anecdotes" (Priest⁶⁴ p.247). Stories themselves are not unknown in the health field, as Vizeau⁶⁵ (p.44) states "through stories, patients inform us about their experiences of health and transition; it has always been a part of how we explore the shared world of our patients." People usually see their lives in a narrative form⁶⁶ and when they participate in narrative inquiry research, they become a part of the decision making process by deciding how the story will be told.⁶⁷ It has been suggested that telling stories regarding life experiences while enduring illness can be therapeutic.⁶⁷ It is apparent that narratives are an integral part of health and healing and thus are eminently suitable for qualitative research in the health field.

Within the scientific paradigm of defining a research problem, the expectation is to find a solution. However, according to Clandinin and Connelly, narrative inquiry can be seen as more

of a searching, a re-searching into new or previously looked at areas of interest.⁶⁸ Narrative accounts detail unique experiences and perceptions pertaining to various aspects of humanity and culture.⁶⁷ Narrative inquiry can be theory generating because “the distinctive feature of narratives is that they refer to meaningful and coherent courses of action...this makes their analysis especially significant and appropriate for theory construction in the social sciences” (Priest⁶⁴ p.248). Furthermore, it is crucial for narrative inquirers to be able to “articulate a relationship between one’s personal interests and sense of significance and larger social concerns expressed in the worlds and lives of others” (Clandinin & Connelly⁶⁸ p.122).

“Although most of us enjoy reading personal accounts, they have fought a long battle for recognition in academic settings, and prejudice against personal narratives, indeed against uses of the first person in general, continues in many disciplines to this day” (Spigelman⁶⁹ p.66). This critique applies to the scientific paradigm which predominates the health sciences, where objectivity is a key element. Objectivity is not possible or even desirable in narrative inquiry. One of the major advantages of qualitative research is that it allows the individual participant to determine the information: “Regardless of its form in first-person narrative or third-person exposition, advocates say, all writing is personal in the sense that both style and interest are features of social, political, and individual values and investments” (Spigelman⁶⁹ p.67). Generalizability is another hallmark of the scientific paradigm. However, in narrative inquiry “the researcher does not seek generalizability; instead as readers we perform this act of generalization...based on the density of detail, the selection of incidents, and the narrative skill of the researcher” (Spigelman⁶⁹ p.66). Therefore, my challenge is to present the data in such a way that the reader can interpret it according to his/her professional or personal position.

3.4.1 The Narrative Inquiry Method

Given the relative newness of narrative inquiry as a method, the practical application of going about doing narrative inquiry has not been well defined. However, Clandinin and Connelly do provide a foundational place of inquiry, which is three dimensional and composed of interaction (personal and social), continuity (past, present and future) and situation (place).⁷⁰ (Figure 3) Theoretically, all three spaces should be kept in mind during every step of the research project, making sure that the accumulation of data fills in each space. “Narrative data

are given in storied form and provide information about connected events that have a temporal sequence and an intentional quality” (Bailey & Jackson ⁷¹ p.59).

Extensive field experience is one of the requirements in the data collection phase. According to Clandinin and Connelly⁷² (p.68), narrative inquirers “settle in, live and work alongside participants, and come to experience not only what can be seen and talked about directly but also the things not said and not done that shape the narrative structure of their observations and their talking.” Being in the field is a continuous shift and change in establishing and maintaining relationships, defining and renegotiating purposes, and transitions in place, time and activity.⁷² Data or field texts can be comprised of personal journals, interviews, letters, conversation, documents, and photographs. Clandinin and Connelly do not want to create a list of possible sources of data; instead they encourage the researcher to remain open about all ‘imaginative possibilities for composing field texts’ (Clandinin & Connelly ⁷³ p.116), but to ensure that the field texts fit within their three dimensional framework.

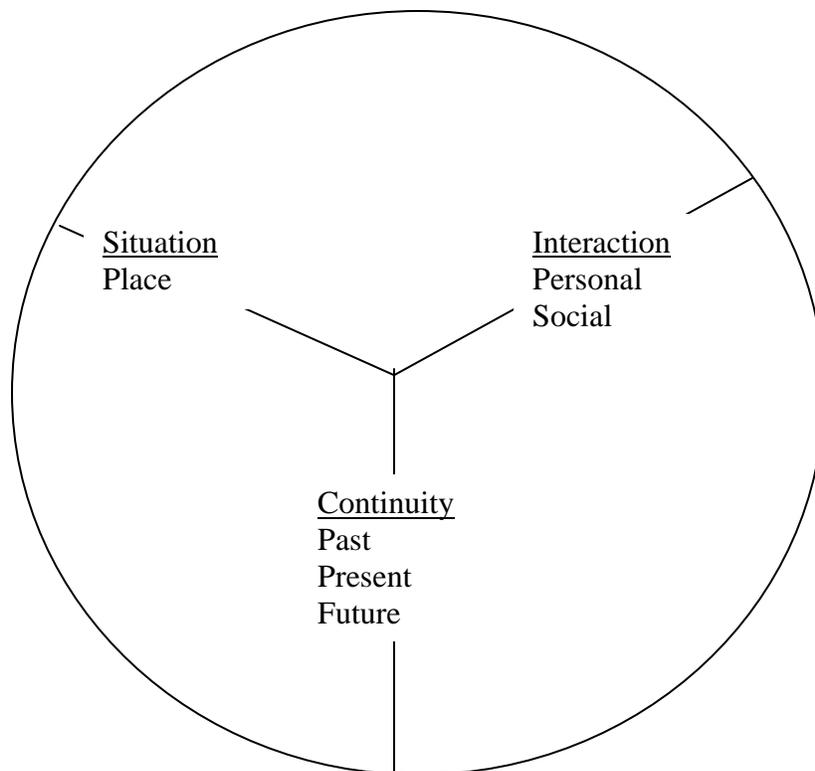


Figure 3 Clandinin and Connelly’s Three Dimensional Narrative Inquiry Space

3.4.2 Narrative Inquiry as Culturally Appropriate

My interest in cancer among the Woodland Cree stems from my experience with my mother's bout with cancer, but I can see the larger social significance of this research being applicable to all Woodland Cree, other First Nations communities, as well as health care providers. Because the social and cultural phenomenon of cancer among the Woodland Cree is virtually unknown, narrative inquiry is a suitable method as it is useful in finding out how a group feels about a certain practice or treatment.⁶⁷ "Narratives have a way of speaking for themselves, rooted in culture and nuances of the individual" (Overcash⁶⁷ p.183). Some critiques of narrative inquiry state that this method tends to romanticize the 'voice' and make it sound like the 'voice' represents everyone. However, in Aboriginal communities, the Elders are the teachers and they have gained their experiences through life and what is wrong in romanticizing their teachings? They are the teachers in the communities so they are representative of one voice.

The following statement found in Connelly and Clandinin⁷⁴ (p.10) epitomizes for me what it is I'm trying to accomplish with my research: "narrative and life go together and so the principal attraction of narrative as method is its capacity to render life experiences, both personal and social, in relevant and meaningful ways." This is particularly relevant to the cancer survivors because I want to know how they have incorporated their illness into how they see the world, which is both personal and social. Bruner⁷⁵ (p.99) states that "adaptation to life itself depends upon the success of the patient in generating a believable narrative, one that in some robust fashion weaves in but does not necessarily mirror the historical truth." I had expected there to be some reintegration or reorganizing of an individual's world view once he/she was diagnosed with cancer.

The method of narrative inquiry and the longevity of stories within our world tells me that the stories I receive from the Elders and the cancer survivors will be around long after they and I are gone. "People are looked at as embodiments of lived stories...people are seen as composing lives that shape and are shaped by social and cultural narratives" (Clandinin & Connelly⁵ p.43). Narrative inquiry is extremely appealing to me because it is the tradition that most closely resembles Aboriginal ways of teaching, especially in relation to Elders and their

stories. “There are narrative and generative principles of discourse, tale-telling, and drama that are also part of any culture’s tool kit” (Clandinin & Connelly⁷³ p.100).

“Narrative inquiry characteristically begins with the researcher’s autobiographically oriented narrative associated with the research puzzle” (Clandinin & Connelly⁵ p.41). My interest arose from my mother having cancer and this story has been interwoven within this dissertation. “Narrative inquiries are always strongly autobiographical. Our research interests come out of our own narratives of experience and shape our narrative inquiry plotlines” (Clandinin & Connelly⁶⁸ p.121). It appeared that no matter which research tradition I followed, the data would come through as stories anyway because they are such an integral part of Aboriginal society and of humanity in general.

3.5 Ethical Protocol and Community Access

Ethics was an area of potential conflict in regards to the differing belief systems. Western style research ethics such as those espoused by the University of Saskatchewan in accordance with the Tri-Council Policy Statement are based on individual knowledge and informed consent. Whereas, in Aboriginal communities there are *knowledge keepers* and in the majority of cases, these are the Elders. The Elders will not claim any ownership to the knowledge, saying that they are merely passing it on to the next generation. So in essence, there is a collective knowledge as opposed to individual knowledge. Individual informed consent needed to be balanced with community consent when it comes to research in Aboriginal communities. Therefore, I had to find a way of bridging both systems.

The first step was to meet with key individuals from the Band to discuss my research objectives. I met individually with Chief Harry Cook, Mary Carlson, Health Director for Lac La Ronge Band and Wilfred McKenzie, Health Director for Stanley Mission Health Services and received encouraging support from all individuals. As an aside, Stanley Mission is part of the Lac La Ronge Band but they took over administration of their own funding in 1998.

I then applied for ethics approval from the University of Saskatchewan Behavioural Research Ethics Board (see Appendix 3). There were several revisions that had to be made on

the ethics proposal, namely that I had to have clearly outlined verbal consent protocols for those individuals that may not be comfortable communicating in the English language. I had to clearly state that I would translate the Consent Form verbatim as well as the Transcript Release Form (see Appendix 4 and 5). The other area of contention was the participants' level of risk in eliciting unpleasant memories. Despite rationalization that participants may be uncomfortable seeking non-Aboriginal counseling staff, I was still required to provide participants with names and contact numbers.

Once I received ethics approval I proceeded to gain entrance into the community by initially making a presentation of my proposal to Chief and Council in La Ronge. Chief and Council meet on average, once every two months, and although it had been less than a week since I had had gall bladder surgery, I attended the September meeting; otherwise I would not have another opportunity until December. I received a very positive response, with Elders Elizabeth Charles and Catherine Charles telling me that I was doing important work and they would send people to come and talk to me. Senator Myles Venne also spoke and told a story about a man in Little Red in 1934, who knew how to cure cancer by placing a still-hot breast of a freshly killed raven on the site and leaving it on there as long as the person could stand it. When the meat was removed, there were white maggot-like worms squirming around on the meat. Senator Venne then went on to say that when the nurses and doctors came to the reserve to talk to the medicine man, he was incarcerated for practicing traditional medicine. Senator Venne said that was the time when the medicine started becoming lost, because the medicine people did not want to go to jail: the story telling had begun. I asked for and received permission to proceed to the next step, which was to speak with the Health Committees in the six different communities that the Lac La Ronge Band is composed of. Chief and Council requested periodic updates on the progress of the research.

The Health Committees of La Ronge, Grandmother's Bay, Hall Lake, Sucker River, and Little Red River convened once every two months, which happened to coincide with Chief and Council meetings. Therefore, I would not be able to meet with them until November. Stanley Mission, however, met on a monthly basis and I was able to arrange to join them the following month, in October. I met with the La Ronge Health Committee in November. I got sick with the

flu after the La Ronge meeting, so was not able to meet with Sucker River, Hall Lake and Little Red River Health Committees until their next scheduled meetings in January. Grandmother's Bay did not currently have a Health Committee since no one had run the previous election. I followed the same protocol with the Health Committees, presenting my proposal and seeking their permission to proceed with participant recruitment. All the Health Committees were receptive to my research and most felt that since I had already received permission by Chief and Council, that I could go ahead and begin participant recruitment.

3.6 Participant Recruitment

Participant recruitment began in Stanley Mission in February. I entered the communities in the order of meetings with the respective Health Committees. The health clinics provided me with office space, telephone privileges and a home base. I suspected that I might have some difficulty in gathering enough participants for my study since cancer is a sensitive topic. Therefore, my participant recruitment protocol was multi-directional by design. I surmised that distributing the information as widely as possible was one method, along with key community individuals acting as liaisons, and the snowball sampling method.

Spreading the information was accomplished through several modes. I designed colorful eye-catching posters, describing the project, asking for volunteers and providing contact information. I also included translations into Cree Syllabics. I put up posters in the health clinics, grocery stores, gas stations, band offices, band halls, elementary and high schools and even bingo halls, basically any place where people congregated. Self critiquing the posters, I realized that anyone who could still read Cree Syllabics would probably be an Elder and unlikely to be going out in public very often. I had also included all my education credentials behind my name and a family member pointed out that it was intimidating to read all those initials behind my name. Therefore, another set of posters was created, using simpler language, more white space, and no initials behind my name.

I also used other media outlets. I had spoken to the Band's Communication Officer on several prior occasions and he published a story in the Band's monthly newspaper, the *Cree Communicator*, in December. The focus was primarily on my doctoral studies but I insisted that

he include information on my project, including contact information. I also placed a separate ad in the same issue. The Prince Albert Grand Council monthly newspaper, *The PAGC Tribune*, picked up the story and ran it in January. I went to the offices of the La Ronge local newspaper, *The Northerner*, purchased advertising space and they also offered to place information in the *free* community announcements part of the paper. It's a small office and it was the editor who took my order. He recognized me from the *Cree Communicator* article; his paper has an arrangement with the Band to include the *Cree Communicator* as an insert. He offered to obtain the story from the *Cree Communicator* and re-run it in *The Northerner*.

I contacted the local radio station, MBC and requested to be interviewed for the Cree program and was accommodated. I explained the project and asked for volunteers. Tom Roberts of CBC's Keewatin Country, a noon hour radio show, contacted me the following week at home and requested an interview, this time in English. The next week, one of the other Cree speakers at MBC contacted me, requesting an interview. I informed him that his colleague had already interviewed me the previous week and he sheepishly told me to pretend that he had never called. In all interviews, I took the opportunity to provide cancer education and awareness, focusing on the specific challenges of northerners with cancer.

Another awareness and education method I used was to go to all the communities during their treaty day celebrations, which are held in May. The Band administration and health clinics make the most of these community congregations by having diabetic and blood pressure screenings, and information booths. I set up information booths with pamphlets from the Canadian Cancer Society, as well as having a sign up book for interested individuals. From the first community it became evident that the majority of people were there to pick up their treaty money and leave. Thus, this method did not prove to be very effective.

Holding community gatherings was also meant to serve a dual purpose; the education of community members about cancer as well as recruitment of participants. Posters, newspaper ads and radio interviews were the means of advertising the time and places of community gatherings. The Stanley Mission Health Clinic offered me 30 minutes to talk about the project at a Community Diabetes Education Day where I also set up a display and included pamphlets from

the Canadian Cancer Society. The Diabetes Education Day was well attended and I had an audience of approximately 50 community members, 75% of whom were high school students. Refreshments, including lunch were provided by the Health Clinic. The La Ronge community gathering was held during the evening. I provided refreshments of coffee, tea, juice, cookies and fruit. I had 10 community members come out to listen, though six were clinic employees and their family members. Due to the apparent lack of interest in the community gatherings, I decided not to hold any in the other communities. I did however; participate in a Diabetic Foot Day in Grandmother's Bay, providing refreshments and serving community members that came in for lunch. This provided me with an opportunity to speak with individuals about my project.

Identifying an appropriate health clinic staff member and asking for their help in a liaison capacity worked in some communities but not in others. I talked to virtually all the clinic staff members in Stanley Mission, asking for referrals of potential participants, explaining that the University of Saskatchewan's ethics protocol prohibited me from contacting potential participants directly, but no one came forward to assume the position. In La Ronge, I talked to the Community Health Representative, and he was receptive and talked to several people with cancer but none of them were interested in being interviewed. There is an outreach program which caters primarily to Elders and the Coordinator took the initiative to arrange a gathering on my behalf in La Ronge. After learning of this program, I attempted to contact the workers in Grandmother's Bay, Sucker River, Little Red River and Hall Lake. I met with success in Grandmother's Bay and Little Red River, resulting in another group meeting in Little Red River. The Outreach worker at Grandmother's Bay contacted potential participants and invited them to come to the Diabetic Foot Day at the clinic, as food would be provided and I was provided with a room for interviews. The workers in Sucker River and Hall Lake were on holidays. I did connect with the Home Care worker in Sucker River and she provided me with names of potential participants as well as showing me where they lived, and that was the extent of what she was prepared to do. I was not able to connect with anyone in Hall Lake, despite multiple phone calls and two on-site visits.

The snowball sampling method is a process whereby one participant will provide additional names of potential participants; the premise being that similar to building a snowball,

the sample size will continue to increase. I had limited success with this method, resulting in two interviews, both of whom were related to the initial participants. The most common response was a noncommittal “I don’t know” when I asked participants if there was anyone else they knew that I could interview. I was hopeful that with this method I would be able to identify potential traditional healers to interview and I did receive some names, but I was unable to interview any healers.

I used a different strategy when I spoke to the Elders of Stanley Mission. It is an accepted cultural practice for a person to speak with an Elder when seeking help. I went for an initial visit with the Elder, which gave us a chance to get reacquainted. If the Elder was interested in being interviewed, I would return the next day. I felt that the time delay would give the Elder the time and opportunity to reconsider the offer to participate. In La Ronge and Little Red River, an Elder was invited to each of the group meetings. I attempted to visit an Elder in Sucker River but she was away from the community, visiting one of her children. I did not approach any Elders in the other two communities.

3.7 Data Collection

The ideal situation when collecting data in qualitative research is to spend long uninterrupted periods of time out in the field. However, this was not an option for me and my trips up north had to be well organized and meetings or interviews had to be arranged in advance from Saskatoon. My travel schedule was usually to drive up on Monday and return on Thursday and I made a total of fourteen trips between February and August. I had to organize my schedule around family responsibilities, primarily the care and supervision of my son, who was 13 years old and still required my presence as a stability factor after divorce. I spent increased amounts of time in the north during the summer since I brought him with me or he spent time with his father.

I had proposed a sample size of 20 to be sufficient to gain a fair distribution of perceptions and get saturation of data. There is no prescribed number of required participants for qualitative research, however, one of my objectives was to provide information to cancer care and other health providers and the assumption was the more participants I had, the more trustworthy my findings would be. I was looking for an even distribution of participants: 5

Elders, 5 cancer survivors, 5 family members of someone who had had cancer and 5 community members interested in cancer.

Giving a gift of tobacco as reciprocity for information received was not likely to have the same significance among the Woodland Cree as it would among more traditionally spiritual First Nations, since the Woodland Cree have been Christianized for over 150 years. This is another difference between Western and Aboriginal ethics, where Western ethics do not adhere to gift giving, the assumption being that it will bias the information received. The problem I have as a Cree woman and a human being is how can I go in and ask for someone to share their knowledge without giving anything in return? Therefore I did give a blanket as a gift and this practice was well received.

After three trips to Stanley Mission, I had approached ten Elders and interviewed four and I had received no response from cancer survivors, family members or community members. Although, in retrospect, all the Elders I interviewed could have fit within the category of family member since they all had known someone who had had cancer. Two visits were required for Elders who agreed to participate, an initial visit to get reacquainted and to ask permission for an interview and the second visit for the interview. The Elders often shared stories right from the first visit. I included only those stories of Elders who agreed to participate in a formal interview in my analysis. I asked each Elder if they would permit me to record them with a tape recorder. I would return at the appointed time, present the Elder with a blanket, explain the consent form, ask for verbal consent, and then the interview would begin. I took along my interview guide to the first interview and felt that it interfered with the flow of story telling. Following that, I memorized the questions and insured that each was answered during subsequent interviews. I found that the tape recorder also interfered with the natural flow of story telling. I could sense the shift in comfort level from the first to the second visit; the Elder seemed to expect more of a question and answer session once the tape recorder was brought out. However, I could not think of any other method of capturing the richness and complexity of the stories. All of the interviews were in Cree.

The next community I entered was La Ronge, and following a similar recruitment strategy, I had a much better response from cancer survivors and family members. One participant came forward after the community presentation, two volunteered after seeing a poster or the newspaper ad, 3 from snowballing and 4 participants came together in a group meeting arranged by the Community Outreach Coordinator from the health clinic. There was an additional six potential participants, approached by either relatives or the Community Health Representative that were not interested in being interviewed. Of the 10 participants interviewed within a two week period, 4 were cancer survivors, 5 were family members, and one was an Elder; although, once again the Elder was also a family member, having cared for her mother from the time of cancer diagnosis to end of life. Once data collection was complete, this represented the best response from the 6 communities I visited.

There were two types of interviews in La Ronge, individual and group. The individual interviews took place in either a room at the health clinic or in the individual's home. I presented each individual with a copy of the consent form; some read it very thoroughly, while others glanced through it and signed it. I verified that they understood what they were reading and signing, and provided them with any clarification that was needed. They all agreed to have their interview recorded on cassette tape. The interview times ranged from 20 minutes to 2 hours, the average being 45 minutes and were either in English or a mixture of Cree and English. I kept a copy of the interview guide in front of me to guide the interview, and participants expected to be asked question after question. I attempted to rephrase the questions in such a way as to facilitate a story telling format i.e. *Tell me what it was like for you when you had cancer, start from when you first thought there was something wrong to today.* This rephrasing method worked in some situations but not all. After each interview was complete I presented them with the blanket, thanked them for sharing their story, and informed them that I would be getting back to them with a copy of their transcript.

The group meeting had a totally different atmosphere from the individual interviews. The Outreach Community Coordinator had called people the previous week, people she knew that were either cancer survivors or family members, and invited them to a meeting. Lunch was to be provided, along with refreshments. La Ronge is quite spread out and the participants lived in all

directions so there were three of us that went to pick them up and bring them to the meeting hall. There were 5 women, one of whom I had interviewed the previous week, an Elder whom I had known from my childhood and three that I had not met before. All the women knew each other and the hall quickly filled with laughter. I explained the project and explained the consent form. I asked for verbal consent and it was given. I also received permission to use a tape recorder. The atmosphere was relaxed and the women shared their stories openly, with a minimum amount of questions and encouragement. They each took turns in telling their story, moving the tape recorder to the front of the person who was speaking next. The majority of the conversation was in Cree, but one of the women did not speak it and therefore her story was in English. The one I had interviewed previously asked me if she had to repeat her story, I replied that she did not have to if she didn't feel like it. She explained to the others that she had already spoken to me and therefore didn't feel it was necessary to repeat herself; the women all nodded and murmured in agreement and understanding. The meeting concluded with lunch, presentations of blankets, laughter and visiting.

My home base was in Stanley Mission, staying with my sister Julie, and I drove by Sucker River on my way to and from La Ronge each day. The Elder who sat on the Sucker River Health Committee was a cancer survivor and he had offered to be interviewed. Therefore, I stopped by Sucker River, located him, and asked if he was still interested in being interviewed. He agreed and a meeting time and place were arranged at the health clinic for the following day. I was 10 minutes late arriving due to the length of the group meeting in La Ronge but he was still there, slightly impatient but in good humor as he sat in the waiting room sofa, wearing his rubber boots, one leg swinging over the other. The interview proceeded in a private room; it was tape-recorded and was completely in Cree. He ended up being the sole male cancer survivor I interviewed.

I made on-site visits to Hall Lake and Little Red River on my way to or from the north on several occasions. I surmised that it was only a few hours out of my way and a face to face meeting would be more likely to facilitate cooperation than telephone calls. On one of these side excursions into Little Red River I arrived at the clinic and the Community Outreach worker was not in at that moment. Another woman recognized me and asked how my research was going. I

replied that I was having some challenges in getting participants and she informed me that she had lost a family member to cancer a few years ago. I asked her if she would be willing to be interviewed and she agreed. I gathered my interview equipment and we headed into her office. The interview was tape-recorded and was in English. After completing the interview, the Community Outreach worker had returned, and I asked if she would be willing to act in a facilitator capacity. She was originally from Stanley Mission so rapport was easily re-established and she agreed to arrange a group meeting for the following week.

I arrived at the Little Red River Health Clinic in the morning and set up the space where the meeting would take place. I had brought lunch and refreshments with me. Four women came to the meeting, two cancer survivors, one family member and one Elder. The meeting space was connected to the kitchen where a woman was cooking for another occasion so there was quite a bit of background noise and a couple of people walking through. However, once she finished cooking, the interruptions ceased. As in the previous group meeting, I explained the research project and the consent forms, asking for verbal consent and receiving it. The women were relaxed and allowed each other to tell their respective stories with a minimum of interruptions. This group of women agreed to the use of the tape recorder. The conversations were a mixture of Cree and English, with the predominant language being Cree. The meeting broke up after an hour and a half, and we shared lunch, visited and laughed. The blankets were presented to each of the participants simultaneously as they were serving themselves lunch.

For the community of Grandmother's Bay, my first stop was once again the health clinic. I met with the Home Care worker, the Community Outreach worker and the receptionist, and brainstormed on what would be the best method to recruit participants. The Community Outreach worker volunteered to call people, acting as a liaison, and the Home Care worker offered to share the resources of the next Diabetic Foot Day. People with diabetes come into the clinic on Diabetic Foot Day; they receive foot care, have some food and visit with other community members. I arrived at the appointed day around 9 AM. The Community Outreach worker informed me that he had contacted about 5-7 people and they were all eager to participate. I had a moment of panic since I had only brought 5 blankets with me, however, as the day progressed one after another cancelled. I had an enjoyable morning meeting and

reacquainting myself with community members I had not seen for quite some time. I asked if they were interested in being interviewed and the invariable response was a kindly 'no'. One participant called and asked if I could go to his house and do the interview. I readily agreed and his brother came with me so I interviewed both of them simultaneously. The two participants agreed to be tape-recorded, each taking turn to tell their story. The conversations were in Cree with the occasional English phrase or word used when a suitable Cree word was not available. Blankets were presented to each of them following the interview.

I returned to the clinic and two more individuals showed up for interviews. The first individual brought her friend with her, but the friend wasn't interested in being interviewed, stating she would only listen. The participant did not agree to be audiotaped so I had to rely on note taking to record the interview. The interview was a mixture of Cree and English and although the friend said she would only listen, she added punctuations to the conversation, such as agreeing verbally, laughing or providing examples. Another participant called the clinic and asked if I was still there and if someone would go pick her up. The interview with her was in Cree and she was also not comfortable with being taped so this interview was recorded by note taking. All four participants from Grandmother's Bay were in the category of family members.

By the time I entered the community of Sucker River in August, the Community Outreach worker was on holidays, as were a lot of others. The receptionist suggested I talk with the Home Care worker, which I did, and the Home Care worker agreed to act as a liaison and call people on my behalf. When I arrived the following week, she gave me a scrap of paper with 8 names. I asked her if she had called them, she replied that she had not but she would show me where they lived so I could go and talk to them. This was not quite what I had anticipated. However, following the feedback I had received from my thesis committee and Elder Rosie McKenzie regarding community members expecting me to go to them personally, I decided that this was the best option for me at the time. We drove around the community, she pointed out who lived in which house, whether they were cancer survivors, family members or Elders. After dropping her off back at the clinic I proceeded to go knocking on doors. There was no answer at five of the eight, the other three were home and agreed to participate, albeit reluctantly. Arriving on their doorstep with no prior knowledge of whom or what I was doing was not conducive to

building a trusting rapport. I also had no close relatives in Sucker River so I was not known locally. I spent quite a bit of time explaining my research project, asking if they had heard of it, and reiterated more than once that they did not have to agree to participate. None of them agreed to be tape-recorded and two of the three spent an inordinate amount of time trying to elucidate my relationship to them, if any. Once they could establish who my relatives were, then the conversation became somewhat more relaxed. All the interviews were in Cree and lack depth and richness of content, reflecting the lack of a close trusting relationship, and lasted on average 20 minutes. I presented them each with a blanket following the interview, one participant appeared shocked at receiving the blanket, asking twice if it was for her.

Having repeatedly attempted to make my presence known at Hall Lake and failing to make any significant connections, I decided that data collection was complete at the end of August. The final number of participants was 26: 6 Elders, 8 cancer survivors and 12 family members of someone who had had cancer. Due to the small size of the communities and the inter-relationship structure, all the participants could fit into the category of family member. However, the selection criteria for placing them in a certain participant category was if they were considered Elders in the community they were placed in the Elder category; if they were cancer survivors, due to the apparent lack of cancer survivors in the north, I felt their input was more important as a cancer survivor. It became evident that any one who would have fit into the category of community member was a family member and this is the reason there were no participants in the category of community member.

3.8 Analysis

Analysis of the data is not specifically stated within Clandinin and Connelly's book but there are multiple examples in qualitative research literature on analysis. For example, Merriam states that analyzing the stories can take on one of three strategies; 1) psychological, where the emphasis is on internal thoughts and motivations; 2) biographical, which focuses on social context such as gender, class, family beginnings and 3) discourse analysis which pays more attention to the written text looking for intonation, pitch and pauses to help identify meaning.⁷⁶ In addition, Polkinghorne identifies two types of analysis for narrative inquiry. One is 'analysis of narratives' which is the breaking down of the stories into their common elements, thus

producing general knowledge. The other is ‘narrative analysis’ which seeks out the particular differences of individuals, in effect describing the person in that particular situation.⁷¹ Poirier and Ayres describe over-reading as an analytic method for narrative inquiry.⁶⁶ The emphasis according to them is the structure of the text, noting inconsistencies, silences, and evasions in a narrator’s story as a relatively unobtrusive kind of overreading.⁶⁶ The style of storytelling may indicate how a person feels about their situation, such as the example of the woman who kept repeating phrases which to Poirier and Ayers indicated that she felt trapped in her situation and she didn’t know how to get out.⁶⁶ Emden also describes a method of analysis coined core story creation where the interviews are rewritten into a core story, without the ‘um’s’ and ‘ah’s’, repeated words or the interviewer’s questions.⁷⁷ The method of analyses I chose were based on my research questions; elucidating the social and cultural meaning of the participants’ experiences in relation to cancer, health and illness. Therefore, it was a combination of Polkinghorne’s analysis of narratives strategies, and identifying common themes thereby creating general knowledge. I also employed a variation on Emden’s method of constructing core stories where I created composite stories to reflect the three distinct groups of participants. Thomas-MacLean also chose two methods of analysis for her research with women that had breast cancer; she analyzed the stories for both content and structure.⁷⁸

Transcription of the data had to be layered due to the use of two distinct languages, English and Cree and two forms of communication, spoken and written. I was concerned that I would lose some meaning and depth during the process of multiple levels of transfer of information. Although as Arvay⁷⁹ (p.1) states “the assumptions of the interpreter are generally not in question, the entire process of transcription is an interpretive practice, they are always partial.” I transcribed the interviews as soon as possible following the interview, being fluent in both Cree and English; the translation was performed automatically in my head. I checked for completeness by listening to the tape and reading the transcript simultaneously several times. In situations where I was not able to find a suitable English word or phrase, I left the Cree word in the transcript. Listening to the tapes resituated me back in time to the interview, remembering the environment, seeing the body language and the emotions involved between the interviewee and I; this ended up being another process for checking the accuracy of the transcription.

I returned to interested participants for transcript review and signing off on the Transcript Release Form as per the University of Saskatchewan Ethics protocol. Some participants did not return my phone calls to arrange for transcript review appointments; I tried to reach them by phone several times. I left transcripts of several participants in sealed envelopes with family members. I included two copies of their transcript, a sheet of directions, and a self addressed stamped envelope for return of the Transcript Release Form. I did not return to the Elders for a review of their transcript, as I felt this was culturally inappropriate. I verified my translational transcription with one of the participants in Grandmother's Bay who is a health worker and has held several positions where he has had to do extensive translation. His interview was totally in Cree and he verified that I had captured the meaning and intent of his interview.

Interpretation of the data followed a qualitative research paradigm. Multiple interpretations are going to be a given, because we are all different and how we see the world is based on our values, beliefs and educational background. "Because readers differ in social, cultural, and historical backgrounds, expectations, and skills, multiple interpretations of text result" (Vezeau ⁶⁵⁶⁵ p.57). However, if one looks at the data and accepts the fact that there will be multiple interpretations, and "if the study is conducted responsibly, faithful to the data and the methods, then the conclusions must be accepted as one, though not the only, valid interpretation" (Priest ⁶⁴ p.248). This quote reverberates with the Aboriginal method of learning from Elders. The Elders will not tell you what you are expected to learn. They only pass on the story and the meaning must come from within you, indicating that there are multiple ways of knowing and multiple interpretations.

Analysis of the data was facilitated by the use of Atlas.ti[®] qualitative software as a data management tool. All the interviews were loaded into one *Hermeneutic Unit* in Atlas.ti and code words, mostly single code words that I felt reflected the intent of the phrase/phrases, were formulated. The first attempt at analysis of the data resulted in codes that attempted to capture each nuance and every topic that was discussed in the interviews and I became overwhelmed with the amount of information. Therefore, I booked time with a member of my doctoral committee who has experience using Atlas.ti as well as qualitative methodologies and we arrived at a workable system whereby I returned to my research questions and formulated codes from

them. We also formulated code words that were in Cree in an effort to capture and differentiate those interviews that were in English and those that were in Cree (e.g. cancer.perception and *munchoosuk*.perception). This coding scheme was able to focus the analysis, maintaining the emphasis on health, illness and cancer. It is interesting to note that as the second analysis progressed, I found myself re-instituting similar codes that I had used in the initial coding scheme. I realized then that the data was so thick and rich and I didn't want to lose sight of any aspect. I rationalized that I had already captured those in the first analysis, which I could still access when necessary and refrained from adding them to the second analysis.

The second stage of analysis was creating supercodes, codes that were used to capture multiple codes that shared a common idea or thought and to create coalescence into themes. Atlas.ti has the capacity to create visual images of the codes and I used this tool to visualize the codes and arrange different schemata for possible connections. Some of the 159 codes were purely for demographic purposes and thus did not fall within the domains of the twelve supercodes I created. Thomas suggests that final analysis of qualitative data should result in three to eight summary categories.⁸⁰ The twelve supercodes were further condensed to arrive at four overarching themes. The condensing of the codes and supercodes was somewhat complicated by the fact that I had 3 distinctive groups of participants. I attempted to separate the groups and analyze them separately but decided against this option as I felt that it was merely another attempt to compare and contrast, a popular mode of analysis by Western research methodologies. Moreover, the participants were all from the same cultural group and I was interested in seeing how the combined groups' perceptions were interwoven into each other, creating an overall picture of how cancer affects the individual, the family and the community.

Creating composite stories was the other analysis method I used. I appreciated this method because it allowed me to recapture the story; one of the premises of narrative inquiry is "the stories of the experiences that make up people's lives" (Clandinin & Connelly⁶⁰ p.20). This method also allowed me to capture important themes from the data and protect the anonymity of the participants. I worked through each transcript and deleted my questions, murmurs of agreement or encouragement, and any type of reference to myself that was in the transcript. I reread the transcript and deleted repeated words or phrases and sounds of hesitation or bracketed

emotional notes. I then started to separate sections of transcript into different topics, usually the topic title was the question that elicited the response. With this method, I felt that the *voices* of the three groups of participants needed to be kept separate and distinct; therefore, I created three composite stories. The topic titles were similar based on my interview question guide, so they were cut and pasted into the same section. The sections were then reviewed and repeated words/phrases were deleted and a composite paragraph was created, using the participants' words almost exclusively. There was a further condensing of the data whereby the composite story was created by the weaving together of the different sections into one seamless narrative. This process necessitated the selection of either a male or female voice to be the primary storyteller; in all three cases I chose a female voice in consideration of the fact that female participants outnumbered the males by 22 to 4. I asked three individuals that were not participants, an Elder, a cancer survivor and a family member to review the composite stories to see if they resonated with them, their experiences and their knowledge base. I have used the participants' words in creating the composite stories, although some are in translation and the composite stories now become the backbone of community and conference presentations. Solomon Ratt, a Cree language linguist who is also originally from Stanley Mission, performed the translation of the composite stories into Cree syllabics. I decided that it would be more efficient to hire Solomon to do the translations since he was instrumental in creating the Cree syllabics font for pc computers and he also understands language subtleties in the Cree spoken among the Lac La Ronge Band members and also because I myself, am not proficient in Cree syllabics, either reading or writing. The following chapter presents the composite stories including a sample of the Cree syllabics version of the Elder story.

Chapter 4. Composite Stories

One of the rationales in using narrative inquiry is its resemblance with Aboriginal ways of knowing; through story telling. Ways of learning through the traditional teachings include the Elder not telling you, the listener, what you are expected to learn. It is up to the listener to understand and learn from the stories or the teaching. Therefore, I have attempted to follow this method in the presentation of the composite stories. You, the reader, are responsible for what you ‘hear’ and ‘learn’ from these stories.

I hope that my research will be more widely read than through academic journals and this was another impetus for creating the composite stories. The process in creating these composite stories has already been described in the methodology chapter. It was not possible to include every aspect of everyone’s story but I made a concerted effort to include themes that were common among the participants. The composite stories will be instrumental in returning the data to the communities and sharing the findings.

Another way of giving back to the community will be through the offering of the narratives in both Cree Syllabics and English in a separate document. Through this process, I feel that I have contributed to maintaining some of the traditional teachings and fostering the written language of the Woodland Cree. Therefore, a section of the Elder Story is presented in Cree Syllabics as an example. I also want to maintain the meaning of the narratives that were held in Cree, because Cree is such a rich language and I believe that the process of translation results in a loss in some of the data.

4.1 Elder Story

4.1.1 What it Means to be an Elder

I get lots of visitors. Kids come in and I give them cookies or whatever treats I have and adults come and visit me as well. But the older ones, the older people are dying and now people that are my age; I guess we’re the old ones now. Somebody who is really old can’t tell stories properly because they forget things, they can’t remember things immediately when someone

asks them a question, because someone doesn't think right as they get older. If that old man Okimakanis was still alive, boy, he could tell stories. He was a good storyteller, a good man.

When I have the opportunity to speak to youngsters as a group, like when we take them on culture trips, I tell them to try and grow up right and to be good kids. I help them say their evening prayers after I've finished telling them legends, then they go to bed. Their favourite time is in the evenings, they all sit in a group in a tent and listen to me telling them legends and then to pray with them, that's what they like. I speak Cree and parts of it in English. When they ask me on parts they don't understand, I'll speak in English because we are also trying to bring the children back to speaking Cree. There is no one speaking Cree and that's the only way we can try to help them. That's how children were treated a long time ago, sitting in a group and listening to legends. When we lived with my grandmother who was a good storyteller, we would sit with her in the evening and tell us legends, that is where I got my legends from, because I listened to her carefully and I enjoyed listening to her as she told us stories. There are still a lot of children that listen carefully, those that understand anyway. One speaks to their little grandchildren gently, to be good children, because that's the only way children listen, to be spoken to gently. If you yell at them angrily, they get mad and they don't listen to anybody...to be spoken to gently, that's when they listen.

The youth are suffering though, the young that are having babies, they drank with them, so when the child is born, they're not right, their brain isn't right because of that alcohol. So those kids today, they don't understand when they are told something eh? And right away they start running around (misbehaving) like their parents, because what we see our parents do, that is what we do. If the youngsters could understand, the future is grim for these children. They have stopped the law that said you couldn't discipline, couldn't spank your child, I didn't like that law and I told them that. I went to talk to the students at the high school here, I told them to learn well, to not quit for any reason and to listen to their teachers. One of the grade 12 teachers told me, "They run all over me, they even smoke here, what am I going to do?" I told him to go see the parents first, the ones that raised them, and ask them if they sent them to school to learn or to misbehave. If the students continue to behave that way, you may as well tell them to not bother coming if they aren't going to listen to you, I told him. I'm very happy about that law that allows

you to spank your children. Because that was how we were raised. If we were asked to do something, we had to do it. You didn't get hit if you listened. But they don't listen today. They can't be disciplined because if you hit your kids they tell the cops, here anyway, they tell the cops right away. And these teachers, they can't do anything. When they first made this big school, I went there, to go see what they were doing, but the teachers were told that they could not discipline the children. They were everywhere, including jumping out of windows, they didn't sit still.

The reason for school, for a Cree to go to school is to learn to live with the whites. But it's good that the schools are teaching them Cree things, not to forget their language. But that's the parent's fault. I've seen that. Because when these little ones are just starting to learn how to talk, all the parents speak to them is in English, including our relatives. They will not understand a word you say to them in Cree. No. This is the parents' fault. I tell them that they should speak to them in Cree. But today, they misbehave so they don't learn. If you can't discipline your child, boy, it's going to get tough in the future. Nobody is going to beat their child to death, only those people that don't have any love for children perhaps. And we say that they are our future leaders, boy I don't see that, especially if they don't listen to their teachers. It is good to be taught, but they have to listen. The parents have to discipline their children.

4.1.2 Remembering Life in the Past

It's good when elders can talk about how life was long ago, but now it's very difficult, they have brought too many bad things today, a long time ago there weren't so many things that interfered, even this tobacco. Life was difficult a long time ago, people had to '*induminahisochik*' (fend for themselves), they only ate Cree food, not like now where they are always trying to eat from the store even if they are healthy. But a long time ago, people fended for themselves, setting nets, setting snares, in the spring the muskrats would be killed, and sugar, tea and flour were the only white man's food.

Everyone stayed at the trapline. We would leave in the fall and only return at Christmas and Good Friday for the church service. We would also come back in the spring; people would come and trade in their furs. In the summer we would travel around by boat, living in different

places. And on treaty day, everyone would arrive again. It seemed like we got a lot of money, because things were so cheap back then. There would be a lot of activities on treaty day, there would be boat races, tug-of-wars and they would kick around a ball. Back then people lived across the river; you know there is a large field, where the graveyard is starting to spread to, that's where most of the playing took place. The elders and us children, would sit with the old ladies, I guess we were the cheerleaders, watching the players. Sometimes, some of them would really get into the wrestling. That was our playing and not only during treaty day but any time there was a gathering of people in one place. There was always a ball to kick around.

We would work outside all the time in the old days. The men would go check their traps in the morning and they wouldn't return until the evening and the women would gather wood. But the men would also use Sunday to stockpile wood; they would make sure the wood was dry. Sunday was also a sacred day, nobody worked at anything, but it's true that even I worked; I would arrange the wood into piles as it was cut or chopped up. It kept us busy, doing little jobs here and there. I regret that I can no longer go the trapline, where one can do everything peacefully for themselves, to be worry-free, to go to bed peacefully but here, *eka itspawatuk*, there are so many distractions.

When I talk to trappers, in the bush, there is no pollution, not a lot anyway, that's the best place to be. Boy, these lakes are so pure, all over, even where we live, you go paddling and you can see at least 10 feet beneath you, the water is so clear, they are so beautiful. I know there are a lot of big rivers up north, like Wathaman River, Johnson River, Brabant River, and I asked the government to not dam them, for power...it's a bad thing, they destroy everything when they dam a river. I don't want the Churchill up north to be dammed, but I don't know if they will listen to me. If you don't have clean water you will get sick, you got to have clean water, but I don't know if they understood me.

4.1.3 Residential School Experience

When I was told to go to school, I went but I didn't forget how to speak Cree. We weren't told not to speak Cree, not like other schools where they say that they weren't treated well, I didn't experience that. We even had church service in Cree, every first Sunday of the

month; you know those Cree prayer and hymn books, that's what we used, here in La Ronge. The principal amazed me, when that first Sunday of the month, he went and stood there by the pulpit and he started opening up that bible and I knew that bible was written in syllabics and I wondered if he was going to read from that, and he did, he started reading, and I wondered who had taught him. I was just wondering how, how could he ever, learn how to read syllabics, mind you he was an Englishman and he was very, very white and I was so amazed.

I was about 9 or 10 when I went to the boarding school in La Ronge and I was there for 6 yrs. We didn't have school all the time, half a day and we worked the rest of the time. If you were misbehaving you got hit, sometimes, but if you listened you weren't abused. There was a man here, his name was Ahab Spence, he was a good reverend. He went to college, and he told me the only way you could get high school was if you wanted to be a reverend and that was what these people at Indian Affairs had decided. That's what he said and I believe that. When I went to school, there were only 2 teachers, the first class was kindergarten to grade 3, there was only 1 teacher and there were a lot of us. And the other class had a teacher from India; he looked Cree, Mr. Samson. And these rows of desks where we sat, you couldn't even talk to the person next to you. If you broke your pencil, you had to lift up your hand; he was the only one that kept the sharpener. We couldn't talk and you had to learn well, including myself, because you had to work on what you were given. If you missed school, the teacher would stand right next to you, at least that is what they did to me; so you eventually learn what you are supposed to do.

4.1.4. What it Means to be a Cree Person

We were taught that you need to have respect, to not *mathithichikee* (disrespect others), and most of all for elders. If we could offer any help for elders we were to do all we could, to haul water, or to haul in firewood for them, anything that they asked us to do we did for them. And in the old days of visiting, if you were a child, when you walked into a house, you took a seat at the door, and that was the only way, I wouldn't go any further onto the floor because I was taught not to misbehave. I was taught to sit at the door to visit and to listen to what the elders had to say. As children we were not to make any noise after the sun went down, because the elders were in bed by then. We couldn't go outside because we would wake them up. My grandmother would make the bedding ready for us and as the sun would go down, we would go

see a grandfather of mine, to go pray with him. Sometimes we would go the other way, where another old man would say the evening prayer. If we went anywhere by boat, then my grandmother would say the evening prayer for us.

Life was so peaceful back then and we were worked hard too as children, with firewood, carrying their wood back for them. My grandmother would still gather wood, she would cut it and I would haul it back in a sled. The best time that I liked going with my grandmother, was when we would go check snares, I would run ahead in my excitement and every once in a while I would see a rabbit hanging in the air. She made these snares (*wepaskoputhichikunis*) is what she called them, and to this day I have no idea how to make them. But I was so impressed with them, because when the rabbits got snared, they would spring up and hang there until they died and nobody could steal them, at least those animals that could run.

There have been a lot of times that I've listened to people telling me things. My father-in-law used to tell me all kinds of things, including words from the bible. And a lot of times, the elders would tell me that I should not take exception and get angry no matter what anybody said to me. Don't talk back when someone is arguing with you, have *seepeethitamowin* (faith), was what they would tell me. And truly, I never argue with anyone for any reason, not my fellow person anyway, my children of course, I give them heck but other people, I never argue with. I have faith, and nobody ever comes and says anything bad to me either, because I never say anything bad about anyone. Before, I used to have people try and argue with me, but I would never respond to them. Nobody ever tries to argue with me.

One should be happy that they are alive on this earth, to be happy that they can joke around with their relatives, to enjoy life, to not be sad, try not to worry so much about other things, it won't matter because living happiest, while we're on earth is what's important. I think this piece of earth we've been given, it's so beautiful. *Peeyutukeethimowin*, (peacefulness) is what we have here, not like in other places on earth, where there is so much suffering, all over, they see their children being killed, but we don't see that. We've been given peacefulness, by our *Munitou*, to raise our children, that's what I think.

Everyone has to have good relationship, to help anyone that needs help. That's how I am. When someone is in trouble, I help them. There was lots of that a long time ago. We were taught not to refuse any help or assistance. If someone was building a house, people would flock there and help you finish it. There's no way it's like that now. You need to love people, don't act strange with anyone. That's why we have so much respect here in this house, even little children, because we love them, we always have candy, as soon as they come in we give them some, they are always coming in and out (laughing) but that's okay. You give them one or two pieces and they're happy. That's all, for one to have good relations, to not have bad feelings for their fellow person.

I'll also speak about this gossip, it's a very bad thing, to speak of your fellow person in a bad way, to gossip, a lot of times it breaks couples up. I was never like that, I had perseverance. It has destroyed too many lives, that is what I've seen; perseverance is the best thing. I think that when someone is truly intent on doing bad things to you, to cause you grief, if you sit and talk quietly to the person, you will forgive that person. That is a good way to be. Gossip is evil, when someone believes in something they can't see, whereas when something is going to cause you real grief, then its okay for you to get angry, I guess. It is good when a person has perseverance. No matter what one says to you, it can't kill you anyway.

4.1.5 Perceptions of Health and Illness

I consider myself healthy when I don't hurt anywhere and when someone is full of energy, to begin working once they get up. For someone not to sit around, I was a hard worker, not afraid to work and I cook my food really well, I didn't eat a lot of white food, even today. That's how someone stays healthy, but when someone injures themselves a little bit, they need to move around slowly, they could make the injury worse, they need to take care. It's not good for someone to work really hard, injure yourself, only work at things you can do properly, you don't injure yourself and you stay healthy. This diabetes that everyone seems to be getting, there is something that we are eating, the doctor said, or else we have switched our foods. And that is where diabetes is coming from, but it's true, they say we should eat Cree foods and move around all the time, but we were always moving around. That's why elders are still so spry because they

were always moving around back then but today, we stay in the same place; it seems that we age faster.

On my birthday I'll be 83 yrs old. It's only been in the last 2 years that I haven't been really healthy. The other year before that, we still went muskrat trapping. It hasn't been too long ago that I stopped working because I can't walk very well, my knees. I can't walk, because I can't take a step, I can stand but I can't step with it. I used to take care of myself real well, while I was still healthy, but now...I can still take care of myself, I can do everything for myself.

I take medicine to make me better, but now there is only bad medicine being used. I think its bad medicine; some of them aren't good for us. I tell them right away if it doesn't work. I drink medicine tea sometimes so I'm getting well. I think it was those pills making me ill. You need to be aware of these things. They make too many kinds. Look at these Tylenol, they say there's good stuff in there, when I have a really bad headache and I take 2 of them, it don't help at all but these (holding up Aspirin bottle) I take one and about 10 or 15 minutes my head is feeling better. These are good, for me anyway. And when my teeth would hurt me, I take one and I'd have a good sleep. Anywhere it hurts. I medicate myself if I have a cold and nothing exciting, mostly Vicks and even when I have a cough, I take a little bit and eat it and it makes my chest cool, I don't cough as much. I rarely use cough syrup when I have a cold. Sometimes when I'm working outside, I hold some *wachuskomitisowin* in my mouth, that's good medicine too; there are still a lot of people that use it.

A long time ago there was no doctor here, only on Treaty Day. People used Cree medicine to make them better; people didn't get well right away without medicine. Sometimes there is sickness that runs through a community. The sick person would be lying on a bed or on the floor if there was no bed, and the stove was kept going especially if one was really sick. The fire was kept going all night so that the person would not get cold and there was no, there wasn't any medicine. I know that some of them were sick for a long time, they hurt everywhere and they didn't know what was wrong with them. They would be lying down all the time. Of course some of them had medicinal tea that they drank. I haven't seen anyone ill like that since I was a child. Today of course, people are in the hospital but back when I was a child, people didn't get sick

often, but still there were some that got sick, especially the elderly, they would be laying down until they passed away. I don't know what kind of illness that was though.

For white man medicine, there was only Aspirin and Vicks, it's been around a long time and painkiller it was called, a medicine that one took for coughing, like when your chest hurt from the effort, they would put a bit of sugar in it, put it in hot tea and drink it. They spread it on their body too, on their chest and throat. There was another medicine, they called it *pimiwi-muskiki*, I don't know what that would be called in English, they used to drink that and spread it on their body. Even when someone would cut themselves with a knife, they would put that medicine on the cut and they would heal quicker.

4.1.6 Christianity and Traditional Spirituality

There is one more truth that I will tell you. Our *Munitou*, he listens to us whenever we pray, no matter how evil we are, that's what I think. I haven't always been a good person and sometimes I would question whether *Munitou* would take pity on me and listen to me. But then I would remember something the principal at the residence would say, 'our lives are like an open book,' he'd say, 'all of us, each of us is like an open book in His sight' was what he would tell us. We can't hide anything from Him, how we think, or even what we do, and He will never deny us. And he would also say, it's true that whatever we ask, it won't be granted right away, but we will see it later, that He really does listen to us. I remember that often. The most helpful is prayer. Even as we sit here, He's listening to us, He that made us, every word we say...that's what I believe anyway. Whatever you ask He will grant, not right away, but He will help you.

In 1937, when I finished school, I was not quite 16, I was given a bible, its right there on top of the TV, when one reads that and ask for blessings once in a while, it works. That's where you get your knowledge, from that book. To understand, it helps people, that's what I've heard...but there are so many evil things going on, it's difficult to turn people around. I have read in the bible that these diverse happenings, are the prophesies coming true and it does say that all kinds of diseases will be here but some of these diseases will not be curable and when those diseases have run their course, then great suffering will follow. That's what it says in the bible and the words in the bible are not lies. Life will become more difficult, when these diseases

run their course, these diseases that keep coming here. Yes, cancer is one that cannot be cured. There is another one, another disease...sexually transmitted disease...that one can't be easily cured too. Life is going to become very dangerous and difficult in the near future.

There have been many times I have thought about that, what we believe in. My grandfather used to say that we had no religion until they (whites) came. What people used to believe in was called *powamowin*. I've heard about that, but they would kill each other! There was one man, my grandfather would tell me he was our relative, his name was Oothapachikew, he was very powerful, a good medicine man. He was the only one who could kill *witikowuk*, is what they said. They said there were really *witikowuk* a long time ago. He was powerful. If there was someone he didn't like, he would take something, anything a frog or a fish, he would send it to someone, like this (flinging his hand as if throwing something away), it would hit that person, I don't know how but by the end of the day that person was dead. He would imitate some people; he was powerful, if he could kill someone without touching them that angered him. But I don't want to tell too many stories about him.

4.1.7 Traditional Cree Medicine

Cree medicine, boy, that's the best medicine. When someone gets hypothermia, the only medicine they need is *pawistikowi-muskiki*. It smells very aromatic, that medicine, when one boils that, that's what I drink, 1 or 2 cups every day. A medicine man from Sandy Bay told me that all you take is *pawistikowi-muskiki*, that's all, and you boil it, boil it very well, and then, you drink that for 1 week and when you go get your blood sugar checked, they will not find any sign of diabetes. I wonder if it's true. But this *pawistikowi-muskiki*, it doesn't grow just anyplace, only in wet areas of streams. It's really good for treating hypothermia, because you know hypothermia kills some people, they get so hot, you drink it, and if you have a fever it's good for that too. As soon as you start sweating, it's working, it's good medicine.

That *wachuskomitisowin* is powerful too, even when one has a cough, to chew on it and keep it in their mouths. That person doesn't cough and even if someone is sweating working outside, nothing will happen to them as long as they hold it in their mouth and swallow their spit once in a while. I've also heard that if someone with diabetes boils *wachuskomitisowin* and

drinks it, they can treat themselves. But there aren't many people that have tried it. When someone gets frostbite, this *wachuskomitisowin* is good.

But the best thing, even if the skin on your hands is frozen white, is coal oil, you spread it on your hands, even in places where your skin is white, as the white skin melts, in the morning, it only hurts a bit and there is no water inside your skin. In 2-3 nights you've grown new skin and you are completely healed. You probably know it as kerosene; I think gasoline is good for that, to soak your hands in it. I've seen people use snow to thaw out when someone was frostbitten but that's not good because you get water in your skin. Kerosene is also very good when someone has lice; that's the best stuff. You just spread it in your hands and smooth it on the children's head, even when they have nits and then, oh maybe, 1/2 an hour, and then you wash their head and then use a fine tooth comb and they will all be dead, all the lice. Even the nits fall off, it's good stuff.

There were a lot of accidents because wood cutting was done by axe and you had to have wood in the winter. There was another medicine, for when one cut themselves with an axe, *neepsi-chipi*, they would chew that up and put it on a piece of cloth along with a bit of lard, they would use that as a poultice. Nobody's leg would start bleeding again, at least not often. But what I was saying is that these Cree medicines are very good.

We had a great healer here, his name was Abel McKenzie. It all started when he and his friend went to Prince Albert to fetch 2 horses and a cart for a man. He had also asked them to buy some alcohol. So they had bought the alcohol and a man came up to them and asked them for a drink. They told him that the alcohol was not theirs and they didn't have any money to buy any more if they drank it. The man kept asking them and they kept refusing. When they departed, the man said 'you will *aswithimin* (beware of me) three times'. They traveled until dark and set up camp. Late in the night they heard noises that sounded like heavy breathing coming from a large animal. They tried to spot what it was and all they could see were the eyes glowing in the dark, but they knew it was a large animal. They did not sleep at all that night, they were scared to let the fire go out and they resumed their journey as soon as there was some light. That day they traveled as far as Montreal Lake. Abel had a first cousin who was a medicine man in Montreal

Lake and they went to him for help. The medicine man made them each a medicine bundle which they were to keep over their left breast pocket at all times. They were warned not to tell anyone about their medicine bundle or the power would be lost.

Once they returned to Stanley, the other man automatically told someone and he drowned soon after. Abel did not tell anyone about his bundle. However, that fall as he was traveling to his trapline, he was flipped over in his boat by something at Otter Lake. He thought he was going to drown when something came between his legs and lifted him out of the water. He pointed towards the shore and the 'fish' or whatever it was took him to shore and saved his life. His bundle got wet and he was worried about what would happen to him but he continued on his way. A few days later he was sitting in the cabin. The cabin had overheated from too much wood in the stove so the door was open when a bird flew in and *chukutuhokoot* (pecked) his knee. From that point on he was in such pain that he could not walk, he had to crawl everywhere and he could not sleep at night because of the pain. A few days later it was a nice day outside and he wanted to go sit outside so he crawled outside and noticed a small dust devil, which quickly enveloped him and some debris got in his right eye and he became blind in that eye.

Then he had a dream about a man who told him to get up and walk with him. Abel got up and walked with the man who took him to a garden. The man said 'this is my garden; I can show you how to use the plants to help people'. Abel agreed that he wanted to learn. The man in his dream showed him a plant that looked like two rabbit's ears and told him that he was to pick the roots of this plant and boil them, then he was to blink into it and that would cure the blindness. Next, the man told him to find a balsam that was 4 finger lengths in width. He was to make a paste of the balsam and place it on his knee. When he awoke he told his mother about his dream and she followed his instructions precisely. Within the first day of the eye medicine, he could see brightness and his vision returned within a week's treatment. The same thing with his knee, within a week he could walk with no pain.

After that he became a great healer, because the man in his dream showed him how to use plants. He was called to help others from all over the place. Once he was called to help a woman who had gone crazy. She had become violent and it took 4 men to control her. He entered the

cabin and calmed her down with his touch. With 2 days of medicine, she was back to normal. I remember once we all had a skin disease, and where our scabs were, he washed them with a solution of *wachuskomitisowin*, then he mixed some *wachuskomitisowin* with lard on a piece of cloth and tied them on our rashes, and in two days we were completely healed.

I don't know where the practice of paying for medicine with tobacco came from but I have always heard of this practice and Abel would pay with snuff because that was what he used but he said it was the same as tobacco. You could also pay with other items but the important thing was that you paid for the medicine or else it would not work properly. He got paid with all kinds of things for his healing; traps, flour, tea, sugar, whatever people could afford to give him. He couldn't cure himself, I think that was what he had said, he couldn't cure himself, only other people and he died of TB in the sanatorium.

4.1.8 Cancer Among the Cree

I never heard of people having *munchoosuk* long ago. But they did say that those that could curse each other, that had evil knowledge, they would give each other the illness but they could also cure each other as well. They used to talk of one here, an old lady who had been sent a curse, she got *munchoosuk* on her nose but she was cured, that's what my grandmother used to say. The first case of cancer here was in 1944, a long time ago, my father was the first to have it in his stomach. But now today, there's got to be something to that, that they are catching it. But this is the worst thing (pointing at snuff). Those that smoke are the ones that are most likely to get cancer too. It's mostly their smoking that causes it, so they say, or so I've heard. There was nothing a long time ago. I was told that when I could afford something for myself, only then could I use it. My father used to tell me that tobacco served no purpose; it's just a distraction, takes money away from one. When you can afford it, you can smoke, he told me. So I didn't even steal his tobacco even though I wanted some (laughing). I smoked for a little while, when I was outside, when I was chopping wood, when I would rest that's when I would have a smoke. I quit smoking a very long time ago. Long ago, people didn't smoke cigarettes, and only the old people smoked and they smoked pipes. And they didn't use pure tobacco either, they would add leaves and some roots, they would dry those and mix them in the tobacco. Oh, the smell was so aromatic when they smoked. Young people didn't smoke then, but today, even those still in their

baby blankets are smoking. It's not surprising that they catch that disease, their bodies aren't strong...and they smoke bad stuff as well.

We've been eating bad a long time too, that's what I think. These foods that are being eaten, I think that's where diabetes comes from because even the meat that comes from cows, they get needles and that gets eaten. A nurse held a meeting for us quite a while ago, in La Ronge. She told us that those canned foods with some meat and potatoes; some are quite big you know, those have to be cooked real well, because they put stuff in there that will make us sick. And the steak, they dip it in a dye, the steak, just so that it will look good when it's cooked, that's what she told us too. That's where cancer comes from, the different kinds of food people eat.

I don't know of anyone that got cured using Cree medicine. Over from Pelican Narrows, I mean Amisk Lake, there is a young medicine man that cured a man. He has good Cree medicine, and he also prays hard for them when he is treating them. I received teachings from Benjamin Ross, how when one has skin cancer and can't heal, there's medicine for that. And I know what the plant looks like but I don't know what else has to be added, it will cure. You wash it in water and use it as a poultice, but that's on top of your body. For inside your body, I don't know if there is anything. Perhaps there is some medicine. Maybe if someone were to chew on *wachskomitisowin*, that it could help someone who had cancer in the lungs eh? Maybe that would be better than if one was to drink a tea made with it, that's what I wonder...but I don't know what kind of illness that is even. I don't know where the word *munchoosuk* came from; it seems that Cree people think the illness works like *munchoosuk*, which is why they call it that. It was already called that when my father had them.

There are more people that are getting them, it appears that the main culprit is tobacco, because it's all those that smoke that seem to be getting it and there doesn't seem to be anything that can be done. A person has to tell as soon as possible if they feel that something is wrong with them, perhaps something can be done for them. I go and visit the sick people that are in the hospital, these cancer patients and they are very happy when they get visitors, maybe it distracts

4.2 Cancer Survivor Story

4.2.1 Perceptions of Health and Illness

I think, I understand, that when someone who is healthy, they are happy on the path they have chosen to follow on this earth and so they probably have no worries. They just follow their thinking, they are not concerned that anything will bar their way because cancer isn't the only thing that destroys people, alcohol destroys too; we have lost many youth due to alcohol. You also got to eat properly, that's what I think. And I don't know if I ate properly or not because I got diabetes now and I got arthritis all over my body and eating didn't seem to help me (laughing). But to be healthy for me means not to be sick I guess, to live the good life. I try to eat more traditional foods like fish, moose meat, traditional Cree food, and berries, stuff like that and I don't eat too much junk food. I guess I was happy to be healthy again, to be able to walk around.

For me, being sick means that I can't help myself. Like when I'm not eating properly, eating white man food, not feeling right, I feel different when I eat white man food. I go see the doctor sometimes, but they...it's not like before when people got traditional medicine, when they were sick and stuff like that, they would eat *wachuskomitisowin* and others, like *amiskowekusk* and sometimes, I use traditional medicine too. My cousin gives me some and sometimes we go collect them in the fall. It was my mother who taught me stuff like that; when we were children we were shown how to pick them and how to make myself a medicinal drink. I take pills too when I have to. I even buy my own medication, I get the doctor angry, I've got sugar free bentalyn, benalyn and Advil, I mean I take ibuprofen, it's easier on my stomach.

4.2.2 Traditional Values and Life in the Old Days

What I was taught was to speak with my fellow *nihithow*, to love Elders, and to not say anything that will anger another person. That's what I try and follow, the way my mother taught me to behave and, to speak politely to others, and if someone says something to me, that I don't retaliate to make it worse or make them angrier, and to not get into a rage. I was taught not to misbehave and to go to church. But for sure the teachings that I did get were from my mother, my father had died. She would talk to me, but I've forgotten some things. Back then, people tried to raise their children properly, there was very little white-man stuff around. It also seemed that

there weren't too many different illnesses going around back then. From what I remember, there was no welfare, people didn't eat all kinds of foods either, people ate off the land like fish, but today there are too many different types of things.

We did travel around long ago, to the trapline, that was the only time we'd be someplace else. I went to school here in La Ronge too. I miss it sometimes, the traveling, but it was my mother's doing, she didn't want me to go anywhere, and unfortunately I was the baby (laugh). Then I eventually got married, ended up staying here, having my children and it was more important for me to take care of them than go anywhere, they've all grown up, and I've got grandchildren; I'm getting to be an old lady, I can't travel around now (laugh) because I babysit my grandchildren, so that takes away the possibility of traveling around.

4.2.3 Cancer Diagnosis and Treatment

I don't think anyone knows right away if they have that. It's probably not for a long time until someone begins to feel it there, but for me, I didn't know it was that. It's difficult, having that illness. I used to be sick, for a long time and I didn't know what was making me sick. And, I never felt like doing anything. Then one night I was sitting on the chesterfield, lying down and I couldn't figure out how I was feeling in my back and I went like this (feeling breast), it was like an egg. 'Come look at this my daughter', I said, and she was feeling it too, it's just like an egg. 'Wa-wa, make an appointment, *seemak* (right away)' she said. But I didn't jump to do her bidding, so she starting giving me hell, '*seemak*'. So I called my doctor and she told me to go down there the next day. 'I have to send you away, to Saskatoon,' she told me. And it wasn't even one day that they called me back, telling me that I had to leave, to go see another doctor in Saskatoon.

So I went to Saskatoon, to go see the doctor that I was supposed to go see. Not even a week after I got back home, he called me and said, 'you got cancer and we'll set a schedule for it, to operate.' and I started crying eh, I don't know why. So I went to Saskatoon and that thing was taken out. The doctor told me that they had to cut it off, my breast, one of them, and they put something inside, only my skin, it was all right and I'm using that artificial breast. I was almost in disbelief, because I never felt any pain, just that pain, on my back eh. So I went and they

operated on me right away but it didn't hurt, you know, after they cut me open, it didn't hurt, I prayed. I had the surgery and then I came home.

About a week later, I left again, to go have radiation over there, at the University Hospital; I was there for 6 weeks of treatment. They gave me radiation and that other treatment, I don't know what it's called, they would inject the medicine in me. I was there for 6 weeks. I was so, so lonely...although my children came to visit me. But I knew I wasn't the only one going through this because I even saw kids that were going through this, poor kids, they are so small when they get it, but me, I knew I shouldn't feel sorry for myself, I knew I wasn't the only one that had it and I started to get over it, after seeing that many other people had it as well eh.

And when my treatment was done, I came home. All my hair fell out and I was so skinny, I was gaunt, even my eyelashes were off and my eyebrows...and the doctor said your hair will grow back, it may be white or you could have curly hair, but I didn't get any curly hair, just getting white hair (laugh). I didn't feel a thing when they shone the light on me. It was only after the treatment, when I came home, although they did tell me that I would get fatigued, oh, did I get fatigued! Sometimes it still hurts so much especially when I'm doing something, like when I'm outside; it hurts when I have to lift something. But it never reappeared again, so, I was quite happy about that and I just keep on praying.

4.2.4 Emotional Impact of Having Cancer

When I first found out, I was just, I didn't know what to think, I was extremely *pukwutamun*(upset), I just stayed home, I locked myself in the house, didn't go anywhere. I felt very bad, I wondered why; I thought I was going to die because I had heard of so many people who had died from cancer. That's what I heard and I would think that I would never get well again. But my family talked to me, they said I should go ahead with the operation.' And I said, 'no I don't think so', I wasn't gonna, I didn't want to go but they said 'your life is, you might get a few years, a few years of your life will be extended if you go for that operation,' so they talked me into it. But there was something else, I began to remember that I had a lot of faith in *Munitou* before and I thought why wouldn't I have faith in Him now and I also know that everyone is going to die, not necessarily from cancer. I believed that *Munitou* could cure me, because these

doctors, they are given the power from the *Munitou* to cure people. *Munitou* uses the doctors and then when people pray for you, *Munitou* hears and helps them and then they have the ability to cure you. One more thing that I believe in, even if I am healthy, there will still be a day when I leave this earth. I also believe that every day, I pray for myself, you understand? I'll tell you one more thing; when one has faith in *Munitou*, there is no confusion. Your soul works for you, fights for you. I'm not saying I'm holy or anything, but that's just my belief, I can't change it.

But I hated it, losing my breast; it was like they took my womanhood away. I couldn't even look at myself for two months. Even when the dressings were changed, my old man was the one who changed them, I never, I couldn't change my own dressing and he was the only one who looked at me when I had my stitches out, I couldn't look at myself. And today it's still hard for me to take off my breast and put my breast in a box and go around with one because I feel so lopsided; my cancer is so visible while others are not. I didn't go for help, to talk to anyone, I didn't want to complain, so I thought, just one day at a time, I took it. It was very hard on me. I shed a lot of tears, my husband, my husband was really supportive.

4.2.5 Cree Medicine and Healing

I believe that Cree medicine will help a person but they also have to believe in its ability to help them, the same way as one has to believe in *Munitou* because if there is even a glimmer of doubt, then we don't believe. The medicines, they are *Munitou*'s creations and they are good to use. I also believe that there is a medicine that can kill cancer, but nobody knows which one it is because *Munitou* made everything we see, all these trees eh? He also made them in such a good way that we can get all our medicines from them too, but some people don't use them properly either, they make bad medicine from it and that's not good. There are all kinds of medicine around, if one was to have the knowledge.

My grandfather was a healer, my mom's father and my mother knew some of those medicines, and that's what she taught me to use. Like when I'm tired, when I'm fatigued, I'll go get some medicine for myself and I boil it, and I'll drink it then I'm okay. He taught my mother only certain things, for women illnesses, to heal herself, to brew medicinal drinks for her children, or when a woman has had a miscarriage, hurts herself inside, she knows that medicine

too. Or when someone has a cold, or a fever, or can't get their energy back. After my surgery I just couldn't feel better, I was really weak and everything, my mother brewed me some medicine, she made it 3 times and that was enough, my energy came back so I was able to bounce back. I think it helped me a lot, and it gave me a boost, my energy a boost.

4.2.6 Spirituality and Religion

Having cancer didn't change my spirituality, I'm Anglican and I also use traditional spirituality. I use both...I enter the sweat when I need the cleansing but I didn't go in the sweat for a while after the surgery. I didn't want to get an infection; I didn't go in until I was all healed up. I don't disbelieve in all these other religions either, because as I begin to understand *Munitou* better, there isn't one other person who is ranked higher, we are all equal, we are all the same, all the souls are equal that seek help from Him. *Munitou* gave us so many days on this earth and if you haven't reached that limit, as we are suffering these illnesses and people are praying for us, and we believe in Him, *Munitou* will help us get better because we haven't reached our time yet, to that point in time that He lent us life. But when we reach that time, that's it, we have to prepare for that day, because when you reach it and you believe and you have prepared, you get to go live with Him where He lives. Because those that believe in *Munitou*, He sees us and watches over us like we do our children. You will help your child to the best of your abilities, and *Munitou* helps us like that too, as we are His children. But if we reject Him, then that who is in charge of the earth, that is who we follow, the bad soul. Therefore, each of us has to decide whether we want to go to heaven or hell, only you can decide. Because as the Day of Judgment approaches there will be diseases, all kinds of illnesses, and we are living with them right now, I think cancer is one, and those other bad diseases (STD's) that can't be cured. It can be anything, when someone's blood is greasy (cholesterol), when they have sugar disease (diabetes). Everyone probably knows this, that one day we will not be well and that we have to do all we can until that day to take care of ourselves. If *Munitou* is using the doctors, if you are to become healthy, He will help the doctors to cure you.

4.2.7 Physical Health Impact of Having Cancer

I started getting ill again, I don't even know if it was for even 2 weeks that I was home and I became a diabetic. I was sitting here, and I don't know how I was starting to feel, starting

to feel ill, I'd drink and drink, I'd get dizzy, I stepped into the hallway and I fell. Thankfully my daughter was here, and she rushed me to the hospital. Almost as soon as I got into her vehicle I lost consciousness again and when we walked into the hospital, the last thing I remember was sitting in the wheelchair that took me from the car to the hospital, I blacked out again. I was unconscious for 24 hours. My sugar had gone up to 29. When I woke up all my relatives were standing around my room, but I did get better. I'm still ill sometimes, my sugar goes high and then sometimes it goes down to 2, even though I try and eat properly and eat enough, maybe I'm just that sweet...but they are bad diseases.

4.2.8 Sources of Support

There was no one to talk to; I was alone, praying for myself and stuff like that, now I pray for others so that they don't have to go through the same thing. Some days I didn't know what to do eh? I didn't have my mother that I could tell things to, she was sick herself, in the process of dying when I had it. My cousin got it last year, the same side as mine. I would talk to her, telling her how I'd feel and she would ask me exactly what kind of treatment I got eh, what they would do to her, I told her it wouldn't hurt too much, if they take out your breast, but I did tell her that she would lose all her hair, but it will grow back. Today she looks quite healthy. I didn't try to think about my own problems, I always tried to look after my little ones. But my kids tell me that, I've got 7 kids, and they tell me that, 'you gotta look after yourself', well, I'm too busy.

4.2.9 Changes After Cancer

I don't think I'm going to die from cancer anymore. My thoughts about that started to change about 3 months after my surgery. After having my medicinal drink brewed for me and then I went to the cancer clinic too and they talked to me and they told me there is no sign of cancer, nothing so I felt really good about it, and I was able to bounce back. But cancer will probably always be part of my life because I still go for check ups every 3 months because of this (right breast) so I get a mammogram all the time too...every 3 months and I do my own breast examination. Perhaps, maybe someday, perhaps they will grow again, I don't know, I can't say. There was a person there when I was in there, it had been 15 years before they came back and he was in there again but I also know, when someone is really going to be destroyed by

them, even if they are killed in one place, that they will grow someplace else, therefore, that's why I think it would be a good idea for one to get earlier check ups and I appreciate life more...life is too short...is what I think. There is one thing that is troubling, your relatives, they also suffer when you are ill, and that bothered me, not for my life but for my relatives suffering.

4.2.10 Knowledge Before and After Cancer

I didn't really know what cancer was eh? Nobody had ever told me anything, I knew about *munchoosuk*, but I didn't know that *munchoos* was a cancer eh? I seen advertisements and stuff like that but I didn't know nothing about it but today I have some knowledge, and how it affects people. And what I know is that anyone can get it, even the youth. And if someone suspects that they have it soon, the treatment isn't that difficult, but as it completes building itself is when you start feeling the symptoms. I don't think there was anything I could have done to prevent my getting cancer. Maybe if I had looked after myself better, feeling myself more often, maybe it wouldn't have got so big eh? But I wonder why I didn't feel that sooner, not until it was bigger, and with the mammogram, I wonder why they didn't see anything?

Boy, I don't know if you can prevent cancer, because a person can't feel anything when it starts. Perhaps, it would also help if one was to go see the doctor for regular checkups; maybe some people do that to ease their worries. Maybe people, like myself, who have this illness, we could pass it on to our children, so it would be a good thing that the youth get checked sooner, so that hopefully, they don't get it. I know that someone can get well again that has had cancer, with surgery and medication.

4.2.11 Perception of Prevalence

When I was a child there was no one, nothing...all there was was TB and sometimes people didn't get sent out right away, and that illness traveled so fast around the community. But cancer, I don't know and before that hospital was built, that old hospital, it used to be a nursing station and my mother used to work there; she never said anything about anyone with cancer being there.

I think more people are getting cancer. I don't really have any idea, maybe the food, the food we eat. I know there's four of us in La Ronge that have had breast cancer, there was five of us but one passed away 3 years ago and my niece also had kidney cancer. If the four of us were to walk around together, nobody would have a breast on this side (right).

4.2.12 Compassion for Others with Cancer

I feel for them and I know what they're going through. But sometimes it's too late...they're too scared to see the doctor or they get the run around from the doctors here because there's so many doctors change and it's a different doctor that they see each time, I think that's what happens or they don't care for themselves. It's not easy, when a person is ill, to tell them that *Munitou* can help them, because if we are going to seek the help of *Munitou*, we have to quit that which we are following on this earth. It's also written, it's dangerous if people pray for us to get healthy and we get better and then resume that path we were following before we got ill, greater harm will come to you.

4.2.13 Health Practices Post-cancer

My life is a bit different now, I don't eat as much white food, still sometimes, but I'd rather eat traditional food, the way we lived long ago because it seemed that people were healthier so that's how I'm trying to live. I try and eat traditional foods, every 2nd day like moose meat or fish. I was living in the city before and there was nothing over there but then I moved back here in 93, so I've been eating more traditional stuff than anything else except for that crazy chickenⁱⁱⁱ (laugh). So I'm trying to be healthier, not eat a lot of junk food, and I try to do things to stay active, to walk, I do traditional activities, I do things like that. I just try to live every day the way I have been since I developed cancer.

I still feel myself to see if there is anything, I did find something else here, small, and I called the doctor right away and they told me to go the hospital, so I went and the other doctor was there and he took it out, it was a cyst, it's not cancer eh but I still go for mammograms every three months. That mammogram, it hurts eh? I tell all the ladies to get that done, it might save

ⁱⁱⁱ "crazy chicken" is referring to Kentucky Fried Chicken

your lives, because you don't know when you have cancer. That's one thing that, go for a mammogram, it's painful but it's only a matter of seconds. Instant pain, a couple of seconds only, when they press it down and that's it.

But, you know, that's what they say, it will come back. The doctors say the cancer will come back. I'm not scared, not at all. It doesn't bother me one bit. If I'm going to get sick, I'm going to get sick. If I'm going to get well, I'm going to get well. I take it one day at a time, I don't worry about it. I have a lot of faith. Whatever happens will happen.

4.3 Family Member Story

4.3.1 Perceptions of Health and Illness

To be healthy for me is be able to work, be able to look after myself, be able to go out in the community and do stuff with people. For me to be healthy also relates to happiness, my goal is to be reasonably healthy and happy, and healthy to me also goes to quality of life, which also makes you happy. It means being physically fit, I mean I've changed so much mentally, you know, you have to be mentally fit and physically fit, I guess I'd have to say spiritually, mentally, all the four aspects. This is what I'm trying to follow, to keep an eye on these but sometimes I forget things, I get angry, frustrated, I think too much about things, I don't always show good relations with people. If you hold a lot of anger or sadness within yourself you will get sick. My father used to tell me that.

I don't drink, I don't do drugs, I go for walks, I do a lot of crafts, I like crafts, painting, spending time with family is really important to me. I try maintain a healthy, a reasonably healthy weight because I'm also arthritic so I can't be too heavy because then my joints hurt too much, but I try and do as much as I can. As I get older, I am starting to take care of myself in my life choices, I wonder if I've done enough bad things in my younger days, as I get older, I'm getting more sense, but, there are still things that bother me. I have to keep working at it, it's not like one day I'll be well, it's a process, and one has to work at those things continuously. If I'm feeling dissatisfied, I try figure out what I'm missing and it's usually because I haven't spent enough time with me, like doing something for me whether it's reading or sewing, it's usually that I've missed me. I'm too busy doing things for other people that I have forgotten about me. To have no pain anywhere, some people suffer from some pain and they think about and talk about it excessively but to be happy, to exercise, I don't want to stay in one place. I was up to 180 some pounds. I just kept walking and not, not snacking so much in the evening, like after supper I'd snack, eat a bag of chips, those 3 for 5 bucks that you can get at the store; you open them up and just keep going. I haven't been snacking so much now, what I have is a fruit tray or a vegetable tray.

If I'm sick or something, I'll take medicine or do what it takes to be as healthy as I can be. I have vitamins there that I take, and I watch my diet too, not too much sugar or salt, that

kind of thing, not using too much oils or anything. I watch what my kids eat. I try to make sure that they eat their vegetables and milk and all that, all the good stuff, make sure meals are balanced but also make like healthy snacks available for them too. Unless I notice something unusual, or different than the other times I've gotten sick then I'll go see the doctor at the clinic. I suppose you can be spiritually sick, I know when I'm sick, I just don't feel like seeing anybody; I just want to stay in bed and get better. I don't want to come in contact with people so I don't get them sick. I stay in bed, watch Oprah...no (laughing) I usually just stay in bed, and try to get lots of fluids, watch out for myself because no one else is gonna, you know. My kids say to me, you have to look after yourself Mom. I go for my annual check up, and my pap tests, and now that I have to go for breast mammogram, I'll go for that, when I'm asked to go, I'll go.

4.3.2 The Traditional Lifestyle and its Impact on Health and Illness

I was raised fairly traditionally. Out of my whole family, I'm the only one that never went to residential school, I stayed up north. We lived on the trapline, we also commercial fished in the summer. I don't consider this place as my home, it's my second home. The trapline is my first home and if it was up to me that is where I would be staying full time but my children need education. Children of today need the education to survive in the white man's world and I have to give them that opportunity. I know my Dad used to hunt lots, it was the only way we could get our meat, you know, ducks, rabbits, moose and we worked hard hauling water, hauling wood, we did all that, helping my grandfather with the fishing net. So in terms of appreciating, I think I developed, I don't know if you'd call hard working being appreciative but, I think I learned to appreciate living out on the land and having a much more closer-to-the-earth lifestyle. I still prefer food closest to its source but in terms of learning all the traditional skills, like hide preparation, making moccasins and mitts and, cleaning fish and all those skills I learned while I was growing up. I don't think you lose the values you grew up with even if you don't follow the traditional lifestyle anymore. Some of those values are hard work, lots of family commitment, like the family has to work together in order to get everything done in a day.

I spend a lot of time visiting Elders, just sitting there and listening to all the stories they have to tell. I don't think they had to do anything to stay healthy long ago because their food was very plain, basic food, it wasn't processed, and it didn't have any added sugar, salt, nitrates or

whatever. They didn't have alcohol; they didn't have tobacco, like Player's cigarettes. I think they lived a lifestyle where they were much more stronger, because they had to be, to survive. Their food didn't have all the growth hormones and all that stuff, plus they were physically active, they had to work, to haul wood, to chop a hole through the ice to fish or to haul water, so I think they lived a much more basic stronger, cleaner life than now. Now you're looked upon as strange, if you're a young person and like smoked muskrat. So I think they led a much more basic lifestyle and that's why they were healthier. I don't think there was much that they could do if they got sick, except to be treated herbally or treat themselves but I also think that their bodies were strong enough to help heal itself. I also think there was an inevitability, that if you couldn't heal your body that you allowed yourself to die, rather than to try and fight it, and I think that's what happened then.

It's a shame that the Elders are getting older because they have so much knowledge which they haven't passed on. The second generation of Elders doesn't have that knowledge, which the Elders currently have because they haven't passed it on. It's going to be a different world. One of the last things, or one of the things my father told me was, don't ever allow a white man to enter the reserve and tell you how you should live your life, because if you allow a white man to do that, then he has taken over every aspect of your Cree-ness.

4.3.3 Family Member with Cancer

Two years ago I lost my Dad on March the 21st, which is 2 days after my birthday, of cancer. It's still hard for me to talk about it. Dad had prostate cancer; he suffered for quite a while, quite a few years. I think he was sick for a long time but he didn't tell anyone. It wasn't until the pain was too much that he agreed to go to the doctor. He was having lower back problems that maybe we should have questioned it more, rather than accepting it as a bad back. But then because he had a very physically hard life that I thought, sure he would be bound to be wearing, stressing his body too much, that's what I thought it was. But then later on, before I knew he had cancer, when I had to start doing heavy lifting for him and stuff like this, then I knew something was going on but he never admitted it until later because I also don't think that maybe he even fully knew.

But he knew there was something wrong because the one time he took off up to the trapline, he used the bush as a place to escape and as a place to relax and get away from things. The cancer clinic had phoned that day and had told my mother, but for some reason she hadn't told my father but my father knew so he spent a couple of days at the trapline and when he came back he was ready to begin his treatments. My father was a very physically active, healthy person, so they went ahead with every single treatment. He had chemo and radiation, but he didn't mind going to Saskatoon because he spoke English well.

The first chemo that he went through, it wasn't too bad. The second chemo, was the worst one, I believe, the second one because his body was just saying, whoa, what is this coming into my system. He was puking up a lot more blood, he was fainting, and he had a bit of memory loss. Living with somebody that had chemo, some days he'll be really, really grouchy, some days he'll be really depressed and some days he's just like his old self. When he lost his hair, the doctor told him 'your hair might grow back.' 'When it grows back can I have it blonde (laugh),' he said. He was so joking about it, can I have blonde hair and the doctor said, that's asking a little too much. It was 2 weeks between each chemo treatment and it was just for 2 days. Mom went with him on his trips south and when they would get home we would phone Mom first and ask her what was Dad like that day and depending on how he was feeling would determine whether he could handle visitors or not.

When he went for his radiation treatments, he was in Saskatoon for a week at a time. There were a lot of things he would not do, like he would not stay at the Cancer lodge, that place where they stay because he didn't want to be with a bunch of sick people, so Mom and Dad stayed in a hotel with a kitchenette during the week while he was here for treatments. It was for a six week period and they would bring down all his favourite food, smoked muskrats, moose meat, all sorts of stuff, smoked fish, and also chocolates. My Dad and I were really bad for eating chocolates. So he tried to maintain a quality of life all along and he had a very good quality of life; he was well for 4 years after he completed his treatments.

And then it came back. 'It's back' he said, 'that feeling is back'. That was the only time I saw a tear in my Dad's eye, when he said that, but its okay he said, he accepted it. So it wasn't

until the last two years that things, the second round of chemotherapy was really wearing him out. I told Dad at the time if you find that you cannot tolerate the treatments anymore, you can tell them to stop, it's your body. So one day at the hospital, he said, "take me home, I don't want to die here", so we brought him, we looked after him here, right to the end. I think if a person is happy where they are and relaxed, and is able to move around, well then that way they don't feel weak, they feel stronger, and they grow stronger, when they like a place where they're living. My kids were there, they would come and go, anytime they wanted to go and see him.

My mother did tell me that when she would take care of him; she would rub his back with medicine, maybe when he was experiencing pain. She told me that she would cry when she did that and my father would tell her not to do that, to not cry when she looked after him. Another thing was we always tried to make sure that he didn't get colds and stuff like that. We would wear those masks around him and made sure anybody who was sick would not come to visit. But he did get a bad cold, which turned into pneumonia and he must have been getting more ill, because he never recovered from the pneumonia. I don't know if the cancer had traveled to his lungs. When he was hurting on his chest, we'd give him *wachuskomitisowin*, I would crush it, and then I would boil water and put that powder stuff on his cup and he would drink that hot. He preferred to drink that, than those Tylenols 3s, that's what they gave him for pain. He used to say that they caused too much pain in his stomach, so that's why he didn't like it.

I really miss him but I always remember what he taught me, it keeps me going, when things are looking down. I miss him. Looking back, I think we could have questioned his aches and pains more. They always say that people go to the hospital for any little old thing but I think now, any little old thing I would question, more thoroughly rather than it being just a fear.

4.3.4 Preparing for Death

Mom and Dad talked about his insurance and his will before he started his treatments, he had everything all covered, because he didn't know how fast his cancer would progress. Because like he said, "I don't know if the chemo will work or it might get worse. I have to get this in order because it might affect my memory." I don't think he was scared; he had talked to the doctors. He told them that he didn't want them to beat around the bush with him or us, he wanted

everything straight out. The first time he got pretty sick, and the second time it killed him, I'm sure it was the chemo that killed him, because he couldn't fight off any infections, and he got pneumonia. That's what got him, was pneumonia.

He had told us not to put him on life support, you know, he had told us that in the end; he said "don't put me on life support, whatever you do." And I think that was the hardest decision we had to make, was telling him, "Dad, we have to put you on life support, you know, we can't just let you go." And we put him on life support, but he had agreed to it. We had said "until all the family get here and we said we'll take the life support off as soon as everyone gets here." And as soon as we were all there, and the nurse and the doctor just basically told Dad that they were going to take the life support off and he squeezed our hands, and he went peacefully, very peaceful, like, he took a deep breath just like he was really tired.

4.3.5 Emotional Impact of Cancer

I was shocked when I heard it was cancer, like I didn't believe it at first, because he always worked and took care of himself. He would go walking every evening, just out of habit and he'd chop his own wood still. It was kind of weird to hear that he had cancer and we of course thought the worst, we thought he was going to die real soon. I think we were all in denial as well. We didn't want to talk about it, you know, we were going to beat it, regardless how long it took, we were gonna beat the disease, we were gonna beat it. My emotions were just all over the place.

But after the second time, people said that I was being a real cold hearted bitch because I accepted that he had cancer and I accepted that he might die, especially near the last 2 years because of the chemo. But I always had hope; I had hope until 3 days before he died. I also knew that he was 70 by that time and that he did live a very good healthy life. One of the hardest things is to have to watch a family member die, and I watched my Dad die and it's just so painful, and here I was taking a university class, we were taking that death and dying class, so it kind of helped me understand the stages that my Dad was going through ...but you want to hope. That's what we did, we would hope.

Throughout my father's illness, he didn't want to be treated like he was sick and so we didn't and it wasn't until near the end that I wished I'd babied him. When he went into the later stages of cancer, was where I had the most problems. I guess the most regret I have is that I never told my father enough that I loved him. But it wasn't something that we did while I was growing up, was show a lot of physical affection and a lot of verbal affection. We would praise each other if we did a good job, but we never really hugged a lot or kissed, but we did do things for each other and so that's the way I was raised. But I wish that I had told my father that I loved him more, but I never did, he probably would wonder what the heck was wrong with me if I went around telling him. My father was proud of me; I know that, even though he wasn't very expressive, I knew that he was proud of me.

It was really rough towards the end; it was really, really hard. It's amazing how grief affects you, because you know, you don't ever think you're ever going to get past it. I did see a counselor for anxiety and depression and that helped. I went to see the doctor and right away, he says 'oh you got to go on antidepressants, you need these to help you get through this'. I think antibiotics were the strongest medication I'd taken, and I did try taking them but I think they almost drove me nuts. They did the opposite (laugh) I was this hyper woman running around town. I think I took them for 5 days and I quit taking them. The counseling worked better, for me anyway. But you know, the loss, to deal with it, it's hard. I still cry but I pray a lot and that helps, it's healing when you cry too. There I said it and I didn't cry (chuckle), but they'll always be there anyway, you never forget them, they're there all the time.

4.3.6 Being a Care Giver

It was rough, rough on all of us, but I dealt with it, the best way I knew how. My father was never comfortable with me providing certain parts of his care, because he'd always wait for my mother to help him go to the bathroom and stuff. I would say no it would be okay because I won't think of you as my Dad, I'll think of you as a person, you know, and help you go to the bathroom. It's hard for a family member to provide personal care of somebody who's ill. I wanted to help my Dad more with the personal care but he wouldn't let me. He'd let me brush his teeth, not in his mouth, but he would let me brush his teeth. I could put his socks on for him, you know, that kind of small stuff but the other personal care, he'd only let my Mom do it.

4.3.7 Changing Family Dynamics

My Dad had always been like the strong, gruff man in our family, and all of a sudden he's weak, and I didn't know how to deal with that, that was really weird, because it was like I was the stronger one now and that was a real switch. My Dad and I were always kind of distant anyway, but then he was telling me more about what he's going through, a lot more personal stuff now than he did in the past, so yeah, our relationship changed. I think it's for the better because like I was saying, my Dad, to me, seemed kind of impersonal and distant but he's not like that anymore and I'm okay with it. It was kind of weird, you know, for him to all of a sudden be that way with me, and I wasn't sure how to take it but I just stuck it out anyway, and just listened.

My daughters were more, like if my Dad came around or if we saw him, they were more caring towards him. When he came around they would talk with him and chat with him about stuff or try to show him things to, I guess, maybe try to make him feel good or something. In the meantime, my mother, who we had wanted her to take more responsibility for him, she couldn't because she didn't want him to leave because my father took care of my mother. My mother would fight with us because we would say you should make sure Dad is taking the right medication and she would get angry and threaten to leave.

I'm the oldest and the bossiest (laughing). I tell people to get to work. Our whole life can be shambles, like everybody can be moaning and groaning and crying or whatever and there I am in the can, scrubbing out the bathroom, at least you can have a clean bathroom. Or I'd go to a wake and I'm feeding everybody and stuff. I'm not good at dealing with grief and stuff, and what I'd end up doing is making tea and coffee for everybody and I'd feed everybody, that's my way, I take care of people, so people actually like me to go to wakes.

Something that needs to be done when someone is terminally ill, is to have a wellness plan and an emergency plan. Because with my family, first it was 'shoot the messenger' mentality, afterwards it was disbelief when I called family members from Saskatoon, they didn't believe me or they said I was over reacting. I became associated with bad messages. Families

need to have a plan. Families deal with a terminal illness in two ways, they either pull together or they fall apart. My family fell apart. My mother got rid of everything of my Dad's. She didn't want to be around us because we reminded her too much of my Dad. It took her a while; she still can't be around me.

4.3.8 Cree Medicine

My grandfather used to do herbs all the time and just go to sweats and stuff, and told us we couldn't go and we were young. This scar I got on my face, my grandfather used herbs to close it up. I got hit with a rock. I think that maybe it was first aid for him, he just knew how to put everything together, and keep the eye from getting infected and the herbs that he knew. But come to think of it, my grandmother never looked after the eye; it was always my grandfather who changed the bandage twice a day and put stuff on. My grandfather passed away probably 20 years, he was 89 when he died of heart failure.

I know very little about traditional medicine. My sister, she'll use teething stuff for her kids but I don't know what's in them and I can use salve and stuff but I don't know what's in it. The very simple stuff I know how to make, where you use spruce gum and fat, you know, but that's the only one I know how to do. I can collect *wachuskomitisowin* and *amiskowekusk* and I found out why cranberries were considered a medicine, it's because they're high in vitamin C.

Dad used quite a bit of traditional medicine. He saw a medicine man from Sandy Bay and a medicine woman from Southend. He believes strongly in that and I think that's what helped him to come around the first time. When he talked to the doctor in Saskatoon, he had asked the medicine woman from Southend whether he should mention it to his doctor that he's on Cree medicine, and she said go ahead, if he says for you to stop, we'll talk about it. So he talked to the doctor after all the blood tests were done and whatever and the doctor says you are improving, and asks what are you doing? So my Dad told him, he says I've been taking a traditional medicine and the doctor says keep doing it.

4.3.9 Supporting the Cancer Patient

I went with Dad on some of his trips to Saskatoon but mostly it was Mom that went with him, and then when he had to go to PA, he usually went with Mom. He had said that he wasn't comfortable with letting us know too much. I guess he didn't want us to see him in a weaker state or something. He's got a friend that he talks to more about all of this than he does with us, or even Mom, like someone outside of the family and I think it's because he doesn't want to frighten us or have us be too worried. I know he doesn't want to be a burden to anybody, he's always been like that, but he'll let us know dates and times and his progress, he'll give us facts and stuff.

I'd call myself a gofer because I would ask my father, well what do you want, and it didn't matter how ridiculous I thought it was, I'd go out and look for it, whether it was French dressing on a Sunday when all the grocery stores were closed or strawberries even though they were out of season, I'd go look for them. I let him choose what he wanted to say or wanted to do, if he didn't want to do anything, that was fine, if he wanted to chat or tell me to go get a book or whatever, or magazines or a comic book, I did, I let him choose what he wanted to do, I didn't come in and say, I think we should do this or if he wanted the weather channel on all day I left it on. But I often wondered about what also went through my father's mind because he did all sorts of things even when he was ill. Some of his friends would come and take him ice fishing, and they would let him do whatever he wanted to do, whether it was stay in the cabin instead of going fishing. We had to buy him extra clothing, and we went high tech to make sure he stayed warm. He also went up to the trapline. One of his friends took him to go goose hunting but they couldn't kill them, they basically just lay in the field and watched the geese. So we wanted him to have a good quality of life. We wanted him to not lie in bed unless he chose.

I also didn't want to interfere with him and my mother's relationship but I regret not doing more, because, he didn't read or write and so at times he would take the wrong medication and my younger sister would go straighten everything out. There were times that he had to be watched all the time, because he was just too ill, he needed help to go to the bathroom, or he needed help eating, and stuff like this. There were times like that in between his treatments that

he had to have help and I would stay with him while my mother went out to visit her friends or something so she could have a break.

I think though he would have died no matter what, whether he was aboriginal or not, because the chemo was very, very hard near the end because I don't know how many series of chemo he had to get, so many, plus the radiation treatment. Near the end, our family was there 24 hours a day. I stayed right in the hospital with him, and we'd take turns, it was mentally, physically, spiritually exhausting for all of us, but we went through it all, you know, he knew how much we loved him and how much he loved us. We prayed with him and took communion with him too.

4.3.10 Healthcare Delivery up North

There's something wrong with our health system in the north, it's not right. Not only do people have to wait a long time to get an appointment in Saskatoon, but I had problems finding help. There was no one to help us as a family. We needed help in nutrition, he wouldn't eat or sometimes he'd eat a bit of white rice just because he knew he had to eat something, and I called the dietician that works for Mamawetan Health Region but she never returned my calls. I phoned the nurses at the band office and asked them questions and they didn't know the answers. We never got nutritional advice. But it didn't seem to matter what we did near the end, we couldn't find anything for him to eat that he liked because his taste wasn't there. He had cases and cases of Boost and stuff like that. We bought him a lot of little applesauces in little plastic cups, all sorts of little things like this to try and get him to eat stuff.

Nobody told me to watch out for certain stages of illness, it wasn't until after he died that I wished I had known that he was dying. Well I knew he was dying but you know, the final stages. I wished I had recognized the final stages because maybe I could have spent a bit more time with him. I was around him, but I didn't know. I knew that he had gotten more quiet, more quieter and he sat still a lot more, but I wished I had known the stages, if that was an indicator that he was near death, maybe I could have given him tea more or you know, been more helpful to him. I don't know.

Another thing is that somehow or another, I call them Indian health, has to somehow be able to care for the terminally ill. To make doubly sure that they're taking the right medication, to get the right nutritional advice, and also have someone who'd be willing to teach a family member or the person that's ill to give needles or have a nurse or somebody give the person who's dying needles. There also has to be some kind of support worker for the elderly or the terminally ill. There has to be somebody who is willing to help because the family can be grieving, the main caretakers can no longer provide the care, so there has to be somebody willing to step in. But if I could have done things differently it would have been to be more adamant about having a nurse color-code the bottles or something because my Dad couldn't read. My sister ended up coding them somehow, but I think it should have been done from day 1 because he had so many pills to take and they'd be different during different stages, like I couldn't keep track. He had all these bottles.

I felt that my father had good medical attention at the Cancer Clinic in Saskatoon, I think though, that it was not very culturally relevant for him but it was the best treatment that he *could* have. But he comes from a different culture and so, it's pretty hard to tailor it to him, it's sort of hard once you're in that clinic sort of setting. When I went with him a couple of times to Saskatoon we'd see other people that have cancer, and I'd sit there and talk with them. It's so neat the way that they have it over there in Saskatoon, there will be a room full of people, like 4 or 5 of us, maybe even more and we'll be talking to each other. But I think it's that support stuff like the cancer lodge, I think they could do a lot more work. When my father was at the hospital, there was that whole food issue; like when he ordered ham on the menu thinking he'd get ham but instead he got these little processed formed ham things, so he never ate it, he didn't like it. You'd think in a hospital they'd serve healthy food. All he needed was just plain, basic food without a bunch of salt and butters and fats and, I don't know, artificial smoke and all this stuff. Like I think to go more basic, I'm not asking for health food stuff, it's just more basic stuff, because he was used to eating wild meat, boiled potatoes, just plain old food; no instant potatoes or Kraft dinner or stuff like that.

4.3.11 Carrying on

I find, with my father gone, even my diet has changed because he was the hunter, my husband doesn't hunt, and it has affected the quality of my life. My diet used to be about 60% or more of wild meat but now what I do is, I buy organic beef, it's the closest thing to moose meat, and we still fish and set rabbit snares. I duck hunted every fall with my father, I no longer do that, I might later, I don't know. I've gone and looked at moose but I've never shot a moose.

I think Dad having cancer changed me; it made me a better person. I was always a person that, I'm right, you're wrong; you listen to me or get out of my face. Maybe that's why I'm so outspoken, but I've learned to start listening to what other people are trying to say to you. It's for the good. Like I don't know, maybe I came out fighting when I was born, a little fighter (laugh)...but it has changed me. My sister told me that too, she said you have changed and I looked at her and asked what do you mean. You are so much more relaxed, you listen to people, she said, and when you're talking to somebody, or when somebody is talking to you, you don't look away; you look at the person in the eyes.

I find that I can empathize with people, and even people that I don't really know that well or whatever, when I hear that cancer is in their family, then I know that they're going through something. Whereas I guess it's easy for people to shrug it off if they don't understand, but I guess I'm more understanding towards people that are going through it. I know what's going to happen, like there's going to be chemo and there's going to be bad days and there's a lot of worry there and concern and sleepless nights, and I find that I'm just more kinder. But not only people that I know that have cancer in their family or whatever, it's just people in general now because you don't know what's going on in their lives, nobody's life is perfect so I just find I'm more open to people, or maybe more friendlier, I guess, because you just don't know, anything could be going on.

I'm willing to do volunteer work because it's easy to say that this should be done and that should be done, but there's always that problem of finding the money or finding the time. I would be willing to go and help another family because I know what it's like to be at a total loss and not be able to do anything about it. Because my Dad has friends that are older and I'd be

willing to go up to a trapline for a couple of months to spend time with someone who is dying but there's always that picky part about interfering with family. My younger sister makes a donation to the Canadian Cancer Society at Christmas as a gift to my Dad. I delivered Meals-On-Wheels at Christmas as a gift to my Dad.

4.3.12 Coping Tactics

Something else that happened was I started smoking again, I hadn't smoked for about 4 years before I heard, but then when I heard that he had cancer, I started smoking, I picked it up again like 2 weeks later. Initially I was shocked when I found out and I didn't really believe it, but then it started to sink in because I knew he was preparing for it, like he was doing these things and I thought okay, this is real. I found that I was really agitated and nervous or restless maybe and I wasn't sleeping good, and that's when I started smoking again, because it would calm me down.

I tried to talk to some friends of mine about the whole thing and they didn't really have much to say but they would just listen to me, they wouldn't offer any advice or anything. In fact, one of my girlfriends was sort of afraid I would say anything to her because I would cry. But I talked a lot with my sister. So that's what I've been doing, talking with my sister and she talks with me. I have friends in town who are counselors but it seemed like they didn't have much to say, which I found really odd so I go see a therapist. I've seen him now for probably a little over a year, and I can say exactly what I want to say to him, I can tell him this is what I want, this is what I want to do, let's work on this and he does it.

We tried to get my mother to go talk to a therapist but she said, 'I'm not crazy, you're saying I'm crazy'...she gave us shit. And I said, 'no, it's a good idea to have somebody to talk to, go talk to somebody' but she said, 'no I'm not crazy.' So we tried to think of somebody else and we found this minister that she could go talk to, so she said it helped a bit. But maybe it's different for her being an older person, because she said that people would ask her how Dad was and if Dad was having one of his down days, they would go for coffee and talk, she has about two or three good friends that I think did that for her.

4.3.13 Perceptions of Cancer

I have been thinking about this illness called cancer, when I was younger I didn't think about it too much, but now as I'm getting older and I also see other relatives besides my Dad, even my age cohorts are being killed by that, so I'm beginning to think that one doesn't necessarily have to be old to catch cancer. I grew up with these people, and I've realized, anyone can catch it, at any age. And now when I have a pain, any little pain, I wonder, I think about it, but, I still smoke, even though I know that is one of the causes, one of them anyway, heavy smoking. So I been thinking about it, my smoking went down quite a bit. I don't smoke in the house, I owe it to my children's health not to smoke in the house and I know how destructive it is. I started smoking at the age of 16, for real anyway, the most I've smoked in my lifetime would be 20 cigarettes a day but that wasn't for a long period of time; certainly not all the time. Right now, I smoke about 3 or 4 a day. I don't smoke a lot and I think that I may as well quit.

So I am thinking about cancer more and more, I guess it worries me, I guess I don't want to catch it, because I know that there aren't very many that survive. Sometimes people around here, it's like they aren't sick very long, they look healthy, they're walking around, working at things, and then suddenly you hear that they have it. And from there some of them don't last long, some last a bit longer, some can still work a bit even after they catch it, so I would guess it affects people differently.

I've heard an illness mentioned by the Elders, they called it *itinoowapiniwin*, and nothing can be done for one that is *itinoowapinit'*. Once someone got that illness, they just waited for the person to pass on. I've been looking for an English translation, like what is the disease called, is there an English name. It may be very similar to, maybe they had cancer and that's what they called it, you know, maybe they didn't have a term for cancer. I mean today, its called *munchoosuk* eating someone, but maybe it was cancer that killed these people that they called this illness.

I think cancer is becoming more prevalent, I think we hid it in the closet, and now it's coming out, just like dung beetles, and I guess there's people who don't like talking about it. For me, I guess because the pain is so raw, you know, and to talk about it, even the word cancer is

scary. I guess because it's a death sentence to a lot of people, you know, it's a scary word, I know for me it's terrifying now, whereas before I wasn't aware of it. But because of my Dad having it and knowing that it seems to run in some families. I went and picked up a bunch of information on diet, you know, how to live and I follow quite a bit of the diets that the cancer society puts out because of my chances of getting it too are pretty high, you know.

I don't know if there is really anything to do to prevent cancer. But we as *Nihithowuk*, our food has changed so much. The way our ancestors used to eat, our grandmothers, our grandfathers, our parents, they ate differently, they ate off the land. But now we are living in small communities that have stores, and so our diet has changed, we eat a lot of white man food, canned food, meat from the store, and so because of our diet, yes, I think that has an effect, and more people will get it. Maybe eating closer to the source, eat plainer food, not so heavily refined junk. Another factor is probably also the way we move or don't move, we don't do enough physical work, where our parents had to do that, so our lifestyle, both diet and physical activity, lack of physical activity, will probably contribute to a higher incidence of cancer, I think. So being more physically active, not jogging or stuff like that but more like doing chores around the house, being active might help. To try and get physicals, it would work for some people but there's no way you're going to get an older person to go for a physical.

I know that it really affects peoples' families. Like when I would hear that someone has cancer, whether it's their brother, sister, mother, father, grandparents or whatever, I know now that beneath the surface, there's a lot more going on than what they show people. I know with some people too, that they don't tell anybody, because maybe they don't want to hear that, 'oh he's probably going to go' or 'she's probably not going to make it'. And I know that people who have cancer and even their friends or their relatives, they all need support, they need to hear from someone else, that yeah, I'm going through the same thing so they wouldn't feel alone, or feel like they couldn't tell anybody. I think providing more information and letting people be aware, you know, like if they check their family history, see if there's things there that they can watch out for, like breast cancer in some families. I'm sure there are some measures you can take so that it wouldn't happen to you or there's less likely a chance that it would. I think for me, I wanted to let people know that it's out there and it doesn't matter who you are, you know, it

doesn't matter. I'm glad I had a chance to talk about it, and to talk about my Dad. I hope that it educates somebody else, and let's them know it's a disease that doesn't discriminate against age, race, or growing old.

Chapter 5. Results of Thematic Analysis

This chapter presents the results of the analysis of data. Demographic information was asked at the beginning of the interview and will be presented here to provide an overview of the participant characteristics. I interviewed 6 Elders, 8 cancer survivors and 12 family members from the communities of Stanley Mission, La Ronge, Grandmother's Bay, Sucker River and Little Red River. The ages of the Elders ranged from 67 to 83 years, for the survivors it ranged from 54 to 74 years and for the family members it ranged from 27 to 65 years. There were five female Elders and one male Elder, seven female cancer survivors and one male, and ten female and two male family members. Six of the eight cancer survivors had breast cancer, one had cervical cancer and the male had prostate cancer. The time since having had cancer ranged from 2 years to 19 years for the cancer survivors. Family members listed the following types of cancer that their family member had: lung, breast, prostate, brain, Hodgkin's lymphoma, leukemia, stomach, Irwin's Sarcoma, and cancer of the liver. Elders had also experienced cancer among their family members and these included: cancer of the stomach in father, cancer of the liver and diaphragm of mother, breast cancer in daughter, leukemia in mother, and lung cancer in brother-in-law. At the time of the interviews there were two related family members whose husband/father was still alive; he has since passed away. The remaining family member participants had already lost their family member. All of the cancer survivors remain alive today and have not had any reoccurrences of cancer. The demographics show how diverse the participants' experiences were and how complex the analysis was to become.

In the presentation of the results, the Elders' identities have not been changed due to their roles in the communities as knowledge keepers; they deserve the public recognition of the knowledge they shared with me and I also received their permission to do so. The other participants will be identified using pseudonyms to protect their identities and maintain their confidentiality. The four overarching themes that I arrived at from the analysis of the data were: *concepts of health and illness, knowledge systems of the Woodland Cree, cancer as experienced by the Woodland Cree, and straddling both worlds*. The first theme, *concepts of health and illness* presents the perceptions of health and illness as described by the participants. The second theme, *knowledge systems of the Woodland Cree* looks at the history of the Woodland Cree, the role Elders have as knowledge keepers and teachers, as well as spirituality, religion and aspects

of traditional medicine. *Cancer as experienced by the Woodland Cree* is divided into six sections, the physical, emotional, intellectual and spiritual experiences along with the support systems and the health care system in the north. The fourth theme, *straddling both worlds*, looks at how the Woodland Cree have been able to select the best of both the Western and the traditional knowledge and belief systems. Each of these four themes will be discussed at length in this chapter.

5.1 Concepts of Health and Illness

Capturing the perceptions of health and illness among the Woodland Cree was one of my primary objectives. I had anticipated that the Elders would provide me with more of a traditional view of health and illness. However, it quickly became apparent that the Woodland Cree worldview was inextricably intertwined with the Western worldview, including complete domination of the Western worldview in certain areas.

It was interesting to see that in many cases the higher educated an individual was in the Western system of schooling, the more precise their definition of health and illness was with respect to the understanding of the Medicine Wheel. The Medicine Wheel is becoming a popular health-teaching model for a variety of disease entities such as diabetes and addictions. The Medicine Wheel is an aboriginal framework in a visual shape of a circle divided into 4 quadrants; each quadrant represents a direction along with the teachings for that direction. An individual is also comprised of 4 areas; these are the physical, the emotional, the intellectual and the spiritual aspects. Skott⁸¹ (p.231) states that “metaphor is principally a way of conceiving of one thing in terms of another, and its primary function is understanding.” Therefore, I used the Medicine Wheel as a tool to help me understand the concepts of health and illness as understood by the Woodland Cree. (see Figure 4)

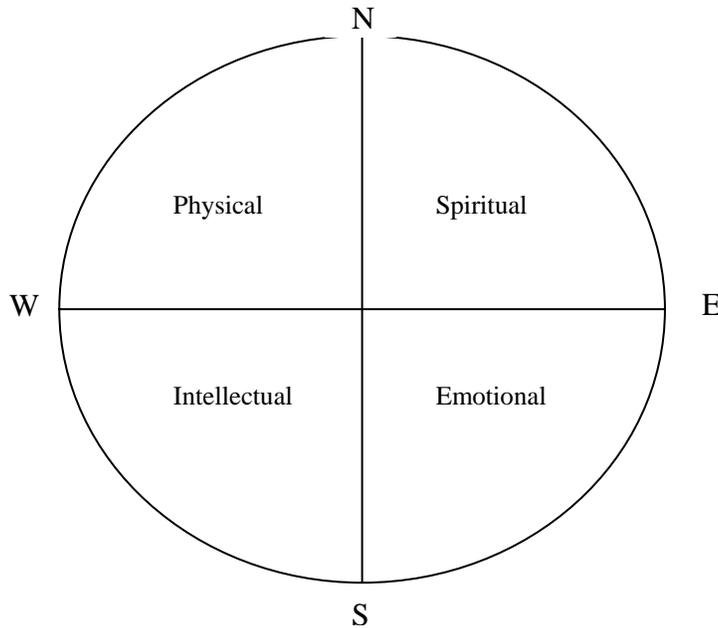


Figure 4. Medicine Wheel

5.1.1 Perceptions of Health

The interviews were held in both Cree and English and there was a definitive difference in how the Cree speakers defined health from the English speakers. As previously mentioned not all the participants could speak Cree. In the Cree language there are two terms that were used to define health; *mithopimatisiwin* which means living a good life and *mithoyawin* which means being in good health. *Mithopimatisiwin* meant living according to the values and beliefs the parents and grandparents had taught the participants such as respect, thankfulness, helpfulness, and being a good person. One of the primary purposes of the Woodland Cree values and belief system appears to be aimed at maintaining good community relationships. The following quote from Elder John Cook expresses this concept very well:

Well, everyone has to have good relationship, to help anyone that needs help. That's how I am. When someone is in trouble, I help them. There was lots of that a long time ago. If someone was building a house, people would flock there and help you finish it. There's no way it's like that now. You need to love people, don't act strange with anyone. Anyone. That's why we have so much respect here, even little children, because we love them, we always have candy, as soon as they come in we give them some, they are always coming in and out (laughing) but that's okay. You give them one or two pieces and they're happy. That's all I see, for one to have good relations, to not have bad feelings for their fellow person.

Maintaining good community relationships would appear to be an effective and necessary survival mechanism for the Woodland Cree long ago. The lifestyle of hunting, gathering and trapping meant a relatively nomadic lifestyle of small family groupings and hardship was common. Elder John Cook is saying that the old ways of relating are disappearing in the communities up north and this was apparent as none of the younger participants listed any of these characteristics as part of their definition of health.

One participant mentioned the term *mithoyawin* but the responses of several participants also fall within this definition. *Mithoyawin* means being in good health in all the four quadrants of the medicine wheel. The terms physical, mental, emotional and spiritual were mentioned by several participants and all four need to be in balance for one to be in good health. Participants mentioned that good physical health entails eating right, exercising, being free of pain, and absence of disease or illness. Mental health included being at peace, being happy and thinking properly. Being *mentally fit* was how Veronica explained what mental health meant for her. Emotional health was often combined with mental health: there did not appear to be a definitive distinction. Being emotionally healthy meant being able to talk to someone regarding issues and as Alice mentioned, the process of talking would allow one to “*get it out of your system*”. Spiritual health was more of an afterthought, Winston openly wondered about whether it is part of *mithoyawin* or not: “*I wonder if someone’s soul, what is called spirituality, is part of one’s mithoyawin as well, if one is to pray, to have faith, to have someone to turn to, this is part of what I’ve read but it’s probably true*”. The goal of *mithoyawin* is to walk in balance but that this is a process, one has to continually work on attaining and maintaining *mithoyawin*.

When participants were asked *what does being healthy mean for you*, the most common responses were *not being sick* and *being free of pain*. So for the majority of respondents, being healthy meant absence of illness and pain, a common perception found among the general public as evidenced by the definition in Webster’s Dictionary; “*freedom from physical disease or pain*”.. The question *what do you do to stay healthy* brought forward the typical response of eating right and exercising. Although Sonya had an afterthought, once she gave the expected response: “*well you gotta eat properly, that’s what I think. And uh, I don’t know, if I ate properly or not because I got diabetes now and I got arthritis all over my body and uh, eating didn’t seem*

to help me (laughing).” Other responses included spending time with family, spending time with self, getting complete physicals, eating traditional Cree foods, not using drugs or alcohol, and having creative outlets such as crafts. Those that had higher levels of Western education provided the more detailed explanations of what being healthy meant and what they did to stay healthy. They almost always worked in the health field as well; indicating that perhaps the Western education they received provided them with more of a holistic view of health.

The question “*How do you think people stayed healthy in the old days?*” elicited responses that related to the healthier lifestyle people followed in the old days. Their food sources were often mentioned; the fact that their meat had no preservatives and they had to work to obtain their food from the land instead of going to the store and buying it. The physical exertion involved in day-to-day survival made them stronger and healthier. Participants reported that they attempt to keep the old traditions by going to the trapline, setting fishnets, picking berries, canoeing and hunting, often with their children.

5.1.2 Perception of Illness

There was no confusion with the term sick, it meant the same in both Cree and English, unlike the differences with Cree and English speakers and health. How an individual described illness was often in conjunction with their definition of health, one is often closely intertwined with the other, where the definition of health was not being sick. Other definitions of being sick were not being able to do anything, not being able to look after self, along with assorted physical aches and pains. Patricia also identified that being unhappy or depressed meant being sick for her and Charlie indicated that his father told him if one held in anger and sadness that the person would get sick. Veronica mentioned that she supposed one could be spiritually sick but she did not expand on this concept. Therefore, the definition of sickness was not strictly limited to physical ailments.

The causes of sickness encompassed the entire spectrum from individual to community wide illness but were limited to physical causes. Elder Betsy McKenzie stated with an air of resignation that *sometimes sickness just runs through a community*. One could infer that there wasn't anything anyone could do about it. Alice also used the phrase *run through a community* in

relation to the spread of tuberculosis when people weren't sent out right away. This was when the only method of treatment involved sending people to the sanatoriums, either in Prince Albert or Saskatoon. Not eating properly or eating too much white man food was a cause of illness in relation to diabetes. The increased rates of diabetes were attributed to the change in diet from traditional foods to store bought foods among the Woodland Cree, along with decreased levels of physical activity. Elder Rosie McKenzie said that not being as active and the disappearing nomadic lifestyle meant that we aged faster, which she used as an indicator of being more susceptible to sickness. Elder Betsy McKenzie and Elder John Cook both stated that Western medicine had made them sick, the medicines were too strong and they were being given too many types. It is apparent that causes of sickness were primarily defined on tangible and physical reasons.

The responses to the question *what do you do to take care of yourself when you are sick* were quite varied. The most common responses were self-medication with over-the-counter drugs and traditional medicine, the respondents replied with one or both types of self-medication. Taking time for one's self was also a frequent response, with activities such as staying home, lying in bed, eating chocolate, and conserving energy. Participants also stated common preventive measures such as quitting smoking, and exercising to prevent joint pain in response to this question. The primary person every participant would seek for help was the Western trained doctor, although some individuals like Teresa state "*I stay away from doctors, as much as possible*" and will only go see the doctor when their illness is unlike similar illnesses they have already had. It is interesting to note that further along into the interviews, several of the participants would expand on this to include therapists, counselors, ministers and traditional healers. It would appear that the phrasing of the question implied a physical illness to them.

With respect to how people behaved in the old days during illness, Patricia responded that she didn't think they got sick as much because they were stronger and healthier to begin with and when someone did get sick, their bodies either healed themselves or they allowed themselves to die. However, Elder Betsy McKenzie said that people used Cree medicine, one didn't get well unless they took medicine. Elder Rosie McKenzie stated that as a child she remembered people that were sick would be lying down, either on the floor or on a bed, they

would be given medicine to alleviate their pain until they eventually passed away. She went on to say that people didn't get sick very often in the old days. It appears that most participants felt that people in the old days did not get sick as often because they were stronger and healthier.

I separated the concept of health and illness into two distinct sections because of the richness of the data and I wanted to see if there was enough difference between the two concepts to warrant a separation. This was definitely the case in certain situations such as causes of illness; it would have been difficult to discuss this topic under a combined theme. However, when it came to using the Medicine Wheel as a framework for understanding health and illness, it became apparent that both concepts could be described together and this was often the case with the participants. One could not achieve good health if one of the four areas was out of balance. Winston explained this concept succinctly in the following quote:

Mithoyawin is what I'm trying to follow, but sometimes I forget things...I get angry, I think too much about things, I don't always show good relations with people, those things aren't good for a person, you know, resentments, those are the things that I need to work on because if those things keep me stuck, such as jealousy, temper, hatred, I will begin drinking again, you know and once I begin that again, everything, the good intentions will be gone

Winston's quote indicates the complexity that lies within the concept of health and illness and how maintaining a good state of health is an ongoing process. The combination of Western health beliefs and traditional health beliefs were briefly touched on in this section. However, this area requires a more in-depth foray into the traditional knowledge systems of the Woodland Cree.

5.2 Knowledge Systems of the Woodland Cree

The Elders provided the bulk of the information in the area of knowledge systems, but there was also input from some of the other participants, especially in terms of perceptions of the old days and how they were raised following the traditional lifestyle. The lifestyle of the old days was believed to be superior by nearly every participant to the ones they are living in today. Some openly expressed their regret at no longer being able to live traditionally while others strived to maintain certain aspects such as going to the trapline as often as possible, moving back up north

to return to living a more simpler life, eating traditional foods at least every second day and teaching their children the old ways.

5.2.1 The Woodland Cree

The Woodland Cree are a relatively small sub-population of the larger Cree populations that span from Northern Quebec to Alberta. The sub-groups are separated primarily by linguistics as well as geography, with the Woodland Cree located on the shores of or in close proximity to the Churchill River in northern Saskatchewan and Manitoba. The lakes and river systems were our highways.

Living in the Precambrian Shield had its challenges in terms of survival. Unlike our cousins, the Plains Cree, we did not have the herds of buffalo to sustain us. The solitary and often hard-to-find moose was the main animal that provided us with large quantities of meat. Deer could sometimes be snared but the deep snows limited the deer population. Woodland Caribou would migrate south into some of the more northern family camps in the winter. Other sources of protein were derived from bears, fish, rabbits, ducks, beavers, and muskrats. Berries supplemented our diet in the summer along with roots of certain plants. The economic base was fur trapping in the winter and staples such as flour, tea and sugar were purchased with the proceeds of the fur trading as well as the money received during Treaty Day.

Extended families lived and traveled together, probably as a measure of ensuring survival. The majority of their time was spent at the trapline, only returning to the community for Holy days such as Christmas and Easter. Spring heralded another gathering, this time to trade in furs, a chance to visit and from there to live a nomadic lifestyle during the warm months. It appears that most people stayed in closer proximity to the communities during the summer. Treaty Day was often held in the summer months and was another reason to congregate. Elder Rosie McKenzie had this to say regarding Treaty Day:

And on treaty day, everyone would arrive again...it seemed like we got a lot of money...I thought, because things were so cheap back then...there would be boat races, that was playing for them, tug-of-wars and they would kick around a ball...and us children, would sit with the old ladies, sitting there in a row, I guess we were the cheerleaders (laughing)...watching the players. Sometimes, some of them would really get into the wrestling...and that was our playing...and not only

during treaty day but any time there was a gathering of people in one place. There was always a ball...

There is a certain romanticism associated with life in the old days but it certainly didn't sound easy. It appeared that everyone, including the children had to work constantly to ensure survival, especially with respect to gathering enough wood. Sunday was a sacred day and no one was supposed to work, but Elder Rosie McKenzie reported that the men would cut wood on Sunday, the women and children would then stack it. During the week, the men would be gone all day checking their traps and the women and children would work around the house. The children were expected to haul wood and water for their grandparents and other Elders during times when they lived in larger groups. They were taught to do the bidding of any Elder and Elders were to be respected above all others. Children were not even allowed to play outside after sunset because the Elders were in bed. Elders were the keepers of traditional knowledge and they were the ones who passed it on to the younger generations through story telling. The children were taught to sit at the door when visiting, and listen very carefully to whatever the Elders taught them.

The collective memories of Elders are respected and valued in First Nations communities and several participants remembered the teachings vividly. Some of the values inherent among the Woodland Cree were hard work, respect for everyone especially the Elders, maintaining good relations with others, not getting angry or retaliating, not to misbehave as children and working together as a family. There were specific roles for men and women. Men were expected to provide food, shelter, and protection and to discipline the children. Women were expected to care for the children, and the home and to teach the children using gentler techniques. Shared responsibilities appeared to be gathering wood, and emulating appropriate behaviour for the children. Women and children also assisted with catching the smaller animals such as rabbits, muskrats and grouse for food, checking the fishnet was also often done by the women. Grandparents were the storytellers and teachers and often a place of respite for the children.

5.2.2 Elders as Traditional Knowledge Keepers

The Elders in First Nations communities are often the collective memories of our communities. There is a distinction between an Elder who is a keeper of knowledge and one who

is merely old. I tried to draw out the distinction with Elder Betsy McKenzie and the following quote elicits the responses I received:

Rose -You are considered an elder here?

Betsy -An elder? No

Rose -No? You don't consider yourself an elder?

Betsy -No.

Rose -Who do you think should be considered an elder?

Betsy -(laughs) There are a lot of elders here. There is one, but they probably wouldn't be able to tell stories, that person is 96 years old and is the oldest here [Stanley Mission], this other old lady here is 95 years old.

Rose -Oh, and what do you think makes an elder, is it how old they are or what knowledge they have?

Betsy- somebody who is really old can't tell stories properly because they forget things, they can't remember things immediately when someone asks them a question, because someone doesn't think right as they get older, they easily forget things

Rose -But you don't consider yourself an elder yet?

Betsy -(laughs) I am an elder, I'm 82 years old.

Keeping in mind that the interview was in Cree, she didn't appear to make a distinction between a keeper of knowledge and one who is old from the word I used, *kitiaya*. There are also Cree words to denote old woman, *noochookeso* and old man, *kisiteno* and I purposely avoided using these words during the interview. I had anticipated that the word *kitiaya* which I had heard being used by the Plains Cree to indicate Elders as knowledge keepers would also have a similar meaning among the Woodland Cree and in subsequent interviews it was used by several other Elders in much the same fashion. The distinction with Elder Betsy McKenzie's understanding just needed to be teased out a bit more. She did distinguish that an Elder is one that can tell stories and this is an important concept to recognize because story telling is the primary method of sharing knowledge.

Story telling continues to be the domain of Elders and a good story teller is highly valued as Elder John Cook stated when he was talking about his grandfather, "*But he wasn't a really good storyteller...if that old man Okimakanis was still alive, boy, he could tell stories.*" Elder Rosie McKenzie talked about her participation on culture trips with school children, and one of her roles including telling the children legends in the evenings and then helping them say their prayers. She learned the legends from her own grandmother as a child and said that they would

go to an Elder's house to say their evening prayers as a group. Elder John Cook stated that it's good when Elders are asked to go talk to young people, and to talk about the old days. He also mentioned that he is often asked to go speak at meetings, and he shares his knowledge with the intent that good will come of it. Not only are Elders keepers of knowledge, they are also keepers of the earth. Elder John Cook talks about this concept in the following quote:

I asked the government, I know there are a lot of big rivers up north, like Wathaman River, Johnson River, Brabant River, that they don't dam them, for power...it's a bad thing, they destroy everything when they dam a river, I don't want the Churchill up north to be dammed, but I don't know if they will listen to me...if you don't have clean water you will get sick, you gotta have clean water...yup, but I don't know if they understood me...boy, these lakes are so pure, all over, even where we live, you go paddling and you can see at least 10 feet beneath you, the water is so clear.

It was unclear how one becomes an Elder and it seems that being old and being able to tell stories about the old days were the only prerequisites. In fact, one of the participants is considered an Elder in his community but when I asked him if he would be willing to talk about the old days, he refused, saying that he didn't remember anything of the old days because he had been drunk all the time. Other participants lamented that the upcoming generation of Elders don't have the knowledge of the old ones because the knowledge hadn't been passed on. So there appears to be a concern that knowledge is being lost as the Elders who are keepers of the traditional knowledge are dying without passing on what they know. Compounding the issue is the question of whether the social and economic supports have been there to facilitate the passing on of traditional knowledge. Has the focus shifted so far towards the Western knowledge system that the traditional knowledge system is no longer valued?

5.2.3 Spirituality and Religion

Another knowledge system that came up frequently was spirituality and religion. The term spirituality, I believe, is separate from religion among the participants and is exemplified by Amelia's comment "*I'm Anglican...and I also use traditional spirituality...I use both...I enter the sweat when I need the cleansing.*" The early missionaries utilized the Churchill River system to spread the word of God. It also explains why the oldest Anglican Church west of the Red River is located at Stanley Mission. The Holy Trinity Church was built in 1854, indicating that the Woodland Cree in the area have been Christianized for over 150 years. This fact was touched

on by Elder John Cook when he said, “*My grandfather used to say that we had no religion until they [white men] came.*”

The Elders used the Cree word *Poowamowin* to describe the traditional belief system. *Poowamowin* can be translated to mean *The Dreaming* and in fact this is how George Nelson, an English clerk for the Northwest Company, did translate it in the book *The Orders of the Dreamed*.⁸² Elder Rosie McKenzie pointed out the power of dreams in her story of how a medicine man received all his medicinal teachings from his dreams. The fact that no one disbelieved that this was possible indicates that this was a valid belief system. A common theme during discussions of *Poowamowin* was that the people could curse each other. Elder Betsy McKenzie told a story of how a woman got cancer on her nose from a curse someone sent her. This woman was cured when she went to go see a medicine person for healing. Elder John Cook also speaks of his ancestor in the following quote:

He was powerful. If something, anything a frog or a fish, he would send it to someone, like this (flinging his hand as if throwing something away) he didn't like, it would hit that person, I don't know how but by the end of the day that person was dead. He would imitate some people, he was powerful, if he could kill someone without touching them that angered him.

The traditional belief system of *Poowamowin* meant that individuals needed protection from others. Elder Rosie McKenzie told of her father-in-law needing a medicine bundle to protect him from a man who he refused to share alcohol with in Prince Albert. It was a few months after the meeting and several hundred kilometers away that his medicine bundle got wet and lost its potency. Shortly thereafter, a bird pecked his knee and he lost his ability to walk, as well as being caught in a dust-devil and becoming blind in one eye. He cured himself when he received instructions in his dreams. So the concepts of good and bad were apparent in the traditional belief system and seemed to be at a baser more immediate level as opposed to Christianity's teachings of heaven and hell. There was no mention of *Poowamowin* among the younger participants, although there were discussions of sweat lodges and traditional spirituality.

The term religion is used in this case to refer to Christianity and it appeared to be a very important component of participants' belief systems. The most common denomination was Anglican. There was one Catholic participant and she had been adopted out of the community as

a child. Prayer was cited as being extremely helpful in coping with illness of one's self or a family member, or during grieving. There was also a very obvious distinction in the intensity of beliefs between the older participants and the younger participants. The Elders placed a great deal of emphasis on the Bible, referring to it as the *Book of Knowledge* and the answer for any question you could possibly ask could be found in the Bible. The prophecies and the Day of Judgment were also mentioned as coming to pass in the near future. Cancer, along with AIDS were said to be incurable diseases mentioned in the Bible and that more and more diseases would be coming; after that time there would be great suffering among the people. As per Christianity teachings, the only solace is for personal salvation through prayer and there was a lot of emphasis on suffering. George seemed to base all his life decisions on his religious faith, as in the following quote:

When one has faith in *Munitou*, there is no confusion. Your soul works for you, fights for you. I'm not saying I'm holy or anything, but that's my belief, and that's what counts, faith, because if I didn't have faith, I'd still be drinking and going to church once in a while, hoping that would save me...and it's not easy, when a person is ill, to tell them that *Munitou* can help them, because if we are going to seek the help of *Munitou*, we have to quit that which we are following on this earth. It's also written, it's dangerous if people pray for us to get healthy and we get better and then resume that path we were following before we got ill, greater harm will come to you, because we have lied to *Munitou*, because we have played with it, that's what's written.

I would like to clarify that there is a distinction between *Munitou* and *Kitchi Munitou* in the Cree language. The word *Munitou* is often synonymous with Creator in the literature but among the Woodland Cree and Christianity, *Munitou* is synonymous with Jesus and *Kitchi Munitou* is synonymous with God. There was virtually no mention of *Kitchi Munitou* in the interviews.

There was also a geographical difference evident when it came to strength of beliefs. As previously mentioned, Lac La Ronge Band is composed of 6 communities, with Little Red River, which is close to Prince Albert, being the furthest south. The Cree spoken in Little Red River was the 'y'-dialect of the Plains Cree. There was more openness when it came to discussing traditional spirituality and there appeared to be more traditional medicine practitioners in the community. When I asked participants in the more northern communities if they knew anyone who still knew the traditional medicines, the invariable response was no, whereas, in Little Red I

received the following response, “*I think there’s a couple of medicine people in the community*”. This geographical difference appears to be related to the length of time of Christianization and the subsequent loss or shame in the traditional belief system.

5.2.4 Traditional Medicine

Traditional medicine or *Nihithowi muskikiyu* was seen as being superior to Western medicine by some of the Elders. Elder John Cook went so far as to state that “*Cree medicine, that medicine that I’m using, boy that’s the best medicine. They [White men] don’t have it.*” I did not have the opportunity to interview a traditional healer but all the participants seemed to have some knowledge or knew of someone who practiced traditional medicine. Grandmothers and grandfathers were most often identified as being those practitioners; some participants reported that they as children were always suspicious of their grandparents’ herbal remedies. It was apparent that in this domain as well, the Elders had the most concrete and detailed information to share, even though none of them were traditional healers. It seems that there were certain medicines that everyone knew about, probably similar to what the general population would call First Aid, including the two most often mentioned medicines, *wachuskomitisowin* and *amiskowekusk* and they received this knowledge from their parents.

Wachuskomitisowin was mentioned most often. The healing properties included preventing hypothermia, easing coughs and sore chests, treating skin infections, controlling blood sugar in diabetics, and included curing diabetes. One participant even wondered if it could be used to treat lung cancer, if one was to chew it or make a tea. *Amiskowekusk* was most often used to ease cough and cold symptoms. There were other medicines that appear to have been adopted among the Woodland Cree from the Western world. The ingenuity of the Woodland Cree became apparent when Elder John Cook informed me that kerosene was the best medicine to treat frostbite and head lice. Other treatments using traditional medicine included thrush in babies, hypothermia, fatigue after surgery, miscarriage, fever, mental illness, Bell’s Palsy and cancer. Elder Betsy McKenzie mentioned a healer in Sandy Bay, “*He has good medicine, Cree medicine and he also prays hard for them when he is treating them.*” It would appear that traditional medicine is more potent if prayer is included in the treatment. Elder Rosie McKenzie discussed the necessity of paying for gathering traditional medicine with tobacco and that it had

always been done, but Elder John Cook stated that this practice was something new. Payment for healing was also a necessity and individuals paid the healer whatever they could afford, whether it was traps, food, sugar, tea etc.

The most common method of becoming a traditional healer was to be a direct descendent of a traditional healer, either a grandmother or a grandfather. Amelia talked about her grandfather being a healer but that her mother received only certain teachings related to women and children's health problems. She does not think her grandfather passed on the rest of his knowledge to anyone else. There appears to be an almost secretive protection regarding traditional medicine and those that practice it. Veronica had only recently become aware that one of her first cousins had received all of their grandmother's healing knowledge. None of the participants voluntarily brought up the subject of traditional medicine. The fact that despite repeated attempts, I could not make contact with any practicing traditional healers to interview also confirmed this predisposition. Elder Betsy McKenzie informed me that she used to practice traditional medicine but she had stopped and passed on her medicines to one of her daughters and would not discuss the issue further. According to Senator Myles Venne, traditional healers were regularly imprisoned for practicing their craft as recently as the 1930s, so it is not surprising that the fear of persecution could still be there.

5.3 Cancer as Experienced by the Woodland Cree

Cancer as a disease entity is not experienced in isolation and this was certainly true with respect to the Woodland Cree. As previously mentioned, participants included Elders, cancer survivors and family members and the process of interviewing allowed the participants to share their varied experiences. “[T]he experience of illness is involuntary, but the meaning one creates from illness experiences is somewhat voluntary” (Thomas-MacLean ⁷⁸ p.1654). One method I used to organize the data was to draw three circles, the inner circle was the individual that had cancer, the second circle was the family and the outer circle was the community. (see Figure 5) The stories I collected are all interconnected and interwoven within the three circles. I also used the Medicine Wheel framework to further organize the data where *The Illness Experience* explores primarily the physical impact of cancer; *The Emotional Experience* captures the emotions, *The Intellectual Experience* captures the mental aspects including knowledge of cancer and *The Spiritual Experience* summarizes the spiritual aspect. *Support systems* was a predominant theme and the *Health Care System* also needs to be discussed separately.

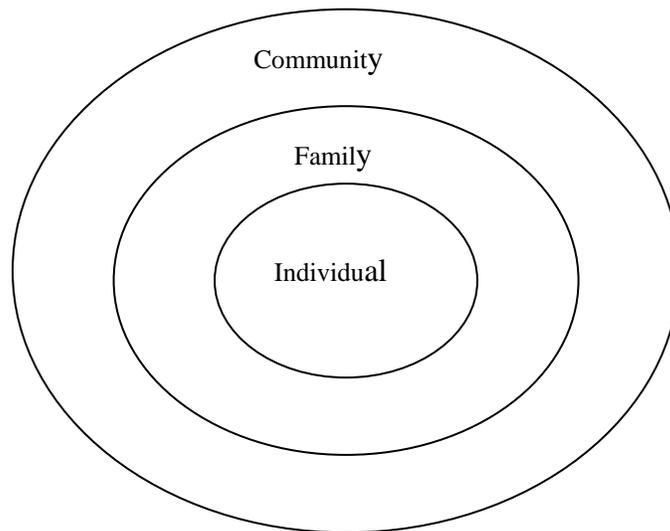


Figure 5. Model of multiple levels of impact of Cancer

5.3.1 The Physical Experience

Being diagnosed with cancer is a frightening experience, regardless of who you are, because we all know someone who has died of the disease and this was no different for the participants. The process of being diagnosed varied with the types of cancer; all the women with breast cancer found the lumps or identified there was something wrong themselves. The cancer

types that are typically found inside the body were diagnosed after the individual experienced continuous physical symptoms. One individual with lung cancer was diagnosed during follow up after lung surgery for another respiratory condition.

Experiences of when to inform family members varied. Betty found the lump in her breast and immediately called over her daughter to come and feel it; her daughter told her to call the doctor right away. Alice had virtually the same experience but with her daughter-in-law. However, when Bertha found the lump in her breast, she did not inform anyone for a year, and Teresa found out her family member had cancer a month after he had been diagnosed.

There were also time lags in the health care system for notifying the individual with their cancer diagnosis. Amelia's experience was a particularly harrowing account of what can go wrong. She found the lump in October and did not receive a definitive diagnosis until February. The following quote provides the details:

the only way that I found out that I had cancer was uh, I left my mother's phone number in PA...they called me at home and they sent me a letter I guess, I never received the letter, they sent it to the medical [clinic] over here and then they sent it here [Band Clinic] and I don't know what happened to that letter in between, the medical clinic and here, my phone number was on it and everything but they never called me at home...all they called was my work number and when I do call they said um, I don't know why, why you were called, they said to me, and then I phone the medical here too and no, they said that they sent the letter to the band office and [they told me] I cancelled my appointments three times, but I never cancelled no appointments, somebody here cancelled them... and then my mother called me, [the doctor's] office is trying to get ahold of you, they called here three times already, she said.

Amelia's experience was the extreme; most participants were informed of their diagnosis within a few days to a week of seeing an oncologist.

Cancer treatments were the typical Western medical system's treatment of surgery, chemotherapy and radiation, and would often mean traveling to Saskatoon. Travel was arranged for most individuals through the health care system, usually by medical van or bus. Participants that were more self-reliant provided their own transportation. Amelia had business meetings in Prince Albert and she combined them with physician visits. Veronica states that her family

member “*was in PA for 4 days. Finally the doctor there said, come and pick [him] up and take him to the University hospital. So, you know, you’d think, [they would] transport him in the ambulance if he’s that sick.*” So they went and picked him up and took him to the University Hospital in Saskatoon.

The individual’s treatment plan would depend on their cancer type. Several participants had their surgery in Prince Albert but then had to travel to Saskatoon for adjunct treatments. Radiation is only available at the Saskatoon Cancer Clinic, but some chemotherapy treatments could be accessed in Prince Albert. Some participants stated that their family members did not receive any treatment, except for pain management. It appeared that these individuals had been diagnosed at later stages. Patricia’s family member was physically strong and robust so “*because he was a very physically, active, healthy person, they went ahead with, all, every single treatment.*” Surgery was most often the first and sometimes the only treatment offered, needed or accepted. Bertha refused adjunct chemotherapy because she believed chemotherapy spread the cancer. Her belief was verified when the two women she shared a room with in the hospital agreed to the chemotherapy and subsequently passed away within a year, while she and the other woman who refused chemotherapy are still alive.

Several individuals combined Western treatment modalities with traditional medicine. Amelia’s mother brewed her a medicine to help get her energy back following surgery. She also used another medicine to limit the spread of cancer once she began to suspect that she had cancer. Teresa’s family member also used traditional medicine in conjunction with chemotherapy and he also informed his oncologist, who encouraged him to continue using the traditional medicine. For some cancer patients, it was often a final treatment option as evidenced by Wanda’s comment, “*and he tried a little bit of Indian medicine too but it was too late for everything, nothing seemed to work.*” Veronica reported that her Aunt had cancer and was being treated by a medicine man; “[*he] was working on her cancer, when she died, she’d been sick for quite a while.*” It appeared that most participants were unaware of traditional medicine for cancer or did not believe that it could help. Matilda, who was a 74-year-old breast cancer survivor, stated, “*nobody knows about cancer, only white man medicine can do anything with*

cancer.” George, on the other hand, had this to say: “*I also believe that there is a [Cree] medicine that can kill cancer, but nobody knows which one it is.*”

An interesting phenomenon was several of the participants were diagnosed with diabetes shortly after their cancer treatment was completed, thus further complicating their healing process. Alice lost consciousness several times and had to be hospitalized, where she was diagnosed with diabetes. George, who has an extremely strong faith, also became a diabetic, but he says that he doesn't follow what *they* tell him to eat

because it's also written in *Munitou's* book, that if you pray for your food to *Munitou*, it can't harm you, it can't poison you, because you gave thanks for HIM feeding you and I believe that too, I don't choose what I'm going to eat, I was told not to eat chicken but I love eating it (laughing).

Amelia also has trouble with “*that crazy chicken*^{iv} (laugh)” and Alice continues to have trouble maintaining healthy blood sugar levels. Participants reported that most individuals now eat healthier, choosing more fruits, vegetables and whole grains and eating traditional foods more frequently. They also self monitor and go for their follow up exams faithfully including Martha who had breast cancer nineteen years ago.

5.3.2 The Emotional Experience

Bertha, a breast cancer survivor, on her opening statement said, “*Three years ago I was diagnosed with cancer...it almost destroyed my life.*” Destroying one's life is a very strong emotional statement and creates a vivid image of the impact cancer has on an individual. Shock and denial were the most common initial emotional response to a diagnosis of cancer. Joan was shocked when she heard her family member had been diagnosed with cancer, she believed that he was in good health because he took care of himself. Emotional outbreaks of crying and expecting the worst, in this case death were also frequently mentioned. Veronica stated that as a family, “*we were all in denial, we didn't want to talk about it, you know, we were going to beat it, regardless how long it took, we were gonna, you know, gonna beat the disease, we were gonna beat it.*” The frequency of *gonna beat it* indicates the vociferousness of the family's belief that they would overcome this illness. The previous knowledge individuals had of people having

^{iv} The ‘chicken’ George and Amelia are referring to is Kentucky Fried Chicken.

cancer and in most cases dying from it, determined their initial response, including Amelia who, in the following quote, stated that she wasn't even going to go for treatment:

when I first found out, I was just, I didn't know what to think, I was extremely *pukwutamun*, I just stayed home, I locked myself in the house, didn't go anywhere, but the guy I'm living with was really understanding and he said you should go ahead with the operation...and I said to him, no I don't think so, I wasn't gonna, I didn't want to go and ...he talked me into it.

Patricia also mentioned that when they first heard the diagnosis they expected the worst outcome, "*so when my father had cancer, we of course thought, uh, the worst, we thought he was going to die real soon.*"

The emotional impact of going for treatment away from home was also difficult for most participants. Martha stated that she was so lonely when she was in Saskatoon receiving radiation treatment. Bertha stated that she cried because she was all alone before she was to go for surgery. Elder Mary Cook shared her experiences of caring for her mother and said that she went to Saskatoon to bring her home, she was afraid that her mother would die of loneliness being away from the community. Dying from loneliness appears to be a common perception among the elderly; both Elder Mary Charles and Elder Mary Cook talked about their fathers dying of loneliness when they were placed in convalescence homes in Prince Albert.

It was interesting that fear was not mentioned more often; one would expect that to be a fairly common response to cancer. Sonya reported that the two little boys she was looking after "*were scared, when I told them I was sick, they, they thought I was going to die.*" The only other reference was made by Veronica when she said, "*...when my son was dying...you just want to be there all the time, you're scared to leave, even just that minute you're gone...*" It appears that it's okay for children to be scared and Veronica phrased the emotion in second person, she could have said *I* or *we* but she chose to say *you*. Perhaps it's an indication of an unstated Cree or human belief that you are not to display or admit to being scared.

Displaying strong emotions openly does not appear to be a common occurrence among the Woodland Cree. Several participants stated that they would shut themselves up in a room or their house and cry. Patricia reported that she would wear sunglasses to hide her tears when she

was with a certain friend because her tears made the friend uncomfortable. Joan also mentioned feeling uncomfortable when her family member started opening up to her during his illness. Patricia regretted not telling her family member that she loved him more often, but as she explains in the following quote, her upbringing prevented her:

...it wasn't something that we did while I was growing up, was show a lot of physical affection and a lot of verbal affection, we would...of course praise each other if we did a good job, but... we really never did much of that...it just wasn't really done...we never really hugged a lot or kissed... or sat in each other's laps but we did do things for each other and so that's the way I was raised but I had wished that I had told...my father that I loved him more...but I never did, he probably would wonder what the heck was wrong with me (laughing) if I went around telling him.

Humor as a method of discussing difficult issues was often used in the interviews, as the above quote indicates. Participants frequently used humor when discussing the loss of hair during chemotherapy including requesting curly hair or blond hair when they were informed that their hair would grow back. Bertha remarked that she didn't believe in chemotherapy and then softened the comment by stating that she was already bald and didn't want to be balder. Bertha also used humor when discussing her mastectomy and the resultant effects, "*when they told me I'm going to lose both of my breasts... like they took my womanhood away, I liked my soccer balls, now I have golf balls (laughing). I was proud of them.*" Humor was also evident when participants remembered their loved ones that had passed away, remembering the good times they had shared.

However, the overall emotional toll on the participants appeared to be heavy, especially for those individuals who lost someone. Grieving was still fresh among several participants and the younger the individual was that passed away, the more difficulty the participants had with their grief. Veronica reported that it was still difficult to talk about her family member, although it was two years since he passed away. She also experienced anxiety attacks after the fact and required grief counseling. Wanda was proud that she was able to share her story without crying but the emotional impact was especially heavy for her due to her familial responsibilities: "*to see my grandson like that was one of the hardest things I ever had to go through plus try and support my daughter and my kids and everything at the same time... it was really, really hard.*" Teresa

said that there were many nights that she cried but she knew she had to be strong for the kids. Caregiver roles appear to add to the emotional load of participants.

5.3.3 The Intellectual Experience

The intellectual aspect of the medicine wheel deals with thinking, problem solving, decision-making, knowledge and creativity. The largest amount of information was in the area of cancer knowledge. Participants were asked to give their thoughts on possible causes of cancer, what they knew of cancer before and after the illness experience and any ideas they had on prevention.

The responses to what participants thought caused cancer were most commonly related to environmental influences such as the preservatives in foods, pollution in the environment, pesticides, emissions from jet planes and motorized vehicles and asbestos. Smoking was almost always the first factor named by participants; only one of the twenty-six participants doubted the connection between smoking and cancer. Some individuals attributed the change in diet and physical activity as being a factor in the increased rates of cancer among the Woodland Cree. Those who were younger and more likely to have a Western education responded with genetic predisposition and not taking care of oneself such as overindulging. Two participants believed that the onset of cancer was caused by a physical injury. However, most participants' initial response to the question was simply "*I don't know*", indicating that the Woodland Cree have no definitive ideas on why they are getting cancer anymore than the general population.

Previous knowledge of cancer was mostly limited to what participants had read or heard in the media. Patricia had even volunteered for the Canadian Cancer Society and she still responded with "*I never knew anything, except that they were trying to find a cure for some cancers.*" Alice said that she hadn't even been aware that *munchoos* referred to cancer and Winston reported what he knew about cancer was stuff he had read but he didn't become concerned until he started to see his age cohorts beginning to *catch* cancer.

The Cree terminology used when discussing someone having cancer was extremely interesting; the word used was almost always a variant of *catching*. Perhaps this is due to the

Cree word for cancer, which is *munchoosuk*, a pluralized form of some kind of worm type organism and it would make linguistic sense to talk about *munchoosuk* in an external sense. The participants that interviewed in English used the term ‘cancer’ and ‘it’, but there again, the term ‘it’ connotes a thing, an objectification of the disease, which isn’t much different from how Non-Aboriginal English speakers refer to cancer.

Prevention of cancer was another question participants had difficulty answering. Some responded that there was nothing anyone could do to prevent getting cancer and the most you could do was hope for early detection by going for regular medical check-ups. Mammography screening was encouraged by Bertha as something that could save one’s life and encouraged women to have them. George remembered that everyone was required to get an X-ray during treaty days long ago and he thought perhaps this would be a useful method to detect cancers growing in the deeper bodily tissues. Quitting smoking was mentioned often, but both Charlie and Winston continue to smoke despite their father having died from lung cancer. Joan and Patricia resumed smoking as a means of coping during the illness and subsequent passing away of their family member. It is likely the addictive nature of smoking will continue to be a challenge for the Woodland Cree for a long time to come.

With respect to other intellectual aspects, Teresa’s family member was concerned about the effects of cancer treatment on his mental state. His concern was the main impetus for preparing his will and setting his affairs in order before he started treatment. His concerns appeared to have been valid as the chemotherapy caused losses to his short-term memory and Teresa mentioned that now “*he’s stuck in front of the boob tube all the time.*” Teresa’s family member did not want to be interviewed during the data collection phase. He has since passed away and Teresa found a diary among his possessions where he had written a personal account of his cancer experience.

Participants reported that they would support their family member in their decisions regarding their cancer treatment and their activities. Patricia provides an example in the following quote:

...there was a lot of things he would not do, he would not stay at the Cancer [Lodge], that place where they stay because he didn't want to stay, be with a bunch of sick people so he stayed in a hotel with a kitchenette during the week while he was [there] for treatments. It was a six week period and he bought down all his food...smoked muskrats, moose meat, all sorts of stuff, smoked fish... so he tried to maintain a quality of life all along and I totally accepted it.

Other instances were when Veronica's family member requested that there be no life support placed on him, as well as Wanda's family member requesting "*one day at the hospital, [Royal] University [Hospital], he said to his Mom, take me home, I don't want to die here, he said, take me home.*" Teresa also encouraged her family member that "*if you find that you cannot tolerate the treatments anymore, you can tell them to stop, it's your body.*"

Several participants were very creative when it came to helping their family members during their illnesses. Patricia's family color-coded the medications since her family member could not read English; they also bought him high-tech clothing so he wouldn't lose body heat when he wanted to go ice fishing with his friends. Elder Mary Cook asked her stepbrother to move in with them during her mother's illness so her mother could have someone to speak Cree with all the time and to provide her with traditional food.

5.3.4 The Spiritual Experience

The spiritual self according to the Medicine Wheel framework relates to our one-ness with Mother Earth, Creator, music, prayer, and meditation. I am also including religious beliefs in this category. Most participants reported that there was no major change in their spirituality. Amelia said that she appreciates life more now, that it's too short. She's also the individual that uses both Christianity and traditional spirituality. Praying during the illness was commonly reported, as well as continuing to pray for no reoccurrences and praying as a form of healing from grief. Praying for others with cancer was also mentioned a few times. The effect of cancer on the participants' spiritual beliefs was not talked about in any great detail, with the exception of George. The interview with George was heavily focused on faith and Christianity. He believed that *Munitou* was using the doctors to cure him and he was not worried about dying because his faith was strong. George believed that an individual's time on earth is predetermined and if he was going to die from cancer, then that was what *Munitou* had decided would happen to him. But

since he was cured, he was not meant to die from cancer. George also stated that his faith was strong before he got ill and had not changed because of his illness.

Both Elder Betsy McKenzie and George seemed to believe that cancer was an incurable disease that had been prophesized in the bible. Elder Betsy McKenzie held especially strong beliefs in this area, as the following quote exemplifies:

Thankfully, I have read it in the bible that these happenings, diverse happenings, are the prophesies coming true...and it does say that all kinds of diseases will be here but some of these diseases will not be curable, only some of them and when those diseases have run their course, then great suffering will follow...that's what it says in the bible and the words in the bible are not lies...life will become more difficult, when these diseases run their course...these diseases that keep coming here.

5.3.5 Support Systems

Support for individuals with cancer comes in at all levels; the individual, the family and the community because cancer as an illness affects everyone in the small communities up north. Support for the self included advocating for personalized treatment care such as Bertha refusing adjunct chemotherapy and Patricia's family member bringing down his traditional foods and staying in a hotel with a kitchenette when he went south for his cancer treatments. As previously mentioned, Amelia had to advocate for herself by trying to determine where the miscommunication occurred with respect to receiving her cancer diagnosis. Taking time off work during the healing process was another method of self-support. Continuing to engage in hobbies such as ice fishing and going to the trapline were also part of looking after the self.

Family support was a very large component of the support systems, both in terms of providing support for the individual with cancer as well as amongst family members themselves. Participants reported that there was one main caregiver involved in the day-to-day activities, most often the spouse or the mother. The caregiver roles included advocacy, accompanying the individual on trips down south, providing daily personal care including nursing care duties such as changing dressings and providing medication as well as being the gatekeeper for other family members. Teresa reported that her family "*would phone me first and say well, what's he like today*" and her response would determine whether they would stop by or not. The main caregiver

also supported the individual with cancer by getting flu shots, wearing masks to limit possible infection, and providing healthy foods including traditional foods.

Family members also supported the main caregiver as much as they could. Patricia, for example, would try to provide some of the daily personal care and would also go sit with her family member to allow the main caregiver an opportunity to go out. Family members also supported each other emotionally by talking amongst themselves. Both Joan and Patricia reported that talking to their respective sisters was beneficial and Alice talked to her daughter during her recovery process.

Family support was especially strong when the individual was dying or in a medical crisis. Veronica stated that her immediate family and extended family surrounded her family member continuously around the clock until he passed away. Sophie also reported the same process when her family member was in the hospital dying. When Alice lost consciousness and was hospitalized for high blood sugar, she said when she regained consciousness all her family members were standing around her bed. Elder Mary Cook said that the doctor told her she would only have her mother for 2 weeks and discouraged her from removing her from the hospital in Saskatoon and bringing her home; her mom lived for another two years. Amelia also believed that being at home is where individuals who are terminally ill ought to be, surrounded by family.

Support from the community included visiting people with cancer in the hospitals or in their homes. Elder Rosie McKenzie said, *“I go and visit the sick people that are in the hospital, these cancer patients and they are very happy when they get visitors, maybe it distracts them and they don’t feel the pain that much.”* Teresa talked about close friends that she goes to have coffee with when she needs a break and someone to talk to. She also mentioned that her family member had a close friend that he talked with so as not to overwhelm his family. Charlie said he was the first one to hear about his friend’s cancer, including when it reoccurred. It seems that friends are often seen as confidants, allowing individuals to speak more freely. However, this was not the case with Patricia and Joan, both of whom felt their friends were not capable of being supportive during their time of need. Employers gave family members extended time off so they could spend as much time as they could with the individual that had cancer. The Bingo Hall also began

to contribute a share of their proceeds to the Canadian Cancer Society as a means of community support shortly after it declared that it would become a smoke-free establishment. Support comes in many forms and from many sources, including being interviewed as Veronica remarked following the interview, *“I’m glad I talked to you, and to let you know about my [family member].”*

5.3.6 The Health Care System

There were frequent mentions of the health care system during the interviews, mostly from cancer survivors and family members. Some of the discussions only related to the interaction with the health care system as part of the illness while some participants actually made suggestions on how it could improve in the area of cancer care. The health care system in the north is quite complex when it comes to providing health care to First Nations people. The federal government has jurisdiction on the reserves, whereas the provincial government has jurisdiction in all other locales including the hospitals and the cancer clinics. The outlying reserves usually have a clinic where nurses are available on a 24-hour basis and are the first line of treatment. Physicians fly in to some of the communities on a weekly basis. Other services provided by all the clinics include: immunizations, home care, addictions counseling, and dental therapy. Organizing medical trips to the larger centers are also the responsibility of the reserve clinics. Participants from La Ronge accessed the medical clinic and hospital services such as emergency. The medical clinic usually operates with a rotating list of physicians, so it is rare for somebody to have one primary physician.

Receiving appropriate attention from the health care providers was an issue discussed by several participants. George said the first doctor he went to go see, who happened to be female, gave him some pills for pain. But when he went back and was seen by a male doctor, the doctor *“suspected right away what was going on, I’ll have to send you away immediately, he told me,”* reported George. Teresa had to demand that her family member be sent out for further testing as evidenced in the following quote: *“I had to take him here to emergency, because his chest was so sore...he could hardly even breathe and I had to take him to emergency and that’s when I said you send him out... like I’m not fooling around anymore, you send him out.”* Sonya finally had enough of not being able to get a definitive answer regarding her cancer and took herself to

Saskatoon. Patricia also reported difficulties with the health care system when she was attempting to find nutritional information, she said that the nutritionist didn't return her calls and that the band nurses didn't have any answers for her questions either. She also wished that a nurse could have been available to administer the medications, especially those requiring syringe injection to her family member.

As previously mentioned, most participants reported that Western medical cancer treatment was the only modality used and it involved traveling to either Prince Albert or Saskatoon. Wanda said that they went as far as Toronto (~2400 km) for treatment, and Veronica mentioned they went to Edmonton (~ 500 km) with the expectation that they were going there for a liver transplant, only to find that this was where they spent their last days with their family member. The expense involved in traveling to these different locations was never mentioned during the interviews, indicating that expenses were paid for, or it was not a concern when it came to supporting the individual with cancer.

Response time for treatment varied. Betty who was living in Prince Albert at the time she had breast cancer, had surgery within two days of being diagnosed. Bertha, who was living in the Northwest Territories at the time of her diagnosis, had to wait 6 months before her surgery, which required traveling to Edmonton. George, who was scheduled for radiation therapy said he waited a long time, he surmised, *“they probably told right away but over there, they must have been too busy even where people can live, only as room becomes available can you go in.* However, the most frequent response was that individuals started receiving treatment within 2-3 weeks of their cancer diagnosis.

There were a few suggestions to improve cancer care for individuals in the north such as creating a traveling hospice care unit so that people could look after their loved ones at home but still get the appropriate medical help when needed. Providing culturally appropriate care within the Saskatoon Cancer Clinic was seen as being difficult to accomplish, however, lodging establishments such as the Cancer Lodge could do more to provide a culturally comfortable living environment for individuals coming south for treatment. There appear to be more and

more First Nations with cancer and the Western health care system will in all likelihood have to work towards providing culturally competent cancer care.

5.4 Straddling Both Worlds

Living in and taking from both the traditional Woodland Cree knowledge system and the Western knowledge system has been a recurrent theme throughout this chapter and I believe it is deserving of a closer exploration. The Cree were predominantly the middlemen during the fur trade era between the various trading companies such as the Hudson Bay Company and the Northwest Company and First Nations trappers, Cree or otherwise. In fact, my paternal grandfather operated a trading post from our traditional trapline, and when my mother informed me of this she didn't seem to feel that it was a big deal; whereas I feel the complete opposite. It confirmed for me that we, as Cree people, have always been able to pick and choose what we wanted from both systems, essentially having the best of both worlds.

Entirely different peoples were created by the combination of both worlds, the Métis that were of French and First Nations ancestry and the *Apitowikosanuk* that were of English/Scottish and First Nations ancestry. We also adopted and customized the Scottish bannock and claimed it as one of our traditional Cree foods. We readily accepted Christianity because there were so many similarities with our belief systems such as doing good to others, living a good life, congregating for ceremonies and believing in one ultimate Being. These are just a few of the more well known examples and this adaptive ability continues to this day and was keenly evident during the interviews.

With respect to the first theme on the concepts of health and illness, participants used both systems to define how they understood health and illness. Most participants felt that the traditional life style was healthier and made attempts to continue to follow it including sharing their knowledge with the younger generations. On the other hand, when illness struck, the first contact was most often the Western trained physician or self- medication with over the counter drugs. Joan, the youngest participant, used the Western health system of diet, vitamins and over the counter medication as her primary method of self- care. The Elders, on the other hand, spoke about the traditional belief systems of *mithopimatisiwin* as being the most important concepts to live by. Those participants that were more educated within the Western health system verbalized a detailed wholistic definition of what it means to be healthy including concepts related to the Woodland Cree belief system.

In traditional knowledge systems of the Woodland Cree, Christianity was a major topic of discussion. The missionaries appeared to have taken the terminology of the traditional Woodland Cree spiritual belief system and applied it to the Christian teachings. Apparently there were so many similar words and phrases, that the only new word that needed to be introduced during the translation of the bible into Cree syllabics was Jesus Christ; the symbol is simply a capital X. Today there is such a deep level of integration; one has difficulty distinguishing what the original meaning of the words had been.

Only one participant reported that her spiritual practices included both Christianity and traditional spirituality. However, several participants mentioned that one had to pay for medicines when harvesting from the earth with tobacco and that this practice had always been done. This practice is a well known custom among First Nations that still practice the old ways in other parts of the country. Elder Betsy McKenzie mentioned a healer that prays very hard when treating people; this is also a common practice among traditional healers who have not been indoctrinated into Christianity.

Traditional healing and Western healing modalities were most often reported as being used together but the beliefs varied on which was more effective. Elder John Cook stated that Cree medicine was far superior to anything the Western world had, and Alice, Elder Betsy McKenzie and Elder Mary Cook affirmed this. Elder Betsy McKenzie felt that Western medicine was *bad medicine*; the amounts and different combinations were not good for one. Elder Rosie McKenzie reported that she used both Vicks and *wachuskomitisowin* for coughs and colds and Amelia also said that she would use either over-the-counter medication or brew herself a medicinal drink.

The cancer experience of the Woodland Cree was also rich in data regarding both worlds. Winston talked about an illness that he had heard about from the Elders called *Itinoowapiniwin* and he began to wonder if this could possibly be cancer. Elder Rosie McKenzie surmised that perhaps the sick people she saw lying down until they passed away when she was a child, had cancer. Elder Betsy McKenzie spoke about the ability of medicine people to send cancer curses

to individuals they disliked, but that other medicine people could heal the cancers. Elder John Cook also reported that he had been shown a traditional remedy for curing skin cancer but he had forgotten the combinations of medicines required. Participants openly discussed the possible connection between the change in diet as a cause of cancer and cancer survivors reported that they now ate more traditional foods.

Three participants reported the use of a combination of both healing systems for cancer care and two participants remarked that the information regarding what was being used was shared openly with Western medical practitioners. Teresa shared an incident where a medicine man extended the life of a cancer patient by four years when the Western medical system had given her two months. George seemed to feel that there was a Cree medicine that could cure cancer, but nobody knew what it was yet. However, Matilda expressed that “*only white man medicine can do anything with cancer.*” There was only a thirteen-year age gap between George and Matilda and they were from the same community. Age or geographical location did not appear to have a significant difference in beliefs on the merits of traditional medicine with respect to cancer care.

Receiving a western education was an important concept for many participants. Charlie said his first home was his trapline but felt that he owed it to his children to live in the community so they could go to school, stating “*children of today need the education to survive in the white man’s world and I have to give them that opportunity.*” Elder John Cook spoke at length on the importance of attending school. He said, “*the reason for school, for a Cree to go to school, [is] to learn to live with the whites.*” He reported that he is often asked to go to the schools and talk to the youth and he encourages them to listen to their teachers and work hard at their education. Therefore, it seems that the Woodland Cree have accepted and support the belief that education is required for the current generation to survive in today’s world. However, there is also the belief that maintaining the Cree language and culture are equally important and to do so is a responsibility of the educational system as well as parents and community.

Straddling both worlds allow the Woodland Cree to have the best from each system and in most cases participants honor and respect both ways of knowing and being. One participant

remarked that we haven't caught up to the Europeans in terms of how our bodies handle the foods we now eat, as well as the smoking and alcohol, and her evidence was the high numbers of First Nations that are lactose intolerant, and have smoking and alcohol addictions. Therefore, straddling both worlds has likely been and will continue to be a survival mechanism for the Woodland Cree.

Chapter 6. Discussion

In this chapter, I discuss the research results and compare them with findings in existing literature, along with deeper discussions on the identified themes. I will also delve further into issues of methodology; the merits and challenges of narrative inquiry as a research method in First Nations communities, as well as my experiences as a researcher. Recommendations and further research are also presented.

6.1 Reflections on the Findings

6.1.1 Perceptions of Health and Illness

One of the expected outcomes was the documentation of the Woodland Cree health paradigm with the hope that this knowledge would assist health care planners in designing programs that incorporated the cultural and world view of health and illness among the Woodland Cree. In fact, the health paradigm was shown to be a complex integration of Woodland Cree and Western medical health belief systems. The integration of both world views is so interwoven that it would be difficult to separate them, and in fact if one was to attempt this separation, it would likely be a step in the wrong direction due to the community health and health promotion principle of starting where the person/community is at.⁸³ Developing a framework to assist health care practitioners in program development, regardless of the disease or illness was another expected outcome. This outcome was not entirely realized and may need more research to focus participants in the specific area, since participants quickly became centered on the topic of cancer when I informed them that was the focus of my research.

It is interesting that Coe et al identified that those more educated were less traditional and yet they were the ones that sought traditional healers more often.³¹ This phenomenon was not revealed in my research; it appeared to be the health workers (i.e. more educated in the Western educational system) that were able to articulate a more wholistic view of health and those that sought traditional healers would not neatly fit within one demographic category. The older participants were found to be more traditional,³¹ which makes intuitive sense and this was similar to the participants' views on health and illness in this study as well. The older participants including the Elders expressed a desire to return to the old days, the perception being that people were healthier back then.

What it meant to be a Woodland Cree revolved around the two words of *mithopimatisiwin* (living a good life) and *mithoyawin* (being in good health). The Elders as well as some of the other participants stated that having good relationship with everyone, respect, thankfulness and helpfulness were important characteristics of *mithopimatisiwin*. *Mithoyawin* was described as being healthy in all four quadrants of the medicine wheel; the physical, the emotional, the intellectual and the spiritual. Burhansstipanov & Olsen citing Bennett state that being *Indian* included the love for family, respect for elders, spirituality, self determination, integrity, pride, understanding, protecting the environment, humor and socializing.⁷ Many of these traits were also reflected among the participants and reported as being important facets of *mithopimatisiwin* and *mithoyawin*.

6.1.2 Woodland Cree Knowledge Systems

It was interesting that any discussions of *Poowamowin* were brief and the topic was quickly changed. Elder John Cook was very clear that he did not want to spend any time talking about *Poowamowin*, stating that it was not part of his belief system and Elder Betsy McKenzie was also somewhat derisive when she spoke of this traditional knowledge and belief system. I believe this is partly a reflection of the teachings of Christianity and the fact that nearly all the participants had been through the residential school system. The conversion towards Christianity was so complete that Elder John Cook's father told him that the Woodland Cree did not have a religion until the missionaries arrived. I also received a similar response when I had asked my maternal grandmother how we prayed before the missionaries had arrived. My grandmother was also a residential school survivor and her immediate no-nonsense response was "*we didn't*." It is regrettable that this knowledge system has now become a topic of shame among the Woodland Cree. This may also be attributed to the colonial legacy.

Elder Betsy McKenzie and George both believed that certain illnesses including cancer and AIDS had been written in the Prophecies in the bible. My mother has also mentioned on numerous occasions that the tragic and often unexplainable events of today were foretold by her grandmother. Since I was told by a clergyman that there is no mention of incurable diseases as a predecessor of great suffering in the bible, the Cree syllabics version of the Bible may be in

question and a comparison of both versions might shed some light on the translation back in the 1850s and thus on some of the beliefs.

Another interesting trend was that none of the participants voluntarily brought up the subject of traditional medicine. I had to broach the subject each time. Elder Rosie McKenzie answered the question regarding what people did when they were sick by telling me about Western type of medicines that were available to the people long ago. Once I asked her about traditional medicine, she then told the story of the traditional healer Abel McKenzie. I wonder if the participants responded after I asked directly because they did not want to appear rude. After hearing Senator Venne speak about traditional healers being imprisoned for practicing their craft, it would make sense that people may still be uncomfortable with this topic. In addition, I have heard that traditional medicines are one of the few areas where all the knowledge has not been taken away from Aboriginal people by the Western knowledge seekers. I have attempted to protect this knowledge by using the Cree words for medicines in this dissertation and I will make no attempt to provide an English translation.

Culturally, the Woodland Cree are not unique in how they handle disease and illness. As previously mentioned, Burhansstipanov & Olsen cite Bennett stating that some aspects of being *Indian* included the love for family, respect for elders, spirituality, and socializing.⁷ The ripple effect of having cancer, which affects the individual, the family and the community, would likely have the same effect in other Indigenous communities and possibly smaller tight-knit communities. Rural communities in Canada have been known to use family as a resource extensively,⁸⁴ and the Chinese also place great emphasis on community and extended family.^{85,86}

6.1.3 Cancer Experience Among the Woodland Cree

6.1.3.1 The Physical Experience

Where cancer survivors started their stories, for the most part reflected Van Der Molen's⁸⁷ (p.49) statement, "for most people, the experience of cancer does not start the minute they are given their diagnosis, while it may confirm their suspicions, the experience invariably starts at an earlier point in time." All the survivors discovered or knew something was wrong before they made contact with the health system. The physical symptoms of the illness and the treatment

were frequently mentioned during the interviews and there doesn't appear to be anything dissimilar with what has already been reported in the literature.

It was interesting that none of the participants opted for a traditional healer as their first line of treatment. Matilda openly stated that only Western medicine could do anything about cancer. This sentiment is correlated with Burhansstipanov and Hollow's article where traditional healers are reported to believe that cancer is a white man's disease and only white man's medicine can cure it.¹³ However, the Anishinawbe Elders in Hart-Wasekeesikaw study stated the opposite, that white man's medicine can only slow it down and traditional medicine is needed to cure it.²⁵ There were several mentions of traditional medicine being used as adjunct treatment to Western treatment among the participants; however, nobody knew of anyone who had been cured of cancer by traditional healing with the exception of those that were sent curses in the old days, who could also then be cured by having the curse removed.

6.1.3.2 The Emotional Experience

Van Der Molen⁸⁷ (p.53) reports, "individuals had to contend with the emotional responses to a cancer diagnosis as well as the physiological changes imposed by treatment. This challenged their self identities." Participants also reported the emotional burden of being diagnosed with cancer, along with the loneliness of having to leave their home community for treatment. Crying and social isolation was a common emotional response.

Fear of death and dying was not openly discussed by the cancer survivors however family members did discuss the death sentence of a cancer diagnosis with me but it did not appear that they discussed it openly with their family member who had cancer. Whereas Van Der Molen⁸⁷ (p.49) reports the opposite, "the enigmatic nature of cancer evokes all kinds of anxieties and all the respondents talked of the fears of death and dying." McMichael and Hart-Wasekeesikaw both reported the perception of cancer being a death sentence among Australian Aboriginals²³ and Anishinawbe people from Manitoba²⁵ respectively. Kaur suggests that American Indians have a tendency towards fatalism.¹⁴¹⁴ The word fatalism is defined by Webster's Dictionary as "a doctrine that events are fixed in advance so that human beings are powerless to change them." While some version of fatalism may have been expressed by George who said we are all going to

die anyway and also by my mother, caution is necessary before one begins labeling an entire population. If there was indeed a fatalistic attitude exhibited by the participants, then none of them would have sought medical treatment, Western or traditional. Perhaps a more realistic explanation is that the participants saw cancer as a death sentence because of their past experiences with the disease entity in their communities. Therefore, the desirability for cancer survivors to become more public, along with increased awareness and education is needed for the north.

The use of humor in dealing with illness or adversity is widely recognized. Research has shown that the use of humor stimulates the immune system; decreases stress levels and may also have spiritual significance.⁸⁸ At the group interview in La Ronge, Alice remarked that crying and laughing were healing. Elder Mary Cook also spoke about the belief that part of happiness is being able to joke and laugh. Johnson also reports that humor was found to be relaxing⁸⁸ and this was definitely the case especially with the group interviews but also with the individual and couple interviews. There was humor and laughter shared with each participant. I believe humor was also used to discuss sensitive subjects, some participants used a double entendre when discussing breast self examination. Several of the female Elders also used humor and sexual innuendo during discussions.

6.1.3.3 The Intellectual Experience

The perceived causes of cancer reported by the participants appear to be commonly held beliefs among the Anishinawbe as well. Some of the similar responses were environmental pollutants, change in foods, physical injury, bad medicine and tobacco. Hart-Wasekeesikaw also reported that some Elders felt that cancer had always been in the community, and that the individual either got cured or they were not diagnosed.²⁵ Similar sentiments were shared among my participants, notably Elder Betsy McKenzie who said that people could be cursed with cancer but could also be cured. Elder Rosie McKenzie began to wonder if those sick people she saw as a child, lying down until they passed away had actually had cancer. Winston also wondered if an illness the Elders had told him about was actually cancer but it just hadn't been diagnosed. These intellectual forays into the prevalence of cancer in historical times have relevance because the participants were also attempting to bridge the two knowledge systems. Considering cancer is

not caused by an outside organism but an over-multiplication of our own cells, there is no reason to disbelieve that cancer has not always been part of the community.

It was interesting that tobacco was most often the first cause of cancer offered by the participants. It became obvious that the public health messages were coming across loud and clear in Woodland Cree territory, even among the Elders, some of whom did not speak English. There was only one participant, Bertha, who disbelieved the connection between tobacco and cancer. What is concerning is that she is a health care practitioner. Is she sharing her beliefs with the clients she comes into contact with? Another implication arising from this topic is that most participants continue to smoke or chew tobacco including Elders. McAlister et al suggest four areas that require action when it comes to behaviour modification; education, persuasion, motivation and facilitation.⁸⁹ It appears that knowledge clearly isn't enough of a deterrent when it comes to tobacco abuse and cancer. Health promotion and prevention strategies will need to target the other three areas as well as other social and economic factors.

The objectification of cancer among participants is a common reaction within other populations as well. The public message of *Cancer, Let's Beat It* is well known. There is ample evidence suggesting that cancer treatment is often seen as a battle, and logically it makes sense to see cancer as something outside of yourself in order to prepare for battle. Veronica's repeated statement of "*gonna beat it*" when she was talking about her family member's cancer illness conveys this sentiment of battling cancer. The Cree word and visual image of *munchoosuk* is an excellent metaphor to objectify the illness. Who wouldn't want to cut, burn or kill *munchoosuk* that are eating your body from the inside?

The concept of *munchoosuk* eating the individual is a metaphor that is commonly found in other cultures. The word cancer itself is usually traced to Hippocrates, who likened the long bulky veins radiating from the breast to crabs.⁹⁰ The term has been widely translated into other languages emphasizing that cancer, like crabs, creep along and eat away the flesh. I wonder if the term *munchoosuk* was an attempt at translating cancer into Cree when it was first noticed among the Cree, since there is no word for crab in Cree. Skott⁸¹ (p.231) states that the metaphor of being eaten from the inside has a deeper meaning and invokes fear rather than an explanation,

“to be eaten from inside is a perversion that evokes the dreadful experience of being threatened by death from within.”

6.1.3.4 The Spiritual Experience

Hart-Wasekeesikaw reported that all the cancer patients in her study sought other ways of healing and she included Christian prayer as one mode of healing.²⁵ Prayer is also a well known alternative therapy in cancer treatment as part of the spiritual dimension.^{91,92} The participants in this research also reported Christian prayer as a common coping strategy. Burhansstipanov and Hollow state that religion and medicine are inextricably linked¹³ and George reflected this position the strongest among all the participants especially with his statement that Manitou used the doctors to cure him. The belief of George and Elder Betsy McKenzie that the Bible Prophecies and cancer are connected is an area of potential difficulty for health care practitioners. Both George and Elder McKenzie are considered Elders in their communities and as such the knowledge keepers and teachers within that community. If health care practitioners were going to use the Elders as partners in health promotion and prevention strategies, they would run into difficulties with respect to the differing belief systems related to the cause of cancer. Finding a way to operationalize health prevention and promotion strategies which incorporate both knowledge systems will be an ongoing challenge.

6.1.3.5 Support Systems

Johnson⁸⁸ (p.694) reported “the women had a strong sense of wanting to protect their families from the fear of cancer and dying, especially their children and grandchildren.” The protective factor was evident among the participants in this study as well. Joan stated that her family member didn’t want to share too much information with her and she felt he was trying to protect her. Teresa’s family member talked to a close friend so as to ease some of the burden on her. George also mentioned that the most difficult aspect for him during his illness was that his family members suffered as well. Self- instituted social isolation could also be seen as a form of protection, negating the need to explain oneself to family or friends.

Van Der Molen’s study participants identified the loss of friendships due to their cancer illness and they also identified the tremendous amount of support they received from their family

members once they decided to share the news of their illness.⁸⁷ This finding was supported in this study where several participants reported not receiving support from their friends and relying more on their immediate family members to help them cope. Amelia and other cancer survivors stated that their respective partners were their biggest source of support during their illnesses. It appears that cancer as an illness entity has the ability to draw a family together in a time of crisis.

6.1.3.6 The Health System in the North

Participants reported frequent altercations with the health care practitioners in the north. Self-advocacy or advocating for a family member was often necessary in order to get appropriate responses from the health care practitioners. The complexities of having both federal and provincial health care systems in close proximity could possibly account for some miscommunication errors. Perhaps the relatively low prevalence of cancer among the Woodland Cree also accounts for the physicians not suspecting cancer as a possible cause of illness. Education and awareness sessions for the health care practitioners could possibly alleviate this issue to some extent.

The semi-isolated conditions of Northern Saskatchewan provide challenges for both health care workers as well as the patients receiving the care, especially in relation to cancer, since treatment is provided only in Saskatoon, Regina and certain procedures in Prince Albert. One of the expected outcomes of this research was that additional knowledge would be generated for the cancer clinics to provide culturally appropriate care. Patricia stated that she felt it would be difficult to provide culturally appropriate care with the cancer clinic but she was mainly referring to food choices and environmental surroundings. However, cultural competence for health professionals implies an awareness, a sensitivity and knowledge on how culture affects human behaviour, including health care services orientation⁸⁴ and there is definitely room for improvement in this area. Cross-cultural awareness workshops for health professionals are one method that could be utilized for anyone working with First Nations and Métis populations.

The distance to travel for treatment and having to leave the home community was a major source of stress. Due to the geographical and population disparities there aren't any easy solutions to circumvent this issue. However, the health care system is using more and more

technologically advanced methods of providing health care. Perhaps some methods such as Telehealth, which uses interactive audio, video and computer hook-ups through distance, will provide an alternative to traveling south for appointments.

6.1.4 Straddling Both Worlds

In a study by Guiliano et al, they found that some Hopi women were successful in combining their Native culture and western medical systems to promote health and suggested that cultural identity may facilitate participation in cancer prevention and control services.⁹³ Burhansstipanov and Olsen also identified that cancer patients who combined western and traditional healing practices had a more positive outlook.⁷ Participants in the present study expressed their health, illness and cancer experiences from within both world views right from the outset. As previously mentioned, the Woodland Cree have had the capacity to adapt and derive the best of both worlds. As further evidence, several participants began making connections between what they had seen or heard from earlier times to what is known at present in relation to cancer, in essence creating their own bridges between both knowledge systems.

6.2 Reflections on the Methodology

The primary reason for choosing narrative inquiry as my methodology was due to the similarity it shared with Aboriginal ways of knowing; sharing through stories. In reality however, the stories did not flow as stories normally do during most of the interviews. There were a few times when I was able to capture the natural flow and these were typically when the tape recorder was not in sight such as the initial interviews with Elders John Cook, Rosie McKenzie and Betsy McKenzie. The Elders started telling stories almost from the moment I walked in. The other time was during the group interview in La Ronge; the other participants all looked at Elder Mary Cook with the expectation that she would go first and she proceeded with a storied structure. Following Elder Mary Cook's story, she encouraged the other women to also share their stories. The women passed the tape recorder around, encouraging each other and sharing a respectful silence while each took their turn to talk.

The group interviews had a different dynamic to the individual interviews. The atmosphere was friendlier, including lots of laughter and general visiting before and after the

interviews were completed. Traditionally, food and drinks are part of any gathering, whether it's between two people or 200. Therefore, providing food is always a good way to attract people to gatherings and it certainly worked with this research. It appears that when a talking circle or focus group format is used, the first person that speaks sets the tone of the rest of the participants. Having the Elder begin the talking within the group interview in La Ronge resulted in much richer data, compared to the group interview at Little Red River when a breast cancer survivor began the interview process. I also had to ask additional questions after each individual finished their story, so that all the research questions were touched on by each person.

I re-introduced the storied structure in the analysis phase with the creation of the composite stories. I removed my questions and responses, along with hesitancy or repeated phrases such as 'um' and 'you know', and the stories of the participants began to emerge. I believe that creating the composite stories also added another layer of participant confidentiality into the research process by the removal of identifying characteristics and creating a story that attempted to represent the greatest number of participants as well as the variety of experiences that were shared.

The tape recorder was a double edged sword during my data collection. On one hand it allowed me to capture much richer data, but on the other hand it created a barrier and appeared to foster a preconceived notion of how the interview would progress. Once the tape recorder was turned on, the participants sat there and seemed to expect a question and answer session. There were several instances where participants appeared to have held back on responses such as Charlie, when he said, "*I almost said something but I better not since I'm being recorded*". He was laughing when he said it, but it did trigger the thought that perhaps others had withheld information because of the tape recorder. For future research, I believe I would continue to use a tape recorder for two primary reasons: the added richness of data including capturing the spoken Cree language and the memory triggers associated with the interview environment and non-verbal cues of the participant when I transcribed the interviews.

Clandinin and Connelly state that the researcher needs to spend extensive time in the field; to settle in, live and work alongside participants.⁷² This was not possible due to my life

circumstances. Spending a prolonged period of time in the community would naturally provide more opportunities for recruiting participants, especially with the snowballing technique. There would also be less time between the interview and review of transcripts, thus decreasing the likelihood of awkwardness and losing potential participants. Having the opportunity to spend extended periods of time in the community would have also decreased my travel expenses.

As previously mentioned, narrative inquiry is most often associated with educational and social sciences research; although it appears that this method is becoming more common in the health sciences. Overcash describes two studies that used narrative research; one study was conducted to help understand why many older people do not seek cancer treatment until they are in advanced stages of disease and another study investigated personal perceptions of health practice.⁶⁷ These two studies shared some similarities with my research, namely cancer and perceptions of health. Thomas-McLean also used narrative inquiry in her research with breast cancer survivors.⁷⁸ Perhaps one of the reasons why narrative inquiry is becoming better known in the field of health research is as Vizeau⁹⁴ (p.44) states “through stories, patients inform us about their experiences of health and transition; it has always been a part of how we explore the shared world of our patients.” Upon reflection, I am satisfied with the results I obtained using the narrative inquiry method.

6.2.1 Strengths and Limitations of Qualitative Research Results

One of the challenges of the health practitioner when it comes to evaluating qualitative research for applicability in their practice is what evaluative tools they are to use to assess the “goodness” of the research. Attempting to superimpose quantitative measures such as validity, generalizability, and reliability onto qualitative research isn’t appropriate, but at the same time there should be some indicators available for which one can use to judge the merits of qualitative research results. Emden and Sandelowski cite authors LeCompte & Goetz, as well as Lincoln & Guba as having made attempts in the earlier days of qualitative research to formulate evaluative measures that are strictly for qualitative research.⁹⁵ However, critiques of these proffered measures indicate that they are merely disguised quantitative measures and therefore, inappropriate for qualitative research. There remains the need for evaluative measures.⁹⁵

Clandinin and Connelly do not seem to be overly concerned with evaluative measures when it comes to narrative inquiry.

However, as previously mentioned, Spigelman insists that the researcher does not seek generalizability but rather the reader performs the act of generalization based on the density of detail, the selection of incidents, and the narrative skill of the researcher.⁶⁹ Furthermore Overcash⁶⁷ (p.182) states that “in terms of generalizations, the researcher must argue that those interviewed are somewhat representative of the study population.” With respect to my research, the participants are all Woodland Cree, they are a combination of male and female, the ages ranged from 27 to 83 and included Elders, cancer survivors and family members and they were from 5 different communities. I believe that this was representative of the population under study and did capture the diversity in experience and knowledge. Therefore, any recommendations derived from this research would likely be applicable to the Woodland Cree population of Northern Saskatchewan.

Sandelowski insists imposing validity testing is completely alien to narrative research and efforts to impose this testing “suggest a misplaced preoccupation with the empirical rather than the narrative standards of truth.” (Sandelowski⁹⁶ p.165). A more appropriate term that is used within qualitative research is trustworthiness.⁹⁷ Trustworthiness is how the researcher can persuade the reader that the results are worth paying attention to.⁹⁷ Trustworthiness is often defined by four aspects: credibility, transferability, confirmability and dependability.⁹⁷ In the case of qualitative research in general, credibility refers to the faithful description or interpretations of the lived experiences and the recognition of these experiences by the participants and others when confronted with it. Transferability refers to the probability that the findings have meaning to others in similar situations.⁹⁸ Confirmability is similar to leaving an audit trail, where the researcher explains in detail the processes he/she went through during the research project.⁹⁸ Dependability refers to the consistency and stability of the procedures to control how the data is collected and analyzed. Consistency in the interview techniques, questions, settings, length etc. tends to provide more similar reproducible results.⁶⁷ If I were to apply the concept of consistency to my data collection methods, it becomes apparent that I was inconsistent. My interviews were with one individual at a time, or with two people present or

with a group of four or more. The interview times varied from 20 minutes to 2 hours, the setting was also varied, including homes, office space in different clinics, a hotel room, and meeting halls. My method of data collection was also inconsistent, where I used a tape recorder, note taking, and field notes. However, this repeatability of data collection can also be viewed as establishing trustworthiness. I obtained data from three distinct groups of participants and I used three types of data gathering methods. In essence, I was using triangulation in my methodology. Triangulation of data collection is espoused to improve the trustworthiness and transferability of qualitative research findings.⁹⁹ I was also consistent in following the interview guides in the individual interviews and everyone had the opportunity to share their story in the group interviews. My emphasis was on getting as many interviews as I could and insuring that the participants were interviewed in comfortable surroundings. With respect to methodological rigor, I could have paid more attention to the process of consistency when I was in the field, but overall, I believe the methodology I followed ensured trustworthiness and transferability of my research findings. Confirmability is typically achieved when credibility, transferability and dependability are established. Engagement in the research and self reflection is thus part of the qualitative research process. Meaning emerges from reducing the distance between the researcher and what is investigated as illustrated in the next section.

6.3 I the Researcher

Situating myself within the writing provides the reader with the ability to see me as the researcher, the Woodland Cree woman, and the daughter of a cancer survivor. “Narrative makes a mutual world where reader, a community of readers, and storyteller meet to share in multiple realities using simple, human language in place of specialized jargon” (Vezeau⁶⁵ p.42). As an Aboriginal researcher who has maintained ties with her home community, I presumed that I would have relative ease of access for research purposes among members of my home community. I thought they would welcome me back and do all that they could to assist me. After all, I thought, my research was intended to help them. Alas, this was not the case. What actually transpired throughout the process of doing my doctoral research continues to be an enigma; a perplexing contrast between supposition and reality or perhaps between academia and community. I had chosen to work within my own Band, considering that I spoke the language and understood the culture and traditions.

When doing research with Indigenous communities, Smith (p.128) states that “in many projects the process is far more important than the outcome. Processes are expected to be respectful, to enable people, to heal and to educate. They are expected to lead one small step further towards self-determination.” Therefore, Smith recommends that Indigenous researchers must be good at defining clear research goals, and lines of relating, at developing skills to say ‘no’ and ‘continue’ and defining closure, in order to be ethical, respectful, reflexive, critical, and humble.

I had been following Fanon’s process of how ‘Native intellectuals’ return to their people before I even knew who Fanon was. I was introduced to the works of Fanon along with other Indigenous writers in a cross cultural research class I took from Dr. Verna St. Denis as part of my course work. Frantz Fanon, a descendent of African slaves, was a French psychiatrist and revolutionary writer who wrote about the effects of colonial repression and culture trauma.¹⁰⁰ Fanon identified 3 phases that individuals will/should go through: 1) assimilation, 2) disturbance and remembering who they are and 3) realigning themselves with their people and producing revolutionary and national literature.¹ The assimilation is something I have been going through since the early age of 6 when I was sent to the Prince Albert Indian Residential School. My love of learning continued the assimilation process as I repeatedly left my home community to continue my education, leading me from a chemical laboratory technician certificate to a nursing degree to a masters and doctoral degrees in community health and epidemiology. The shift into the second phase began in nursing school where I started to realize that in order to successfully complete my nursing degree I would have to shed my Cree cultural coat and don the Western medical white lab coat. I inherently knew that this wasn’t the way it should be but lacked the self esteem and conviction to fight for my right to live by my Cree values and beliefs. Upon completion of my nursing degree, I slipped my Cree coat back on and began working with Aboriginal people, living and working within the two paradigms. When I returned to graduate school, I quickly began to see a difference in the type of learner I was invited and expected to be: I was valued for who I was, a Cree woman who had previous knowledge. The shift into Fanon’s third phase, realigning myself with my community, began to emerge during my doctoral work, particularly after taking St. Denis’ class. Ermine’s ethical space framework¹⁰¹ assisted me further in making the transition from a colonialist-educated researcher to an Aboriginal

researcher who chose to combine Western and Aboriginal paradigms and pedagogies. Ermine's premise is through the purposeful disconnection and contrasting of the Western and Indigenous cultures and worldviews, the intent is then to reconnect the entities with the notion of a bridging concept called the 'ethical space.'¹⁰¹ Through personal conversations with Ermine, I began to understand that I am a bridge between Western research and my community. Furthermore, my allegiance must always be first and foremost, to my community. And so being firmly ensconced in the ethical space, I took my proverbial toolbox of Western methodologies and ethical protocols in hand, and departed on my research journey back home.

Operating on the assumption that I would encounter the greatest number of individuals wanting to participate in my home community of Stanley Mission, I went there first. For participant recruitment, I put up posters in every location that people would likely see it. The health clinic offered me 30 minutes to talk about the project at a Community Diabetes Education Day where I also set up a display table with pamphlets from the Canadian Cancer Society. I talked to all the clinic staff members, asking for referrals of potential participants, explaining that the University of Saskatchewan's ethics protocol prohibited me from contacting potential participants directly. I talked to people who came into the Health Clinic, informing them about my research project. I began to feel like a piranha, waiting for unsuspecting prey. Everyone I spoke to was very supportive of what I was doing but no volunteers came forward to be interviewed.

Through a process of self reflection, journaling and discussions with my dissertation supervisor and committee members, Elders and colleagues, certain possibilities began to emerge that could explain the lack of response I received from cancer survivors and family members in Stanley Mission. I don't believe there is one definitive explanation for what happened, but as with most things there were multiple possible explanations including the following. There is no doubt that my home community, along with the entire band membership, is proud of me for pursuing my doctoral degree, but this, I feel is more of a tribal pride, a community pride. At the individual level, perhaps community members did not feel comfortable and may have felt they were putting themselves at risk by talking with me about such a sensitive topic. Cancer is a sensitive topic, difficult for people to discuss. This was affirmed by one of the interviewees from

one community: *“I think it’s becoming to be more prevalent, I don’t know, I think, we hid in the closet, you know and now it’s coming out, just like dung beetles, you know, and I guess there’s people don’t like talking about it,”*

Small communities are usually hubs of gossip and everyone in the community knows when someone has cancer. Perhaps individuals felt that an interview with me would further compromise their perceived sense of privacy. When asked why people weren’t coming forward to talk to me, one Elder suggested that community apathy might have been a factor. *“I don’t know why nobody will talk. And they do that anyway, these people, when they are summoned to go somewhere, they don’t go. Even when there are meetings, hardly anyone goes anymore.”*

The conflicting values between Western research ethics and community expectations are another possible factor. The ethical guidelines defined by the University of Saskatchewan Behavioural Research Ethics Board stated that while I could not approach potential participants directly, I could use a community liaison to speak to possible participants on my behalf. But I could not find an appropriate liaison within the health clinic because staff felt there was no reason why I couldn’t just go to the individual’s house and ask each one myself. This was also reflected in the Elder’s comments. When asked why she thought people weren’t coming forward, she replied, *“maybe they are just waiting for you to go see them, to talk to you.”* Furthermore, the two most frequent names mentioned to me by various people in the community were the two individuals with terminal cancer. I was extremely uncomfortable with the prospect of *barging* in at a time of family and personal grieving to seek information for what, at the outset, would be for my personal gain. But along with the ethical conflict between the University of Saskatchewan’s ethical guidelines and the community member’s suggestions was my research protocol of wanting to interview cancer survivors. In retrospect, perhaps the people with terminal cancer would have appreciated an opportunity to talk with someone about their illness and their lives.

My separation from the community may also have contributed to the situation. I have been living off reserve for the past fifteen years only going home for visits on long weekends and holidays. Had I been absent from the community for so long that I had lost my sense of

belonging and therefore was no longer trusted to keep the best interests of the community at heart?

Perhaps, as Smith suggests, my home community could not accept me in the double role of researcher and community member.⁵³ Regardless of the possible reasons why few participants came forward, I personally felt betrayed and hurt. After all, I reasoned, I wasn't doing this for my personal benefit; I was doing this ultimately to help the community, to increase the awareness of cancer, the treatment options, and to have an impact on health policy for future cancer care.

Therein lays the crux of the recruitment problem: the community had not brought this health issue forward. It had not identified or prioritized cancer as one of the areas of importance. *I* felt it was important and *I* expected cooperation so that *I* could elucidate the importance of it. The fact that my mother was a cancer survivor and I had walked with her on parts of her healing journey had been the impetus for my research path. In wanting to get a broader understanding of the impact cancer has on individuals and communities, I embarked on my doctoral research. But in the process, had I ultimately let down my community at the most crucial juncture, by not allowing them to decide what they wanted to be researched and working with them from the outset in determining a topic of research?

However, if I had not gone ahead with *my* research topic, the voices of the participants may never have been heard. The stories they shared were heart-wrenching, illuminating and profound and have forever changed me, both as a person and as a researcher. Throughout my research journey I encountered many crossroads, diversions, and road blocks but I have come to realize that I have not been alone on this journey; my research participants have agreed to walk with me. My responsibility now lies in ensuring that their stories are allowed to touch others' lives, including my home community, members of my Band, Aboriginal communities and others.

Perhaps my home community could not accept me in the double role of researcher and community member, but being Aboriginal and being able to speak my native language did open doors in the other five communities and I was made to feel welcome. Relational identification

was also a factor. The Elders in the other communities would ask who my parents and grandparents were as if to situate me within their relational space. This relational identification became especially relevant in one community where most of the families had been part of my home community two or three generations ago and their responses were very warm and welcoming.

Aboriginal researchers will continue to have challenges researching in their home communities, and finding the balance between Western and Aboriginal world views, paradigms and pedagogies. My experience is only one example of possible outcomes. It certainly wasn't the one I expected but it has been a tremendous learning opportunity.

6.4 Recommendations

6.4.1 For Healthcare Providers

This study delved into the relatively unknown areas of health, illness and cancer experiences of the Woodland Cree in Northern Saskatchewan. This population is a fairly small section of the Indigenous population in Saskatchewan and the overall general population. Therefore, any recommendations that are offered are primarily for those health sectors that provide services to the Woodland Cree. Ward et al. make the recommendation that in order to provide culturally appropriate care, cultural attitudes towards illness and death between health care practitioners and their patients and families must be understood.²⁸ This study began the process of eliciting the cultural attitudes towards health and illness among the Woodland Cree, specifically in relation to cancer. The Woodland Cree have adapted both their traditional knowledge systems and the Western medical knowledge systems in defining their concepts of health and illness. Therefore, any program development must also use a combination of both systems if there is to be any measure of success. In addition, the Elders are the knowledge keepers and health care practitioners need to seek and adhere to their input and advice.

The highest response (22%) for proposed solutions to the health problems of aboriginal people in Canada from the 1991 Aboriginal Peoples' Survey were increased education and information⁶ and this was also applicable in the current study. Several participants recommended increased awareness and education and appeared to be one of their primary incentives to

participating in this study i.e. “*I hope that it educates somebody else*” (Veronica). Another participant requested as much information on cancer as I could provide. Patricia also wished that she had known what the stages of dying were, so that she could have spent more time with her family member during the last hours and days. There is a definite need for more public education and awareness among the Woodland Cree in the area of cancer knowledge, awareness and palliative concerns. Health care practitioners also need to be provided with updated epidemiological data and their awareness of cancer as a possible illness entity has to be intensified. The findings of this research can also help educate health care practitioners on the Woodland Cree understanding of cancer, the metaphor of *munchoosuk* can become a powerful teaching tool in bridging the two knowledge systems. Cancer is a debilitating phenomenon even before it is diagnosed. Individuals should not have to struggle to be heard by the health care practitioners.

The next highest response in the 1991 Aboriginal Peoples’ Survey was better service access and counseling.⁶ Access to appropriate services once diagnosed with cancer did not appear to be an issue within this study. Having to leave the home community and travel long distances for treatment was the most commonly identified challenge. I am aware of several First Nations organizations that have created hostels in large urban centers for their community members that have to travel south for treatment. Considering the First Nations bands in Northern Saskatchewan have successfully partnered together, i.e. Prince Albert Grand Council and Northern InterTribal Health Authority, the political and administrative structure is already there to investigate this option. A First Nations operated hostel in Saskatoon would certainly be capable of providing culturally appropriate living arrangements so that individuals like Patricia’s family member would not have to live in hotel rooms for extended periods of time. Having someone to talk to in your first language would also decrease the sense of social isolation experienced by participants in urban treatment centers.

Support services for family members including counseling were another identified need in this study. Family members felt that there was no place to turn to for additional help, no one they could talk to during their grieving. The emotional toll on family members was heavy so there needs to be support provided for families.

Patricia suggested a traveling hospice unit could have made their situation easier, especially when it came to administering medications. Many First Nations families, not only the Woodland Cree, want to take care of their family members in their homes for as long as they can. The health care system should foster this desire, it will not only ease the anxieties of the family but it will also ease the financial burden of hospitalization. Talking about death and dying appeared to be an uncomfortable topic with the participants, however, open discussion can sometimes ease anxieties and concerns, and perhaps create a safe environment for the family member who is dying to talk openly with others. We, as health care providers have to become more comfortable in talking with our clients regarding all life stages and processes. Palliative care training such as the *Responsive Hospice Palliative Care with Aboriginal Clients in Rural and Remote Settings* program, designed by Gaye Hanson and Michael Aherne along with development of a palliative care team could be initiated as part of the services provided by the reserve health clinics.

Cancer screening programs for breast and cervical cancer are provincially operated in Saskatchewan and appear to be attempting to capture their at-risk population to the best of their ability. The Saskatoon Mammography Unit approached me several years ago to translate their information packages into Roman Orthography, a form of written Cree using the English alphabet. I did the translation but informed them that if anyone can read Roman Orthography, they can also read English. I believe what would be more beneficial is providing oral translations, which could be audio or video-recorded and played for people. The traveling mammography screening bus does go to the north every other year; however, low participation is sometimes an issue. Orians et al (2004) identified the importance of personal reminders for women due for screening appointments.⁸ Brenda experienced fear and anxiety upon receiving repeat letters in the mail to go for a mammogram, she thought *they* knew something she didn't, and her fear was also exacerbated by the fact that her mother had been diagnosed in the advanced stages of cancer and passed away within 5 months. Depending on the written form of communication isn't necessarily the best option when working within First Nations populations. Screening programs need to come up with alternative strategies, such as radio and television commercials. Furthermore, all of the breast cancer survivors had found the lumps in their breasts themselves. Breast self examination needs to be taught at a wider level and starting with younger

age groups. Those individuals at highest risk of breast cancer are probably ones that would feel uncomfortable touching themselves, and consequently, culturally sensitive health promotion messages need to be offered.

High levels of traditionalism were found to correlate with healthier lifestyles among Hopi women including less likely to smoke, less likely to drink alcohol and to be obese.³¹ Perhaps if communities were to re-institute their traditional activities and way of life, this would lead to healthier lifestyles and decrease risk factors for cancer. Cancer survivors certainly reported that they were trying to live more traditionally as a prevention strategy for recurrence of cancer and Elders expressed their belief that the traditional lifestyle was much healthier. It is perhaps unreasonable to re-institute the nomadic lifestyle of hunting and trapping, but there can be altered activities introduced into communities. For example, the one week cultural camps the school children attend in Stanley Mission is an excellent program but students can only go twice during their school years, once in Grade 5 and again in Grade 8. Two weeks within a 13-year timeframe does not come close to approximating the traditional lifestyle.

The close association between Western medical therapies and traditional Cree medicine indicates the level of importance the Woodland Cree place on both knowledge systems. The physician being the first point of contact when it comes to suspicious health concerns shows a high level of respect for the Western medical system. In the spirit of reciprocity, those health professionals trained according to the Western medical system, should show the same respect for traditional Cree medicine. There needs to be more collaboration and cooperation between traditional and Western medical systems and practitioners in the efforts of improving the health status of First Nations people.

Tobacco use in First Nations communities has been reported to be as high as 62% compared to 23% in the general population.² Tobacco is one of the four traditional medicines but today there is rampant abuse of this medicine, and this is a population health dilemma right across Canada. I also saw ample evidence of this abuse during this study. Two participants admitted that they had resumed smoking as a method of coping during their family cancer crisis, despite the fact that one of them had a family member with lung cancer. Elder John Cook stated

strongly that tobacco was the absolute worst thing as he pointed to his can of chewing tobacco. You enter a health clinic and health care workers are sitting or standing by the outer door smoking. Bertha, a cancer survivor insisted that she did not believe there was a connection between smoking and cancer and continues to smoke to this day. George informed us that children will copy their parents so even with tobacco prevention messages aimed at the youth; they may be getting stronger signals from their parents, grandparents, aunts and uncles. The underlying issue isn't as simple as tobacco abuse and chemical addiction; it is a multitudinous layer of social, economic, cultural and spiritual degradation arising from colonialism. Battiste and Henderson ¹⁰² (p.13) state that "colonization brought disorder to Indigenous peoples' lives, to their languages, to their social relations, and to their ways of thinking about, feeling and interacting with the world." Unfortunately, the effects are not going to be mitigated any time soon. The process of healing and decolonization will be long and difficult, healing at the individual, family and community levels need to occur so that at some point in the future, tobacco, alcohol, drugs, gambling and food will not be necessary to dull the generations of accumulated pain.

6.4.2 For Researchers

Being an Aboriginal researcher does not necessarily imply easier access to communities. The dynamics of researching with Aboriginal communities are vastly different from researching within other environments. Community access is more process oriented and developing trust at the community level is a crucial factor. An important first step is initiating contact with key informants, who may also happen to be the Elders in the community. As previously mentioned, Elders are the knowledge keepers in Aboriginal communities and as such they should be the primary participants in any research project; they will provide a baseline reference point from which to proceed. They may also hold a position of such high esteem that if they do not agree with the intents of the research project, then the research will not be successful in meeting its objectives.

The Elders, as well as other community members, including Chief and Council need to feel that their concerns are being heard and they have a say in what type of research is going on in the community. With this in mind, the researcher should first approach the Aboriginal

community to gain ethical approval prior to applying for ethical approval at the educational institutional level. The responses I received from clinic employees and community members at Stanley Mission was an indication that my behaviour towards approaching potential participants should have been revamped to respond to what I was hearing. My first commitment should have been to the ethical expectations of the community, not those prescribed by the University of Saskatchewan ethics board. Researchers need to be open to suggestions from community members and make suitable revisions to the educational institutional ethics protocol.

The researcher needs to be adept at creating welcoming environments for potential participants and creativity is a crucial element when doing research within Aboriginal communities. Individuals often feel more comfortable in a group setting when strange and new processes are unfolding. This was evident in the group interviews at La Ronge and Little Red River. A group setting allows community members to support each other. Food is an important cultural activity within Aboriginal communities and researchers should keep this in mind whenever they are in a group setting; providing refreshments when initiating a group meeting is a requirement of the researcher. Refusal of offers of refreshment when visiting participants in their home will be seen as rude and inappropriate behaviour, which will start off the interaction on a negative note. Living within the community over a prolonged period of time during the data collection phase will also help to establish trust at both the community and individual levels.

6.5 Further Research

It was hoped that with an increased understanding of the perceptions of cancer, more appropriate cancer screening and cancer education programs could be developed so that early detection and subsequently cancer survival rates would improve among Aboriginal populations in northern Saskatchewan. This expectation appears to have been too broad for the study population. The Woodland Cree have specific cultural and world views, and these will not necessarily be shared by the Métis and the Dene populations. Further study will be needed to explore the perceptions of other Aboriginal populations.

Mammography screening and cervical screening are provincial prevention strategies and appear to be doing an effective job in identifying and notifying their at-risk population, although

there appear to be low participation rates in some communities and research in this area is needed to determine potential factors. Canales and Geller identified four factors that affect the mammography screening decisions of American Indian women in Vermont; connecting to native identity, taking care of self, financial implications and trust issues with the health care system.¹⁰³ Perhaps three of the four identified factors would be applicable among the Woodland Cree, the exception being financial implications because of the health care coverage differences between Canada and the United States.

This study looked primarily at participants that lived on reserves. There is a need for future research to look at participants that live in urban areas. One study out of Arizona identified urban American Indians as having higher rates of smoking, binge and chronic alcohol drinking, higher rates of obesity and lower rates of physical activity.¹¹ The inference is that those that leave the reservations lose their traditional activities and ways of living which will have an impact on their lifestyle. The loss of their home community will also likely have a negative impact on their life overall. However, in the area of cancer, one would think that living within the urban setting, where most cancer treatment occurs, would improve access to services. There will likely be different issues related to cancer care for urban First Nations and it would be interesting to see if there are commonalities with the results of this study.

Healthier lifestyle is a health promotional mandate and the issue of the high rates of tobacco use in Aboriginal communities is an area for further research. Hodge and Caskin identified a lenient community and individual attitude among American Indians in northern California towards tobacco use.¹⁰⁴ Anecdotal evidence suggests that this is also the case in Aboriginal communities in Saskatchewan; especially with the Federation of Saskatchewan Indian Nations recent decision to allow smoking in First Nations' run casinos despite a province wide ban on smoking in public places. As previously mentioned, this area is fraught with complex issues and further research will by necessity need to be broad and inventive.

6.6 Conclusion

This study was qualitative by design because one of the intents was to perform an initial foray into the understandings of health, illness and cancer among the Woodland Cree. The next

phase for my research is to develop a survey instrument based on the themes generated from this research, to assess similarities and differences in perceptions of cancer among other First Nations and Métis populations. One of my goals will continue to be to assist health care practitioners to provide culturally appropriate education, promotion, prevention and cancer care strategies for Aboriginal populations in Saskatchewan. Having completed a quantitative based master's thesis and now a qualitative based doctoral thesis, I have the skills of both research paradigms and since I am becoming proficient in bridging paradigms, world views and pedagogies, mixed methods research seems like a logical next step.

There have been many personal benefits that have arisen from this research study including reconnecting with my heritage, my home community, and my Elders. Perhaps the most beneficial has been the renewed and strengthened sense of pride in who I am and where I have come from. My name appears on the face of this document but I am being supported and pushed forward by untold generations of strong, resilient and creative *Nihithowuk!*

Appendix 1

Elders Interview Guide

Interview Guide:

1. Basic demographic questions of age, gender, educational level, interviewee category of cancer survivor, family member of cancer survivor, Elder, or community member, preferred language to be spoken during interview.

2. Questions regarding health and illness:
 - What does it mean to be healthy for you? For the community to be healthy?
 - What kind of things do you do to stay healthy? What kind of things does the community need to do to become healthy or to stay healthy?
 - What kind of things did people do in the old days to stay healthy? What has changed?
 - What does it mean to be sick for you? What causes people to become sick?
 - What do you do when you are sick?
 - Who do you go see? Anybody else?
 - What kind of things do you do to make yourself well again?
 - What did people do in the old days when they got sick?
 - Do you still follow any of the old ways? Would you like to tell me about them?

3. Questions regarding cancer:

What do you know about cancer? Cause? Treatment? Prevention?
Is there a word for it in Cree? What does it mean?
Did people get cancer in the old days? How did they know? Did they get treated for it?
How many people do you know that have had cancer? What happened to them? Do you think there are more people getting cancer?
How do you feel when you hear that somebody has cancer?
How do you think you'd feel if you were told you had cancer?
Is there anything that can be done to prevent more people from getting cancer? If yes, what kinds of things?

Community and Elder responsibilities:

- What role/s does traditional healing have with people who have cancer?
- What role/s does the health care system have with people that have cancer?
- What responsibilities does this community and its members have where cancer is concerned?
- What responsibilities do Elders such as yourself have where cancer is concerned and for keeping the community healthy?

Appendix 2

Cancer Survivors Interview Guide

Interview Guide:

1. Basic demographic questions of age, gender, educational level, interviewee category of cancer survivor, family member of cancer survivor, Elder, or community member, preferred language to be spoken during interview.

2. Questions regarding health and illness:

- What does it mean to be healthy for you?
- What kind of things do you do to stay healthy?
- What does it mean to be sick for you?
- What do you do when you are sick?
- Who do you go see? Anybody else?
- What kind of things do you do to make yourself well again?
- What kind of things did people do in the old days to stay healthy?
- What did people do in the old days when they got sick?
- Do you still follow any of the old ways? Would you like to tell me about them?

3. Questions regarding cancer:

Tell me about your cancer experience? Type? Age? Treatment? Current status?

How did you feel when you were told you had cancer?

What did you know about cancer before you got it?

What do you know about cancer now?

How many people do you know that have had cancer? What happened to them? Do you think there are more people getting cancer?

How do you feel when you hear that somebody has cancer?

Who do you talk to about your cancer illness?

Do you think there was anything you could have done to prevent you from getting cancer? Was there anything you could have done to get diagnosed earlier?

Are there things that can be done to prevent other people from getting cancer?

4. Integration of cancer in world view:

Will cancer always be a part of your life? If yes, in what way?

What kinds of things do you do now to prevent getting cancer again?

What has happened to the way you think of life since you had cancer?

Do you do different things now to stay healthy? What about when you get sick?

Appendix 3

UNIVERSITY OF SASKATCHEWAN
BEHAVIOURAL RESEARCH ETHICS BOARD
Application for Approval of Research Protocol

1. **Supervisor:** Anne Leis, PhD, Department of Community Health & Epidemiology
- 1a. **Ph.D. Student:** Rose Roberts, RN, MSc, Department of Community Health & Epidemiology
- 1b. **Anticipated start date:** September 2003
Expected completion date: August 2005
2. **Title:** Stories about Cancer from the Woodland Cree of Northern Saskatchewan
3. **Abstract:** As more Aboriginal people survive into their 70s and 80s, there is also the increased risk of chronic diseases such as cancer that accompany this increased life expectancy. The incidence rates for cancer have increased by 100% in a 20 year period in Northern Saskatchewan, while the survival rates continue to be below those of the general Saskatchewan population. The purpose of this study is to find out the perceptions, attitudes and cultural world view of cancer among the Woodland Cree in Northern Saskatchewan, through narrative inquiry research methods. The research questions will be based around the domains of culture, psychosocial aspects, and spirituality. Interviewees will consist of cancer survivors and their family members, Elders, and community members of the Lac La Ronge Band. The communities of La Ronge, Stanley Mission, Grandmother's Bay, Hall Lake and Little Red River will be invited to participate. The interviews will be 1.5 hrs long, with a possibility of another interview if everything is not covered in the first interview. They will be taped unless the participants say otherwise. There will be another visit of approximately 1 hour to review the transcripts. It is hoped that the research will dispel the fear and shame associated with cancer within these communities. Other anticipated outcomes include culturally appropriate cancer education programs and increased rates of cancer screening participation.
4. **Funding:** N/A
5. **Participants:** The researchers hope to recruit at least 5 cancer survivors, 5 family members, 5 Elders and 5 key community members into the project. The participants will be interviewed in 1-2 sessions of approximately 1.5 hrs each. Recruitment and advertising of the research project will be accomplished through posters, newspaper and radio ads in both English and Cree. A community meeting will be held in each community to introduce the project and interested participants will be told how to reach Rose Roberts. Further recruitment will be accomplished through the health clinics, where the Health Director or Nurse in Charge will be asked to identify and speak to cancer survivors and their family members to see if they would like to participate in the study. If they agree, Rose Roberts will ask the Health Director or Nurse-in-charge to accompany her on the initial visit to facilitate introductions.

Rose Roberts is originally from Stanley Mission but has lived off-reserve for the past 15 years. Any participants of close familial relationships from Stanley Mission will not be included in the study.

- 5a. The Committee will require a sample copy of all recruitment material (i.e., posters and advertisements) only if the research project was originally designated as above minimal risk.
6. **Consent: Describe:**
- i. The participants will be responsible for getting hold of the researcher and agreeing to participate in the study. After agreeing to a suitable location for the interview, the researcher will describe the research project and will explain the consent process. If the participant does not have any literacy issues, they will be asked to read and sign the consent form (Appendix 1). If the participant does not speak or read English, then the consent protocol (Appendix 2) will be followed.
 - ii. The participant will be asked if they feel okay with the interview and its progress after the first 15 minutes. They will be reminded that they can withdraw at any time if they feel uncomfortable in any way.
- a) The consent protocol (Appendix 2) will be followed if the participant is uncomfortable communicating in the English language. The language preference will be the participant's.
 - b) Consent to access the communities will be through several organizations. Rose Roberts is a member of the Lac La Ronge Band and she has already initiated discussions with the Chief, several councilors and the health directors for La Ronge and Stanley Mission on the applicability and credibility of this proposed research project. She has received enthusiastic responses from all. A formal approval process will be initiated which will comprise of a presentation to Chief and Council, followed by presentations to the Health Committees for the communities of La Ronge, Stanley Mission, Grandmother's Bay, Little Red River and Hall Lake. Letters to Chief and Council of the Lac La Ronge Band and a form letter for the Health Committees are included (Appendix 3 and 4).
7. **Methods/Procedures:**
- a) Permission to proceed with the research project from Chief and Council and the Health Committees.
 - b) There will be community presentations given on the research project and volunteers will be sought at each meeting. An information sheet with a contact number for the researcher will be given to each person who attends the presentations. In addition, the health committees, health directors and nurses will be asked to identify and speak with potential participants on behalf of the researcher. Potential participants will also be provided with an information sheet with a contact number for the researcher.
 - c) Once the potential participant contacts the researcher, a suitable place will be agreed upon to meet. After introductions are made, the consent process will be reviewed and either verbal or written consent obtained. The participant will be asked if they are comfortable with having their conversation recorded. Their response will determine whether the tape recorder will be used or not. If the interviewee does not want the conversation taped, then the researcher will make field

notes. The interview guide will depend on who the participant is (see Appendices 5, 6, 7&8). The amount of information received in the first interview will determine if a second interview is necessary.

d) The researcher will return for another visit once the interview has been transcribed and review the transcript with the participant. At that point the transcript release form will be signed or the transcript release protocol will be followed if the participant is non-English speaking.

8. **Storage of Data:** The storage of all data will be in a locked cabinet in accordance with the University of Saskatchewan regulations under the supervision of Dr. Anne Leis in the Department of Community Health & Epidemiology for a period of 5 years.
9. **Dissemination of Results:** The data will be used for the doctoral dissertation of Rose Roberts. Other potential uses include community presentations, conference presentations and journal articles.
10. **Risk or Deception:** There is the potential risk of the participants experiencing painful memories related to family members who have passed away due to cancer, or to current cancer survivors remembering their illness. There is also the potential risk that cancer survivors will have an increased level of fear related to the thought of reoccurrence when talking about their cancer. The participants will be given opportunities to discontinue with the interview if the researcher receives any indication of unease by their body language. The researcher will ask if there is anyone that she can contact for the participant if they are upset or if there is anything she can do to help.
Rose Roberts is familiar with the cultural orientation of the Woodland Cree and the northern communities they are from. Therefore, she knows that there will be language barriers between the participants and health professionals who could provide counseling services and would not likely access their services. Elders do not have the same reverence or roles as counselors in these northern communities as they do in southern First Nations communities, therefore, accessing them for support would not be appropriate. There is also an aspect of fear and shame associated with cancer; this has prevented the establishment of cancer support groups. However, the researcher will provide names and numbers of health professionals or lay community workers who are employed in the local health clinics that can be contacted for support.
11. **Confidentiality:** Only Rose Roberts and the supervisor, Dr. Anne Leis, will know the identification of participants. Pseudonyms will be assigned to each participant unless the participant is an Elder and requests that their real name be used. There have been instances where Elders want to be acknowledged for information they have provided to researchers. Parts of the data will be reported in aggregate form but there will be some direct quotations, for which a pseudonym will be used and any other identifying information removed. Due to the small size of the participating communities, there is a possibility that someone reading the findings will be able to identify participants, therefore, each participant will be notified of this possibility at the time consent is sought.

12. Data/Transcript Release: For all taped interviews, each participant will be provided with the opportunity to review their transcript and asked to sign a transcript release form (Appendix 9) if they are comfortable communicating in the English language. Verbal consent will be sought if the participant prefers to communicate in Cree. The protocol used for the transcript release is outlined in Appendix 10.
13. Debriefing and feedback: Once the formal interview is completed, the researcher will spend some time talking about the interview and how it went. The participant will be asked how they feel and if the interview elicited any unpleasant memories or feelings. The participant will be informed that they can contact the researcher if they have anything else to add to the interview. The researcher will inform the participant that she will return with the transcript at a later time to make sure they are comfortable with what they have said. She will also inform the participant that she will be providing preliminary findings at community gatherings and that the participant will also be provided with a summary of the final results of the research.
14. Required Signatures:

Dr. Bruce Reeder
Department Head
Community Health & Epidemiology

Dr. Anne Leis
Supervisor
Community Health & Epidemiology

Ms. Rose Roberts
Student

15. Contact Name and Information:
Dr. Anne Leis
Department of Community Health & Epidemiology
Rm 2732 Royal University Hospital
103 Hospital Drive
Saskatoon, SK S7N 0W8
Ph: 306-966-7878
Fax: 306-966-7920
Email: Leis@usask.ca

Appendix 4

CONSENT FORM

*You are invited to participate in a study entitled **Stories about Cancer from the Woodland Cree of Northern Saskatchewan**. Please read this form carefully, and feel free to ask questions you might have.*

Researcher(s): Rose Roberts (Doctoral Student), Department of Community Health & Epidemiology, University of Saskatchewan, ph: 306-966-6232 ; fax: 306-966-6703.
Dr. Anne Leis (Supervisor), Department of Community Health & Epidemiology, University of Saskatchewan, ph: 306-966-7878 fax: 306-966-7920

Purpose and Procedure: The purpose of this study is to collect stories about cancer, health and illness as experienced by the Woodland Cree of which you are a member. You will be interviewed once, with a possibility of another interview if all the questions cannot be answered in the first interview. The time expected of you will be approximately 1.5 hours for each interview and another hour to review the transcript and provide feedback at a later time.

Potential Risks: There is the possibility that talking about cancer will invoke unpleasant memories and feelings, especially if you have lost a close family member or you have had cancer yourself. If you would like to stop at any time because of this, we will. If you would like, we can continue at a later time or you have the right to withdraw from the study and we can stop the whole interview and your information will not be included in the data if you so wish.

Potential Benefits: Through the telling of your story you may feel a sense of relief and a sense of accomplishment and sharing, knowing that your story may help others face cancer knowingly. Your story may help healthcare workers provide better care for Woodland Cree people that have cancer and may also assist health educators to develop cancer education material that is suitable for the Woodland Cree. These benefits are not necessarily guaranteed.

Storage of Data: According to the University of Saskatchewan's guidelines for storage of data, all of your information will be kept in a locked cabinet for a period of five years under the supervision of Dr. Anne Leis at the Department of Community Health & Epidemiology. Your information will not be used for any other purpose other than what is stated above and after 5 years all of your information will be destroyed.

Confidentiality: The information you provide will be used for the doctoral dissertation of Rose Roberts and the findings will be published in a thesis as well as the probability of being published in scientific journals and presented to the Lac La Ronge Band Chief & Council, Health Committees and Health Regions. Parts of the data will be reported in aggregate form but there will be some direct quotations which will have a pseudonym unless you decide that you would like your real name to be used. Your transcriptions, tapes and files will be assigned an identification code which will be known only to Rose Roberts and her supervisor. Due to the small size of your community, there is a possibility that someone reading the findings may be able to identify you.

Right to Withdraw: You may withdraw from the study for any reason, at any time, without penalty of any sort. If you withdraw from the study at any time, any data that you have contributed will be destroyed if you so wish.

Questions: If you have any questions concerning the study, please feel free to ask at any point; you are also free to contact the researchers at the numbers provided above if you have questions at a later time. This study has been approved on ethical grounds by the University of Saskatchewan Behavioural Sciences Research Ethics Board on (insert date). Any questions regarding your rights as a participant may be addressed to that committee through the Office of Research Services (966-2084). You will be provided with an opportunity to review your transcripts and Rose Roberts will be making community presentations of the preliminary findings. You will be provided with a personal copy of a summary of the main findings.

Consent to Participate: I have read and understood the description provided above; I have been provided with an opportunity to ask questions and my questions have been answered satisfactorily. I consent to participate in the study described above, understanding that I may withdraw this consent at any time. A copy of this consent form has been given to me for my records.

(Signature of Participant)

(Date)

(Signature of Researcher)

(Date)

Appendix 5

Transcript Release Template

I, _____, have reviewed the complete transcript of my personal interview in this study, and have been provided with the opportunity to add, alter, and delete information from the transcript as appropriate. I acknowledge that the transcript accurately reflects what I said in my personal interview with Rose Roberts. I hereby authorize the release of this transcript to Rose Roberts to be used in the manner described in the consent form. I have received a copy of this Data/Transcript Release Form for my own records.

Participant

Date

Researcher

Date

Appendix 6

Consent Protocol

1. The participant will be asked if he/she can read English. If he/she responds negatively, then the researcher will proceed with the protocol for verbal consent.
2. The participant will be spoken to in Cree and the consent form will be translated as closely as possible.
3. The researcher will ask periodically if the participant understands and if he/she has any questions.
4. Following the translation of the consent form, the researcher will ask the participant if he/she agrees to participate with the research.
5. The participant will be deemed to have agreed with a reply of yes in either English or Cree and the interview will proceed.

Appendix 7

Letter to Chief and Council

Chief & Council
Lac La Ronge Indian Band
Box 480
La Ronge, SK.
S0J 1L0

Re: PhD Research Proposal

Dear Chief & Council;

My name is Rose Roberts and I am originally from Stanley Mission, although I have lived off-reserve for the past 15 years. As you may know, I am in the process of obtaining my doctoral degree through the Department of Community Health & Epidemiology, at the University of Saskatchewan. One of the requirements is the completion of a thesis and I would like my research to benefit members of our Band.

I would like an opportunity to present my PhD thesis proposal at the next meeting of Chief and Council for your review and approval. Following the presentation to Chief and Council, I will also be presenting to the separate Health Committees of La Ronge, Stanley Mission, Grandmother's Bay, Hall Lake and Little Red River for their approval.

There are more and more Aboriginal people getting cancer and although non-Aboriginal people are surviving longer, this is not the case with Aboriginal people. I would like to look at cancer perceptions among the Woodland Cree, mainly members from our Band through personal interviews with cancer survivors, family members, Elders and any interested community members.

I am hoping that through my research, health care providers will be able to design cancer prevention programs that are culturally suitable to the Woodland Cree. I am also hoping to find out why Aboriginal people have lower cancer survival rates and what we can do to increase the survival rates.

I look forward to your response.

Sincerely,

Rose Roberts, RN, MSc
Ph: (306) 966-6232
Fax: (306) 966-6703

Appendix 8

Letter to Health Committees

Health Committee
Lac La Ronge Indian Band
Box 480
La Ronge, Sask
S0J 1L0

Re: PhD Research Proposal

Dear Health Committee Members;

My name is Rose Roberts and I am originally from Stanley Mission. I am in the process of obtaining my doctoral degree at the Department of Community Health & Epidemiology, at the University of Saskatchewan. One of the requirements is the completion of a thesis and I would like my research to benefit members of our Band.

I would like to know if I could have the opportunity to present my PhD thesis proposal at your next Health Committee meeting for your approval. I have already presented this proposal to Chief and Council and I have received their approval for me to proceed with this next phase.

There are more and more Aboriginal people getting cancer and although non-Aboriginal people are surviving longer, this is not the case with Aboriginal people. I would like to look at cancer perceptions among the Woodland Cree, mainly members from the La Ronge Band through personal interviews with cancer survivors, family members, Elders and any interested community members.

I am hoping that through my research, health care providers will be able to design cancer prevention programs that are culturally suitable to the Woodland Cree. I am also hoping to find out why Aboriginal people have lower cancer survival rates and what we can do to increase the survival rates.

I look forward to your response.

Sincerely,

Rose Roberts, RN, MSc
Ph: (306) 966-6232
Fax: (306-966-6703

Appendix 9

Community Member Interview Guide

Interview Guide:

1. Basic demographic questions of age, gender, educational level, interviewee category of cancer survivor, family member of cancer survivor, Elder, or community member, preferred language to be spoken during interview.

2. Questions regarding health and illness:
 - What does it mean to be healthy for you?
 - What kind of things do you do to stay healthy?
 - What does it mean to be sick for you?
 - What do you do when you are sick?
 - Who do you go see? Anybody else?
 - What kind of things do you do to make yourself well again?
 - What kind of things did people do in the old days to stay healthy?
 - What did people in the old days do when they got sick?
 - Do you follow any of the old ways? Would you like to tell me about them?

3. Questions regarding cancer:
 - What do you know about cancer? Cause? Treatment? Prevention?
 - How many people do you know that have had cancer? What happened to them?
Do you think there are more people getting cancer?
 - How do you feel when you hear that somebody has cancer?
 - How do you think you'd feel if you were told you had cancer?
 - Do you believe cancer can be prevented? What do you think the community needs to do to prevent cancer?
 - More and more people are surviving cancer but that doesn't seem to be happening here, what do you think the problem is? What can be done to increase the survival rate?

Appendix 10

Family Members Interview Guide

Interview Guide:

1. Basic demographic questions of age, gender, educational level, interviewee category of cancer survivor, family member of cancer survivor, Elder, or community member, preferred language to be spoken during interview.

Questions regarding health and illness:

- What does it mean to be healthy for you?
- What kind of things do you do to stay healthy?
- What does it mean to be sick for you?
- What do you do when you are sick?
- Who do you go see? Anybody else?
- What kind of things do you do to make yourself well again?
- What kind of things do you think people did in the old days to stay healthy? When they got sick?
- Do you still follow any of the old ways? Would you like to tell me about them?

Questions regarding cancer:

How did you feel when you heard that your family member had cancer?

Was there anything different you as a family member could have done to prevent or get an earlier diagnosis?

Who do you talk to about your family member's cancer illness?

How many people do you know besides your family member that have had cancer? What happened to them? Do you think there are more people getting cancer?

What kinds of things do you think can be done to prevent more people from getting cancer?

Tell me what you knew about cancer before your family member was diagnosed with it?

What do you know now? Cause? Treatment? Prevention?

Appendix 11

Transcript Release Protocol for non-English Speaking Participants.

1. The participant will have identified that they preferred to communicate in the Cree language at the initial interview.
2. Reviewing of the transcript will be comprised of the researcher translating the transcript from English into Cree.
3. The participant will be asked if what has been translated is what was said in the interview.
4. The participant will be provided with opportunities to make changes to the transcript.
5. Once all changes have been made, and the researcher reiterates the changes then the researcher will ask the participant if what has been translated is what they had said.
6. Verbal consent will be verified by the participant responding with a yes.



**UNIVERSITY OF SASKATCHEWAN
BEHAVIOURAL RESEARCH ETHICS BOARD**

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

NAME: Anne Leis (Rose Roberts)
Community Health & Epidemiology

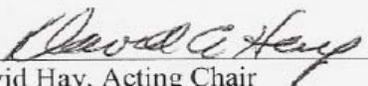
BSC#: 03-1186

DATE: October 22, 2003

The University of Saskatchewan Behavioural Research Ethics Board has reviewed the Application for Ethics Approval for your study "Stories About Cancer from the Woodland Cree of Northern Saskatchewan" (03-1186).

1. Your study has been APPROVED.
2. Any significant changes to your proposed method, or your consent and recruitment procedures should be reported to the Chair for Committee consideration in advance of its implementation.
3. The term of this approval is for 5 years.
4. This approval is valid for five years on the condition that a status report form is submitted annually to the Chair of the Committee. 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. David Hay, Acting Chair
University of Saskatchewan
Behavioural Research Ethics Board

DH/ck

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