

University of Alberta

An Exploration of High Cancer Morbidity and Mortality
in a Cohort of Aboriginal People

By

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Abstract

This study of an Aboriginal cohort with unusually high incidence of mortality and morbidity was conducted with the permission of the Elders of the Goodfish Lake Community, Treaty Six region of Alberta. The study is insider ethnography of a cohort comprised of the band members who attended a special school on Goodfish Lake Reserve as children between 1959 and 1963. Of the 38 members of this cohort, only seven are alive now (a mortality rate of 81.5%), and the remaining survivors are struggling with cancer. This is a descriptive study of the perceptions and experiences of this cohort, with special reference to their common experiences at that school, in an effort to explain this tragic situation and to set it into the context of the community's health today. The major outcome is an affirmation of the community as a determinant of health within a socio-economically-challenged community.

Dedication

I dedicate this thesis to my three lovely children and mate in this millennium year
and to my Mother and Father who departed to the other side
before the completion of my studies.

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This study would not have been possible without the financial support of the Canadian Circumpolar Institute. I would sincerely like to thank the communities and the Elders for their assistance and guidance through this research process.

I struggled with the assistance of four committee members who believed in me, in my theory of life, but whose names out of respect I have left out.

One who saw and took care of my medical needs. Next, an academic that exposed flaws in me so that I would see them. The other, an academic as well as 'family' to me providing me that emotional support. A supervisor who worked too hard to make me a scholar, but in doing so made me angry at times. In her, I learned how to use my anger to my advantage.

As well, I thank Ginger Gibson who saw many mistakes, some that were real mistakes, others that she made up for me to find in the context of countless drafts of this final document. I want to thank whoever it was that carried me personally when I was tired.

Finally, I thank Colleen for her untiring work in the completion of this thesis.

Table of Contents

Chapter I. Introduction	1
Statement of the Problem	4
The Elders	5
This Study as Insider Ethnography	7
Historical Background.....	8
Community Subcultures.....	10
The Treaty and Health Policy.....	12
Goodfish Lake	15
Chapter II. Aboriginal Perspectives on Health, Research & Methods	18
Aboriginal Perceptions of Good Health	18
The Spirit.....	19
The Mind.....	20
Race and Health	21
Methodology	22
Oral History in Research	22
Elders Statement on the Research.....	23
Ethnography.....	24
Participant Observation	24
Interviews.....	25
Socioeconomic Survey.....	25
Data Sources for Mortality and Morbidity Information.	26
Research Statements	27
Research Questions	28
Chapter III. Findings	30
Initial Findings.....	30

My Cohort	30
Genesis of the Research: The School	31
Possible Contamination of the Polio Vaccine – a Hypothesis	34
The Interviews	35
Interview with Chief Houle	37
Interviews With Nurse’s Aides: Excerpts from Oral Interviews.....	39
Profiles from the Cohort Group Data.....	40
Case Studies	42
Deline.....	42
Esther	44
Lotte.....	45
Viola C.	47
The Other Two Survivors	48
Chapter IV. Contemporary Health in Goodfish Lake Community	49
Health Determinants From an Aboriginal Perspective.....	49
Results from the Socio-economic survey	50
Community as a Determinant of Health	55
Chapter V. Conclusion	57
Reference List	62
Appendix 1A. Comparison Group	65
Appendix 1B. Cohort Group	67
Appendix 2. Treaty No. 6.....	69

List of Tables

Table 1. Aboriginal People's Attitudes Towards Health Care	51
Table 2. Attitudes Regarding Death: Personal Observations	56

Chapter I. Introduction

This is a study of a cohort that has unusually high incidence of mortality and morbidity compared to the norm for Aboriginal people today. The average life span for Canadian Aboriginal people is 58, but 31 out of 38 of the members of this cohort have passed away at an average age of 36 years. Of the 38 members of this cohort, all of whom attended a special school on Goodfish Lake Reserve as children, there are now only seven alive (a current mortality rate of 81.5%), and all of the seven survivors are struggling with cancer today; in other words, there has been 100% morbidity in the group. The average age of the remaining seven is 47.57. However mortality and morbidity rates are expressed, both rates, for this cohort are exceptionally high.

This is a descriptive study of the perceptions of the community regarding their health today, their perceptions of events that took place at a school that all the cohort attended so long ago, and the experience of the surviving cohort members. It is an effort to provide an explanation for this tragic situation.

This research was conducted with the permission of the Elders of the Goodfish Lake Community in Treaty Six region of Alberta.

A study presented by an insider ethnographer is often biased towards the people for whom the study is intended, in this case the survivors and the community. The inside information generated is filled with detailed descriptions of events and drama that unfold as each idea is tracked and traced to its origin. The intent here, however, is not to fill the study with phenomena that one feels are necessary to tell a story, but rather to uncover truths about a group of people that

wish to tell their own story from their own perspective. My job, as a researcher and as a member of the group myself, is to listen, to use their words, and to tell the story of all of us in a way that is worthy of the silent members of the group.

Aboriginal people, especially Treaty Indians, have been traumatized in the past by events that did not serve their needs, such as residential schools. These factors have affected the real culture. However, the elements of the culture that went underground are beginning to surface, and with the blessing of the Elders in the community, this thesis brings some rationality to the understanding of the high mortality and morbidity rates within this indigenous group in Alberta.

The main part of the study is based on interviews with Elders and with four of the seven survivors in the cohort of 38 people. A survey of the attitudes about health of the community today is included, as well as summary comparative data from a group with similar characteristics to the cohort. Library research and interviews with health professionals, plus experience as a participant observer, complete the picture.

The research question has been stated in several ways by the Elders:

- What are the causes of the unusual morbidity and mortality rates in this northern Alberta community in this age-specific cohort? Or, stated in terms that focus more closely on specific factors,
- What agents or traumas might be responsible for these unusually high rates of morbidity and mortality?, Or, more generally,
- What is (are) the cause(s) of the high level of cancer in the community of Goodfish Lake?

The contribution of this study to the community is a description of a time and place in its history that has not been discussed before in a public forum, and rarely even in private, because of the stigma associated with the nature of the deaths of the members of the age cohort. The Elders believe it is time to temper the past. The study also establishes a foundation for further research within this community on this and other health-related topics. Finally, it provides a case study of the contemporary and past perceptions of health and wellness in a particular Aboriginal community, with specific reference to the cohort of students from a special school, whose illness pattern presents a continuing challenge to the field of health research.

The thesis has been written in such a way as to try to find a path between the academic requirements for standard research and the pattern of thinking and analysis that is inherent in Cree culture. Taiaiake Alfred writes of the challenge of conveying the basic teachings of traditional indigenous cultures in an academic forum: "The meanings of our traditional teachings are embedded in the structure of the narrative as much as in any words one might write in order to explain them" (Alfred, 1999). Where university protocol follows a structured, sequential pattern, Cree concept development is cyclically incremental. Integrating two approaches to knowledge generation and transfer has been a challenge. Insofar as possible the university format has been followed. However, important themes may be introduced, then arise again later on in a more developed context to preserve the Cree presentation style.

The remainder of Chapter 1 continues the brief introduction, and then provides an overview of the history of the community. Chapter 2 provides

Aboriginal perspectives on health and research. Chapters 3 and 4 provide the research results for the study, including interviews with the members of the cohort, Elders and nurses' aides. Finally, Chapter 5 concludes the thesis, summarizing the key results.

Statement of the Problem

The starting point is the documentation of high morbidity and mortality rates in a specific age and social cohort in the community of Goodfish Lake, Alberta. The field data reveal high rates of disease (morbidity), and the related high rate of death (mortality) among this specific group of people, all close to the same age. This research attempts to examine the cohort from the past (retrospectively) and to describe a situation that coincided with, and may have contributed in some way to the high morbidity and mortality rates of the cohort, and thus to the community. As casual discussions of death can be sensitive in small communities, certain protocol (rituals for gaining access to information) has been used in this research to protect the indigenous peoples.

The study focuses on a given time period for a specific population cohort comprised of 38 Aboriginal children. These children were all born between 1949 to 1956, and were all schooled in a separate Catholic school in the Aboriginal community of Goodfish Lake, Alberta during the three school years 1959-1960, 1960-1961, and 1961-1962. There is data provided for a comparison group of Protestant children whose school and life experience has differed from Catholic children. The mortality rates for Protestant children were lower than the research cohort, with 21 out of 38 still alive (see Appendix 1A).

Appendix 1B details the date of birth, date of passing (if applicable), and health and mortality status of the individuals in the age cohort that is the focus of this study. Cause of death is also indicated for those from both the cohort and comparison groups who have passed on.

The diseases that are discussed in this thesis have many names in the communities, and in order to abide by standard research practice, and to preserve respect for those who have provided information, the terms that are used in the community to discuss death and disease will be used in discussion in this thesis. The terms that are used in the thesis which imply relationships between disease and dying are those terms that more closely approximate those concepts as they are understood in the community of Goodfish Lake. For example, one person from the cohort who perseveres in life (given the nature of her morbidity) has “rights” to designate words for her diseases, in addition to practicing protocols for an “after life”.

The thesis investigates disease and death in this one cohort, but it also attempts to explain in the words of these people the inner reality that the remaining people from this cohort live in. There is no set belief of life expectancy in the Plains Cree but rather a system of aging which is included in the cycle of life. In simple words there is no “life expectancy”, just “life expediency”.

The Elders

This research acknowledges and works under two realities in indigenous communities, one regarding the documented and written perspective of Aboriginal history in Alberta and the other regarding indigenous people’s

perceptions of themselves. Difficult internal politics in Indian reserves, poverty, the loss of personal prestige, poor health and disease characterize the contemporary history of indigenous people in Alberta.

In an Aboriginal community history is explained relative to specific events or traumas (indigenous time) rather than by measurement of hours or years spent. Therefore it can be difficult to work on research with indigenous groups that constantly refer to specific events as a frame of reference rather than a specific 'time period'. Using another example, the Cree calendar has 13 months to coincide with the 13 full moons in a year, each month or moon represented by a period of 28 days. This is in respect to Mother Earth's time; the menses of all women are indicated by 28-day intervals, cycling completed throughout a 28-day period. This entire Cree calendar would have a total of 364 days for a full year; June 21st was counted as 'two-day' in pre-contact era, a spiritual connectedness to their cosmology. In contrast the calendar used by mainstream Canadians has a total of 365 days with adjustments made every four years, where we have a 'leap year' (February 29th) to attain the 366 days every four years.

Contemporary Aboriginal people have to define themselves through the cultural dimension, as well as by referring to health status indicators through biological, cultural and legal dimensions (Waldram, Herring, & Young, 1995). Disjunction between two global perspectives has caused the Aboriginal people to see themselves as part of the "burden of disease" of the nation. Consequently, self-hatred has become an inner reality expressed through violence and a loss of personal integrity. Many Aboriginal people believe that the experience of being labeled as a sick population has had a negative effect on the Aboriginal place in

the health care system, despite the promise made to them in the Treaties. Many Aboriginal Elders still feel that sharing the land with newcomers should have brought about positive effects and they are deeply disappointed.

The Elders' perspective of 500 years of immigration was illustrated at a seminar in the Alberta Manpower and Immigration Retreat in 1980. When questioned about the 'boat people' (Vietnamese immigrants) in 1979, some Elders replied to the Premier, "Most everyone in this room was a boat person at one time in history, 1492 merely being a time period when this immigration began". The positive consequence of sharing the land, as seen by the Elders, will be realized when the provisions of the Treaty, if fulfilled, provide for equity in education, health care, and social justice; and in the recognition of the sovereignty of First Nations in their establishment of self government.

This Study as Insider Ethnography

This study is part of an agreement by the Cree people and the researcher to examine unusually high morbidity and mortality in a specific group of people, in a given time period. When we observe a life span of 58 years for the Aboriginal people in Alberta in contrast to 78 for all Canadians, we must examine those key health determinants that account for the disparity. The results of the disparity may be expressed as Potential Years of Life Lost (PYLL) for the indigenous populations. This study seeks to investigate factors that lead to a marked disparity in life spans with specific reference to one relatively small cohort in a local population.

The research effort therefore is to reconstruct the events in history that had a key role in the health of these people. It seeks to understand where the people stand today through the study of their own health discourse. The question as to why Aboriginal people seem to be more ill today can be investigated through an insider-ethnographer approach. Shi (1997, p.128) says, of this research strategy, "by capturing insiders' view of reality, qualitative researchers can understand the logic of viewers that may seem implausible to outsiders." The membership of the researcher himself in the cohort, as well his membership in the community, increases access to relevant data, provides strong motivation, and may provide for a greater measure of validity. The researcher's commitment to the health and welfare of the Aboriginal people is well established in the community and it is understood that the researcher will still be there after the research project is over. This factor has led to a high degree of community support for this study. In the past, most researchers left the community when their work was completed.

Historical Background

The Canadian Wesleyan Society had the very first Indian mission in Alberta in present day Whitefish Lake Alberta in 1855 under an Ojibway-Cree missionary, Henry Bird Steinhauer, 50 years prior to Alberta becoming a province and 21 years before Goodfish became a reserve in 1876. Diseases new to the Plains Indians began to sweep across the prairies in the 1800s. As early as 1864 missionaries were concerned about "vaccine matters"¹ from Fort Edmonton. The

¹ Indian Affairs as early as 1864 began vaccinating Indians for measles, influenza and scarlet fever

Whitefish Lake mission (*aka* Goodfish Lake) had been impacted by measles and scarlet fever epidemics, said to have originated from the Blackfoot people (MacDonald, 1997). In 1870 the smallpox epidemic further diminished the non-immune reservoir that might have existed within the Goodfish Lake people. Goodfish Lake at the period of time had a population of just over 100 people.

In 1876 at the time of Treaty Six, Whitefish Lake was under the leadership of Chief Pakan (later to be known as James Seenum after his conversion to Christianity). Goodfish Lake and Whitefish Lake were two lakes in the Reserve. At Whitefish Lake, Henry Bird Steinhauer had built a mission prior to the Treaty era and had established a following because he had taught them to rely on agriculture, Christianity and education. The community soon developed an agrarian society as well as a communal system. The missionary was the leader while the Chief followed behind. Ironically, James Seenum was to be a vital force in the signing of Treaty Six, which includes 17 bands of Plains Cree Indians. Largely because of his seemingly strong sense of independence, self-reliance and negotiating skills, Seenum was selected as a key signatory in the Treaties. He was a respected leader in that time period, a period when other bands of Indians were half-starved from disease and loss of buffalo. He was skilled in English as well as in developing trust with settlers in the immediate area. The settlers depended on him for protection against the warrior-like Indians that wandered onto their newly developed farming plots. He often told his followers to support the newly arrived settlers any way they could and especially to settle down in the land adjacent to the Reserve.

At Goodfish Lake, which was only five miles away (south) from Whitefish Lake, there was a different story. The Chief (Onchaminahos) had no desire to be linked with the people of Whitefish Lake, due to their continual disinterest in their own traditional belief system. The people of Goodfish had no interest in Christianity or agriculture nor in learning a new language, because they had had all of these prior to Henry Bird's entry in the community. The people of Goodfish Lake were suspicious of Seenum's inability to see through the intents of the missionary and settlers that were by then (1860s) living immediately adjacent to their hunting territory and sacred grounds. By 1867, they had selected Onchaminahos as their new Chief, settling in now what is known as Saddle Lake. With the community split into factions, with two belief systems and two political systems, it was not difficult for the community to perpetuate that instability to the present time era.

Community Subcultures

Two subcultures emerged in the community: people who had become acculturated into an Euro-Canadian lifestyle and those that embraced the traditional Plains Cree culture, for whom spirituality and health were one and the same. For those in the traditional culture, sound health is an indicator of one's harmony and balance within the ecosystem. This is supported by the models of community-based health research, which distinguish proximal from distal social forces and factors from social causal variables of health. Distal social factors include the more pervasive forces in a society such as cultural interaction, integration, how the Canadian social system is organized, the roles of men and

women in society and racial factors that determine health policy. Proximal social factors are more tangible and readily identified in day-to-day life, including the family, biology, education and the overall community status (Amick, Levine, Tarlov & Chapman-Walsh, 1995). Aboriginal health status indicators tend to differentiate healing practices from disease control in a manner consistent with this model.

The cohort group in this study is comprised of the Catholic families of Goodfish Lake, or more specifically those who were baptized as Catholics. Within the community there are five families that include the South Cardinals, Bulls and Houles, Jacksons and Memnooks, Hunters and North Cardinals, and Steinheurs. The division of power and leadership shifts, through elections, every three years from the Goodfish Lake to the Whitefish Lake community. When there is a shift in the election, health policies within the reserve are revised to accommodate the needs of the newly elected Council and Chief. The rivalry still appears from time to time. For example in 1976 a Band Council Resolution (BCR) was introduced to remove me, C. Cardinal, from the Reserve Council due to the possibility of the return to the pagan ways of the traditional people. The intent was to please the white Indian Agent, nuns and priests that tried to convert the Cardinal family, because more people then spoke in favour of assimilationist policies and against the traditional belief system. Today about 5% of the community supports the Cree belief system while the 95% still tries to please agents of the federal Department of Indian and Northern Affairs and support all programs they perceive to have been initiated by White outsiders.

The Treaty and Health Policy

Treaties Six, Seven, and Eight are the major treaties in Alberta between the Crown and Aboriginal people. Health policies of regions covered by Treaty Six differ substantially from those covered by the other two, although Alberta Health treats all Indians as being alike. Treaty rights in regard to medical care have become increasingly relevant in this land where everyone had access to universal health care (Waldram et al., 1995; Morrison & Wilson, 1995). Treaty Six Health Policy was different in that it included the enigmatic “Medicine Chest clause”:

That in the effect hereafter of the Indians comprised within this treaty being overtaken by any pestilence, or by a general famine, the Queen, on being satisfied and certified thereof by her Indian Agents or Agents, will grant to the Indians assistance of such character and to such extent as her Chief Superintendent of Indian Affairs shall deem necessary and sufficient to relieve the Indians from the calamity that shall befall them.

And that a medicine chest shall be kept at the house of each Indian agent for the use and benefit of the Indians that shall have befallen them. (See full text of Treaty Six in Appendix 2.)

The medicine chest was effectively and functionally a continuance of the indigenous Mediwin Society that existed until 1919. The interpretation of the medicine chest clause has been a challenge for health authorities, as it appears to imply comprehensive medical coverage.

At the time of this treaty, the Indian Agent (Wall) wrote of one Chief, “The Chief here is a careless and indolent man of low mentality and the mentality of

the Band as a whole appears to be lower than the average". Such reporting has not changed much, perpetuating the view that Indians are promiscuous, amoral, and inexplicably incompetent, as evidenced by statements such as this: " I do not believe that an Indian can be treated for any sickness unless he is hospitalized as he cannot take medicine intelligently" (Waldram et al., 1995). Such reporting serves only to demoralize the disadvantaged but such treatment continues today in some communities where welfare is the main source of sustenance and survival. Social well-being is a starting point in the personal growth as prescribed in the holistic paradigm and is a primary factor in the development of good health and a deterrent in disease (Wilkinson, 1996).

A summary statement of the changing health policy is included here as it brings to the reader a better idea of the mainstreaming process and provides as well a frame of reference for the significant cultural changes which Plains Indians have undergone since treaty signing. Before signing, we see people who had a vision of health prevention, insurance and treatment, long before the time of general health insurance. These people, however, are now assigned to 42 small Reserves in Alberta, a total land mass less than 1/100ths of their previous domain.

Health Canada has implemented the Indian Health Policy to include as a first consideration "The importance of socioeconomic, cultural and spiritual development in attacking the underlying causes of ill health of Treaty Indian people" (Waldram et al., 1995). Cultural diversity is a topic of concern for health planners and service providers. Rates of utilization of health services have also shown to differ within different ethnic groups, including Treaty Indians. Culture

therefore has been increasingly at the forefront in the determinants of health as included in the Indian Health Policy. Cultural variables within ethnic groups are looked upon as a collective matrix but are inclusive of individual beliefs and lifestyles that have an impact upon the Aboriginal health. The emphasis on health and healing the sick calls upon a different mode of operation for the Aboriginal people; healers were conveyors of good health. Healers are chosen by inheritance and divine selection as well as through direct teaching, as in health science itself.

Today, many Treaty Indians are still fearful of living off reserves even when they have that opportunity. Like in prison the Indian people have evolved a language system defining their state of being enclosed in reservations. For example, names of modern diseases reflect the containment. The disease tuberculosis is referred to in Cree as “the state of the totally locked-up lungs”, *Kahto pihn niyh wihn*.

Institution-based outsiders have almost always conducted cross-cultural studies in health care, medical anthropology and medical research using Aboriginal people as middlemen and subjects. Many Aboriginal leaders feel that the credibility given to this standard research model limits the reliability and acceptance of current indigenous people’s research. Ethnosemantic discourses regarding the etiology of disease, as well as clear-cut interpretation of the causes of death amongst the Aboriginal populations in Alberta are at issue, with some supporting traditional biomedical perspectives and others supporting the emergent voices of Aboriginal researchers (insider researchers) (Kleinman, 1995).

Each distinct 'band' of Treaty Indians recently adopted the term "First Nation" to imply distinct rights as the first citizens of Canada. This practice began in 1982 with the revision of the Canadian Constitution. By 1999, most Indian reserves in Alberta had integrated that system to symbolize the customary practices outlined in the treaties with the Dominion of Canada in the years 1876 (Treaty 6), 1877 (Treaty 7), 1899 (Treaty 8). Goodfish Lake in 1982 became part of Whitefish Lake First Nation. It was almost incumbent on an Indian Reserve to become a First Nation.

Goodfish Lake

The population of Goodfish Lake (Whitefish Lake First Nation #128) today is listed formally at 1500 residents with full membership rights. There were 250 people who came in as Bill C-31s in 1987. Bill C-31 was a Bill entitling women who had married off the Reserve to regain their original Treaty Status. For a woman to marry a person without federal Indian status prior to 1987 it meant automatic enfranchisement (she could vote in Canadian elections but lost her Treaty rights). Membership was reduced whenever women married a non-native person, or a non-Aboriginal. After 1987 the membership soared across Canada, however each band was given one full year to design their membership rulings according to the customary laws entrenched in the Treaty of 1876 (for the Treaty Six area).

In the period of this study (1959-1963) the population was listed as 450 Indians, as posted in the Reserve Boundary entering the Community. The sign actually read:

You are now entering the Indian Federal Reserve

Of

Whitefish Lake #128

Population 450

Anyone entering was supposed to have had permission from the Saddle Lake/Athabasca Indian Agency or face a fine of \$50 dollars and 30 days imprisonment.

Some people (nuns, priests) came in and out of the reserve with impunity, as did teachers and officials from the Indian Agency that brought rations each month. In fact the sign was actually used to keep people in rather than out as the Indians were fearful of losing the rations that fed their families. Under subsidiary legislation (i.e., rules with the force of law that the minister was empowered to create and enforce) Indians were not allowed to leave the Reserve without written permission from the local agent.

Our home was just outside the Reserve line and we would see the people coming in to sell goods to the Indians. Our neighbors consisted of Ukrainians, Polish immigrants and the odd traveling settlers at the time. Often these immigrants sought help from the healer of the community who was my grandfather, a Mediwin leader, the healer that trained me.

In the attempt to provide an introduction to a thesis, or any hypothesis, it can be said that too much has been said too soon. As I have I introduced the community, I have focused away from the one characteristic of my community

that motivates this study: an unusually high mortality rate, and a morbidity rate in a small age and social cohort that has soared to 100%.

We find that Cree people have a wide range of cultural constructs that continue to inhibit progressive change. The cultural disparity continues to be evidenced in differential health status between Aboriginal peoples and other Canadians. Within the 60 days preceding the completion of this work (May-July, 2000) there has been one suicide, one murder, one accidental death with a gunshot, three cases of death from cancer, and one unaccountable death amongst the 1500 people who live at Goodfish Lake. The mortality rate is staggering and yet there is little effort to address the causative factors.

In that context, this work focuses upon a cohort within the community, with remarkably high morbidity and mortality.

Chapter II. Aboriginal Perspectives on Health, Research & Methods

Aboriginal Perceptions of Good Health

Aboriginal people had an intricate medical care system that fitted the needs of their populations prior to the arrival of the European. Ceremonialism is/was not dependent on nor synonymous to medicine, although the science of anthropology builds upon the theory that ceremonies are almost always a prelude to the traditional healing. Healers in the community are usually validated by a group of other well-known Healers, while anyone can perform a ceremony. Religion beliefs, taboos and customs however, are widely included in the healing practices, perhaps because cures are attributed to a higher power in most indigenous cultures in the Americas.

Good health is measured by a holistic paradigm and reflected in the quadrant cycle of elements that describes the total person. If one of the four elements is compromised, or not in sync with the rest, disease may follow. The *human-self* comprises the total aspect of wellness and healthiness. It encompasses the *spiritual-self* of obedience as opposed to superiority. The *physical-self* involves self monitoring, the upkeep of your own body. The *spoken-self* is how one perceives oneself and is regulated by a stringent measure of humility, often downplaying personal place within an environment. Drawing from this concept, we begin to see the nature of a group of people who are neither superior nor inferior in attitude, attaining respect rather than employing or demanding respect, surviving individually rather than drawing from other sources and being proud, rather than arrogant.

The Spirit

The spirit is believed to encompass everything worldly. This includes all things that comprise the world including rocks, soil, trees, plants, air, water, wind, minerals, animals, and even things that have been made by man through ingenuity. It is difficult to imagine that each of these things can have a spiritual base. How man integrates with each spiritual element accounts for his place in the world and ultimately his health and disease factors.

Elders provide the teachings to 'would be' healers on how to integrate with the elements around them, and also, how each 'would-be traditional healer' interprets the ecosystems that exist immediately around them. Confinement to reserves (prior to 1966) has diminished that special bonding relationship with the spiritual and healing forces of nature and the range of ecosystems.

In June 1999, at the invitation of Archbishop Desmond Tutu, I was asked to speak of today's botanical supply of traditional Cree medicines, at the International Peace Summit in The Hague. The nature of the discussion was the loss of indigenous knowledge of traditional health. My discussion detailed the findings from the last 35 years when we began noticing the changes (mutations) in the herbs that we use. Although the changes were subtle, plant-life mutates seven times faster than the human mutation rate (Dornreiter, Hoss, Arthur & Fanning, 1990). Therefore the anatomical properties of medicine as used in traditional healing medicines are compromised and may be less effective. Elders and healers choose not to use mutated plants as they are considered to be altered by the malevolent spirits. They are, however, used in the concoction of bad medicines such as causing someone to have Bell's Palsy; (e.g., the mutated

rose stem has a very toxic substance that induces neurological disorders).

People who choose to practice that type of medicine use mutant plant life forms for bad effects. In all, it is presumed that Spirits process good health through healthy plant life forms, free from contaminants and mutation.

Ceremonies were endorsed by the '*Grand-fathers*' or spirits.

The Mind

The mind is used as a measure of one's place in society. We view individuals by where they come from and are amazed when they are able to rise above that level. Health is synonymous with a good mind. Different from other religions, Aboriginal religion does not seek converts, nor does it teach one how to think. Thinking is often seen as the reason why one gets sick. To think too much is to leave one susceptible to disease. Aboriginal philosophy determines how we perceive our personal health status. Our health status is also affected by how we are perceived and treated by the mainstream society; largely we are categorized as marginal.

This view, however visionary and idealistic it may appear, was the measure of health before the Plains culture was compromised through the Treaties. Today Aboriginal people have one of Canada's highest suicide rates, one of Canada's highest welfare dependencies, and one of Canada's highest crime rates. Alberta's penal populations tell of the Aboriginal struggles and failures to make sense of the world around them.

In the interface of the idealist vision and the demands of mainstream healthcare, a compromise becomes necessary for the Aboriginal people.

Modification of their ideals and values is most urgent. In particular, spiritual discourse and bureaucratic demands are on two ends of the table, with the emphasis of the latter primarily on 'objectivity'. The primacy of personal achievement in mainstream society remains a primary factor, emphasizing individual goals rather than the communal goals of Aboriginal people. The emergence of exciting new health reforms (for example, the adoption of Wellness in the Alberta Department of Health) could lead to open-ended inductive approaches in future health-policy, responsive to the needs of Aboriginal people.

Race and Health

At the turn of the century, the distinguished American sociologist, W.E.B. Du Bois (1903, quoted in Amick et al., 1995), declared that the problem of the twentieth century was the color line. The issues of race and racism have plagued this country since its very beginning and remain a disturbing and volatile component of the North American dilemma. For reasons unknown, white people have in history established the notion they are superior, intellectually, socially, morally, technically and politically, to their darker counterparts. Uncivilized, dirty, paganistic, and heathens comprise some of the words used to describe the Indian. A notion that they were lower became a concept that could not be driven out from the Reserve Indian. It has long been acknowledged that social status and self-image influence health (Wilkinson, 1996). Social stress and low self-confidence have a direct effect on health, lowering the immune system and endangering mental health.

To avoid the soaring mortality rates in the Hobbema Reserve, Chief Robert Smallboy decided to move his small band of traditional Cree to the foothills in 1968. Alcohol, drugs and the possible corruption from money they would be receiving from oil and gas revenues forced him to lead his band back to the ways of the traditional Indian. The impact of race on health depends on the contextual setting in First Nations communities as well as the social strata and perceptions of surrounding communities.

Methodology

Oral History in Research

In the attempt to reconstruct events for a retrospective data analysis we must discuss first the social and cultural frames of reference. This is best discussed through the oral tradition of First Nations culture. Oral history as a method of data collection has recently been demonstrated to be a viable and reliable means of gathering observational and historical data (e.g., Cruikshank, 1981, 1998). In a remarkable decision, the “Delgamuukw case”, Canada’s Supreme Court examined encyclopedic oral history data, and substantive challenge to it, and in effect documented its validity (Supreme Court of Canada, 1998). Oral traditions are founded on respect, honor and dignity, and exclusively practiced authoritatively by the elderly and honorable people. The practice of relaying this type of information is contingent on who is asking and for what purpose. Therefore a certain protocol is required to procure and access information from oral history. More importantly, the Elders will always determine if

the data will be used wisely and they can choose to give either proper or silly information based on their judgement.

The validity and trustworthiness of information is conceived of in indigenous terms as involving relationships of respect and authority, directly related to specific protocol (Urion, 1999). The process of data collection for this project was done according to the cultural practice of attaining specific knowledge and rights to access the knowledge. A ceremony was conducted in August 27, 1999, for permission to consult certain Elders that may or may not have knowledge of current health issues. Due to the nature of the ritual, it will not be detailed but I will refer to what the Elders shared at the time.

Elders Statement on the Research

1. The morbidity and mortality rates should be investigated.
2. Causes of the high mortality need to be researched by one of us.
3. The research must be conducted in conjunction with customary and natural laws.

By the use of Cree oral tradition as a method of data collection we study the history of health care as it is articulated by a collective, rather than by an individual case history. The likelihood of designing an instrument that is flaw-free from 'cultural barriers and bias' is provisional on the political orientation of our personal social infrastructures. An example of this is the recent addition of the broadened concept of Wellness by the Alberta Health Ministry. This includes mental health, emotional, social, physical, spiritual, generally mimicking the holistic paradigms used in Aboriginal philosophy. A notion of the Medicine Wheel

states that the mind, the soul, the body and the society must be harmonious (Aboriginal Health Unit, 1995).

Ethnography

Wolcott (1990, quoted in Amick et al., 1995) believes a good starting point for writing ethnography is to describe the culture-sharing setting.

Description is the foundation upon which qualitative research is built. ...

You become the storyteller, inviting readers to see through your eyes what you have seen . . . Start by presenting a straightforward description of the setting and events. No footnotes, no intrusive analysis...just the facts carefully presented and interestingly related at an appropriate level of detail. (Amick et al., 1995)

This form of descriptive analysis relies on a chronological order of events. The intent of this approach has led me to use the meaningful traditions of qualitative research, participant observation, interviews and a survey—ethnography—to create a case study of a community. This research design also uses an epidemiological approach to present some concepts and define the life span of the cohort.

Participant Observation

The participant observation method relies on what people are willing to say or share with you. Shi states that, “it sensitizes researchers to the research setting and often enables the researcher to see the world as an insider” (1997, p. 129). In this study the researcher is a full member of the community as well as being a central figure in Aboriginal health matters for the last twenty-six years.

The study is an observation in its natural setting, relying on the recent and past history to detail the relationship this author has had with the cohort. This study relies on the researcher's observations, as well as those of fifteen other community members, some of whom are named in the study, and others whose input has been integrated into this discussion to preserve their anonymity.

The field experience and fieldwork for the study have taken place in the last ten to twenty years, because I shared the sum of my life with these subjects. The methods being used are those used by others in the field of qualitative research and ethnography in a natural social setting. By no means was the study designed to explore discovery of a phenomenon but rather to investigate complex events that correlated with the high incidence of morbidity and mortality in the community.

Interviews

Other methods used included in-depth interviews with key informants and with remaining individuals from the cohort. This method was chosen primarily because it examines a single social setting (the community) and details the cultural matrix of an exclusive clan society, which exists as a partnership.

Socioeconomic Survey

This was designed to create a profile of the health concerns and socioeconomic status of the community today. For the small community of Goodfish Lake, 100 people are a powerful sample for a survey. Although the intent of the study was to explore the factors influencing the high morbidity and mortality rates of a specific cohort, I felt it was imperative that the survey includes

the same population I would be encountering in the cohort study. My intent was to have a large enough sample to establish content validity when assessing the perceptions of health and quality of care in the wider community in this age group.

The survey interviews were conducted in the field with research assistants so as to remove any vestiges of the researcher's manifest influence. The sample criteria were people living in Goodfish Lake who were registered Treaty Indians (not including people who had been accorded registered Indian status under provisions of Federal Bill C-31 or those who had married into the band), in age groups that would reflect the cohort population group within a <5> year span. These subjects would be born between 1945 and 1965, a period of twenty years. Another important indicator was the last name of the subject, as the original members in the band roll membership have one of seven family names. Please see the Appendix for the table of a comparable group of individuals with a much lower mortality rate than the cohort. The survey data will be discussed in Chapter IV.

Data Sources for Mortality and Morbidity Information.

There are multiple sources for information about individual morbidity and mortality. First, there is informal knowledge. The community is small and cohesive, and the cohort members are people I have known closely my entire life. Medical diagnoses and causes of death are in the realm of "common knowledge" about close associates, but informal knowledge as a data source may raise a question of reliability. In fact in all of the subject cases for those

departed, diagnoses and causes of death that are in the realm of “common knowledge” are confirmed in personnel records maintained and updated yearly by the Goodfish Lake Band. The source for that information is individual medical records. The seven surviving members of the cohort have told me personally and in detail of their medical histories, and personal observation confirms the nature of morbidity. Most reliably, I have been involved with most of the cohort in medical settings and in traditional health settings.

Research Statements

The major reason for this inquiry is to build upon a base of knowledge that is not by any means readily accessible to anyone outside the parameters of traditional reserve upbringing. The greatest accomplishment of the research is the means by which the researcher followed a trail of ideas in a community.

Empirical evidence results from observation. Empirical observation can provide for judgments about cause and effect. It is a scientific observation in that it is systematic and based on assumptions of regularity: specific conditions are observed and described, conditions that correspond with observed and described action. Data therefore comprise description and measurement of both social and physical phenomenon. Similarly, the study of theory must not be constricted but challenged by standard rationale and should be approached with creative criticism by well-versed opinion. “The fact that there are exceptions to regularity is sufficient evidence to overthrow the assumption that regularity exists in both physical and social phenomenon, because scientific inquiry is concerned with the study of patterns rather than the exception” (Shi, 1997, p. 27). That fact that

scientific truths are being replaced by newer truths all the time is evidence that science is open to change through contradiction.

With these statements I have established some research propositions with the notion of seeking new truths through the research previously denied members of the cohort who have 'left'. In addition it must be noted that aspects of mortality and morbidity are understood differently by the Cree. Furthermore, discussion itself, as in psychotherapy, can bring about healing. Thus, bringing the survivors together from time to time during this research can be seen therapeutic, even though research is not often seen as a healing process among Aboriginal people.

Research Questions

(Written in Cree Orthography in respect to Elders.)

1. What are the causes for the unusually high morbidity and mortality rates in a northern Alberta Aboriginal community of an age-specific cohort?

Tahniyikih ekwa kahnohtiyiks kayitamahn eyakoh

2. What agent(s) or trauma might be responsible for these rates?

Kiyikwayi ekwa

3. What is the cause of a high level of cancer in the community of Goodfish Lake?

Tahnsiyi ekwa oma kakiyiks kayitemakwahk manchosahk

I have included what the Elders stated at the start of this research, without the context of their comments. There is a lot of expectation in this undertaking from within my community. It is taboo to examine death directly in this tribal

community. But we ask, should a group of children (now adults) continue to suffer and believe that that they might have broken a taboo, when something other than angering a “higher power” may have caused the mysterious illnesses and deaths.

In the Cree belief system it is almost always believed that any disease or disorder is an act of “God” upon a human being. Everything hinges on how we bring to task our essence as creations of a greater power on earth. Our nature expresses our being.

Chapter III. Findings

Initial Findings

My Cohort

It was in the early 1980s when I started to become intensely concerned with the health of our community of Goodfish Lake, Alberta. My basic human intuition beckoned me to see beyond the pain and suffering of our people, my people. I was the Tribal Community Healer. The frequency of suicide pacts and persistent head pain led me to question the cause of these illnesses among a specific group in my community. In 1986 I too was diagnosed with a brain tumor (meningioma sarcoma), and promptly underwent surgery. By 1987 there were three others who had similar surgery and four more had died by 1994 during in the processes of removal of brain tumors and the treatment of pain. There were some that had their own means of dealing with the problem. They committed suicide, as suicide seemed easier to some than dealing with the pain. The odds of getting a brain tumor were not high at that time in the general Aboriginal population and so intuition led me to question why such a close cluster of Cree children had to live in fear of getting brain infections, brain tumors or brain aneurysms. I decided to seek the answers to these issues after my slow recovery from my own brain surgery (November 28, 1989). In 1997, under the guidance of the Elders I entered the Faculty of Medicine and Dentistry with that expressed notion.

The first question I asked was whether the research questions carried enough evidence and strength in the scientific community. First, the terms morbidity and mortality must be clarified in Cree etiogenesis to cross the so-called racial barriers encountered in medical anthropology. Mortality implies one's entry to the other side, while morbidity implies a higher power's effect on someone's life's essence on earth, their tangible existence.

Genesis of the Research: The School

The effect that illness and dying had on the community was an irresolvable conflict within a poverty-stricken lower class system that enshrouded the whole of one community. Among the many poignant aspects of this case were the strong emotional conflicts that existed where parents were unable to provide the means to prevent the suicides that prevailed in the community. In all there were four complete suicides in the cohort in Goodfish in a period of four years (1984-1988). The community's Elders could only view the young people's self-destructive behaviour as utterly pointless and incomprehensible—not in their own worldview.

The cohort is not just a research conceit, but a social reality. Over the years the cohort developed into an alliance. The group had nothing to lose as they took the taboo to task—the taboo against open questioning and discussion for causes of death—by asking why they were being punished. Something always pointed to the direction of that special school. Attendance there was the single most enduring common experience of the cohort. This concern was established well before my entry into the Faculty. I often had asked physicians if

something might be wrong in Goodfish Lake with all the people at that 'age' being sick and dying. Not one physician discussed this problem with me or listened to my growing theory. My theory concerns a link to the inordinate amount of vaccinations for polio we in that cohort received in a matter of three years in that special school (3 oral doses per year and 1 immunization shot per year, when the normal dose was one single treatment with a booster a year later). Nor was I ever told or consoled by the fact that well known and established molecular scientists had been doing the work to investigate the theory that SV40 was carcinogenic in humans and that it was found in contaminated batches of polio vaccine in the 1950s (Bookchin & Schumacher, 2000).

When I had asked the Elders as to why this illness may have happened in our community, I was informed that it was due to the special school we attended as children and the special privileges we had during the years 1959-1960, 1960-1961, and 1961-1962. Consequently, some suffering would have to be endured by this group (the cohort). That Elder who told me this was Joe P. Cardinal, an Elder well recognized in Alberta. Everyone in the community knew that all the children at this special school near the Reserve did not pray, did not study or learn, but played at that school while the other children were taken away to residential schools. That impression of privilege stayed in everyone's minds and remains with us today.

I interviewed eight community Elders. I was careful not to ask leading questions, but questions that were descriptive (to sample some of the participants' knowledge), structural (to discover basic units of knowledge), and contrasting (to provide various terms in the participant's language). My priority

was to ask general questions that elicited the history of the case and to limit my own statement (or comments). Elder Albert Houle's response to my question about the history of this group of Cree children was as follows:

The children were being punished by a higher power because the other children were taken away from their home. These other children often ran away in an attempt to go home, even if it was for one night, as they knew they would be caught anyway. In addition the winter of 1960-1961 was a winter with no snow. The bitter cold and an occasional rainfall left the wild grasses inedible by the deer that led to their starvation. This was seen as an omen by the Elders who proclaimed a taboo had been broken by the children in the special school.

The special school was run by Mr. W. Haënsell with the aid of the community nurse, Miss Rüdolff, for the three school years it was in operation. Mr. Haënsell taught classes and had installed a camera monitor in the classroom, as well as televisions in the two rooms. There was only one room for teaching, while the other room in the school was the teacher's living room. The cameras were noticed by all of the children, however only later on did we know that these machines were cameras (as at the time we didn't know what cameras were). Across from the school was the small nursing unit that was installed on the Reserve at the same time as the school. This special school was six kilometers away from the main school, which had the regular school population of the Roman Catholic Day School, for the Grades 5 and 6, and the Protestant School that had Grades 1 to 6. At that time Treaty children usually only went to Grade 6, or age 16, but in 1966 the Government changed Indian policy to allow

attendance in off reserve schools (residential schools) and we were then finally able to go beyond grade seven.

Of the 38 students who attended the special school between 1959 and 1962, by the time this research was begun, 31 had died, beginning in 1984. Most of the deceased died from cancer-related causes. There was always a need to seek answers to the unusual mortality rates, for I never believed that all the children could anger a heavenly creator or a higher power. I believed there had to be a medical reason and not a punishment as suggested by the community.

Possible Contamination of the Polio Vaccine – a Hypothesis

In 1989, Martini found that when hamsters are injected with the SV40 virus they had a 99.99% chance of developing tumors (Martini, Iaccheri, Lazzarin, Carinci, Corallini, Gerosa, Iuzzolino, Barbanti-Brodano & Tognon, 1996). “SV40 has ATPase and helicase activities, binds to viral and cellular DNA, inducing their replication, and forms a complex with the products of p53 and Rb suppressor genes, inactivating their functions” (Dornreiter et al., 1990). Consequently, the etiology and risk factor for the children in question remain to be determined in laboratory investigations, something that this thesis does not purport to undertake.

Additionally, based on reports from members of the cohort, neurological disorders that were encountered in this cohort increased overall, and there is a possible risk factor for their offspring—gene p53, a gene that suppresses tumors is an inheritable factor. This is a serious concern for the cohort and their children. When harmed and violated by the virus SV40, p53 is rendered almost useless

and can produce sarcomas (Baker, Fearon, Nigro & Vogelstein, 1989). P53 is located on the small arm of chromosome 17, while SV40 antigen sits on the long arm alongside the exons (the coding section of the genes are interrupted by genes, introns) that are located next to (∞ - glucokinase) an enzyme that produces a rare-limiting glucose-6-phosphate in the pancreas.

In the plague-ridden period of the early 1950 and 1960s, the Indian Reserves of Alberta were prone to contagion and disease through infection (the passing of disease through direct or indirect contact). The natural immunity that was present was not sufficient. Vaccines being developed as attenuated vaccines (Sabin vaccine) were often used on the isolated populations, testing live vaccines upon different immune systems (Bookchin & Schumacher, 2000).

In Goodfish Lake, an Elder stated, "that the children would benefit from the vaccines"". This statement offers suggestion that even as an Elder he did not see how an established route of protection could predispose these same children thirty years later to other side-effects from the attenuated vaccines. It is my belief that we, the cohort, received tainted polio vaccine and that this is the cause of the high mortality and morbidity rates. It is not the purpose of this paper to prove that, but rather to establish this possibility and to describe the cohort.

The Interviews

This section examines the personal side of the issue on morbidity and mortality. It gives the reader a feeling of the suffering the cohort experienced since 1984 when the first person of that school died (Joe). Subsequent sufferers did not feel the connection to the school at all until John Bird (a former Chief of

the Whitefish Lake Reserve) brought it up with the members of the Chief and Council in response to a request for an inquiry in 1989.

It is difficult to determine what really happened during the years at the small school, but all seven present survivors recalled being there and doing nothing at all but watching television all day for three years. Mr. Häensell was in fact a good person who often went along with the needs of the students, if only to settle them down or occupy the students until he was finished for the day. He never participated in community events, but allowed the community to come and watch television on weekends. He left in 1963.

Two years after he left, in 1965, our late Chief responded to what he considered to be mistreatment of a youngster (incidentally, myself) by the local priest and nuns, and took steps to ban them from the reserve. The conflict was resolved when a religious from outside, from the Sisters of Charity, came for a three-week stay, to visit "the Indian children." She attempted to bring reconciliation between the band and the nuns who had been requested to leave, and in the process she formed friendships with some community members, particularly with the children. Her affection and concern for Goodfish Lake was affirmed in 1982, when she renewed acquaintance with her Goodfish Lake friends when the University of Alberta awarded her an honorary degree at a special convocation in the nearby town of St. Paul. Many of us remember her, as she won a Nobel Prize in 1996 for her work in Calcutta in humanitarian concerns. One of the questions she asked on her last visit to St. Paul, was "Where are the Indian children?". The question is both poignant and ironic when we realize that

the small group of children she befriended in the mid-1960s is the same group of individuals who later experienced high mortality and 100% morbidity.

Interview with Chief Houle

This research began in 1997 long before the proposal was to be sent to the Ethics Committee. My initial contact was to the Chief of the time who is still alive today. The following is an excerpt of an extensive dialogue I had with him while he was waiting for his leg to get cut-off at the University of Alberta Hospital in December 3, 1997. That method of interviewing requires the subject's knowledge of the topic, their experience, and how they interpret the inquiry, and specifically not what the interviewer wants to hear. It was a conversation directed as much by the subject as by the interviewer. Part of the dialogue with Chief A. Houle is as follows:

December 3, 1997

Question: Do you remember Mr. Häensell at around 1960 or 1961?

Answer: ehi ah, oh sahm ehk e miotoht [Yes he was a good man].

Question: Would you be able to talk openly now that we are no longer bounded by secrecy from Indian Affairs and that we have more freedom to talk?

Answer: Around 1958 I was just a young councilor, I didn't know much. I basically learned from Mr. Kartousen the Indian Agent about law and how the outside was like. Sometimes it

would scare me, telling me about taxes (taxes are something you have to pay). Rueben was the Chief but he didn't get along with the Agent, I believe he didn't speak English too well. The school was put there because families would get more rations but it was just an idea so that our children would not go to Blue Quills. Students were lucky because they had the chance to stay home while nearly everyone had to go there.

December 4, 1997

Question: I came to visit, I am concerned about your leg; you do not have to get it cut off you know. You can tell your Doctor that it's up to you. (Albert's leg was about to be cut off, there was no apparent sign of infection, but because he had the other cut off the year before the Doctors were not willing to risk further infection as he had Type II Diabetes.) [I would later use this situation in a poster presentation in "Ethnosemantic problems with physicians and their Aboriginal patients".]

Answer: Do you think I have a choice? The doctors feel it's for the best that my other leg should be cut off too.

Question: Albert, you were a Chief, something these Doctors can never be.

Throughout the course of the month Albert would call upon me to encourage my study as well as to provide other valid data on the special school. However the life history of one person does not illuminate an entire society, or a full statement of a specific society. The secondary data from these dialogues with the Chief reveals two things: the lack of personal power of one Chief in relation to the Indian Agent at the time, and the knowledge of the existence of the 'special school' at that given time period (1959-1962).

Interviews With Nurse's Aides: Excerpts from Oral Interviews

Aide 1: I remember that time when children of the Catholic School were taken to a new school built for that German teacher [she did not quite remember the name, Mr. Häensell]. My job was to remember which child received a cube every three months as well as to remember which child received a needle from the nurse Miss Rülloff. Miss Rülloff always reminded me not to talk about immunizations, or in fact anything we might have done during those three years working for her. I kept in touch with the nurse for a few years after the school closed suddenly. When my brother died, I told her, "what if it was those sugar cubes?"

She never wrote to me after that, maybe she thought that I spoke about something that we had shared. She might have thought I blamed her for Joe's death, but I didn't. She was a good person. I never was told about those cubes other than they were always locked in an aluminum case, if that's what you want to know.

The other Aide provided the details Dela could not and are as follows:

Aide 2: I don't know much about that time other than it was hard working for

someone you never had a chance to talk to. There were only three of us looking after the school, Dela, the nurse and myself.

Someone would have to be dumb not (to) think what (I) am thinking. Since turning to a higher power, I see things very different than I did then. I remember clearly though that the nurse was not a nurse but a doctor and didn't want to deliver babies at all. In the minds of the Indian Agents (there were two during the three years, one came at the same time as the nurse and left the same time as the nurse did), the sugar cubes were always important, as were the rations the families received. The families whose children went to the school received extra rations. Other than that I don't know why.

This aide was crucial, as the school files were hidden in her house. My visit to her home was always postponed due to her failing health status, however she did confide in me that they were labeled as being important. She viewed the files as her property. At the moment the secrets in the files from the old nursing station are as they were in 1962, when the last school year ended.

Profiles from the Cohort Group Data

The 31 members of the cohort that have departed had an average life span of 36.13 years, the age of dying beginning at the age of 30 and the oldest departing at the old age of 49. The seven who remain have an average current age of 47.57 years. The average life span for Aboriginals in Canada is 58 years,

for non-Aboriginals 78. One way of expressing early mortality is to consider the lifespan of each departed individual in the cohort and subtract years lived from either average, Aboriginal or non-Aboriginal, and express the result, either individually or summed over cases, as potential years of life lost (PYLL). The average PYLL for those who have departed is 24 years per individual considered with respect to average life-span for Aboriginals. Another way to summarize the situation in epidemiological terms would be to speak of rates, both mortality rates and morbidity rates, but the abstract expression in terms of “rate” misses the point that the incidence of morbidity and mortality in this group of 38, identified collectively in terms of school, age, and religious identification, is very unusually high.

“Potential years of life lost” is not a meaningful concept for the people in the cohort nor the community. These people did not nor will they conceive of this notion because those years did not happen. Potential in the Cree context implies the possible: it refers more to chance, than possible, *ka kehi kihn*. Destiny is still a powerful element of the Aboriginal culture, and the researcher was often reminded of his role in the community. When a young person is chosen by a higher power, it is seen as divine destiny to die young from natural sources such as disease and sickness (morbidity). In this culture, morbidity is observed as something to hasten one’s life suffering, something that has been sent to you. Then the healer’s role is to remove the obstacle, proving the worthiness of the patient in the eyes of the supreme being.

The first person to die was Joe, in 1984, leaving six children and a wife. This was the first brain-tumor tragedy, when Joe died after his surgery. Joe was

a prominent member of the Shirt Clan. This clan should be viewed as the more traditional Cree sub-society of Goodfish.

Other members of the traditional clan would be affected (21 out of the 31 deaths), and as a result blame could be placed on that factor as well (traditionalism). The other victims included the Cardinals. This researcher's cousin (Lotte) survived the removal of two tumors of the brain in 1985. Suffering from too many surgeries and 'doctoring' from various healers that did nothing but lay blame on others within the community, she never overcame her obstacles and succumbed to her own morbidity. She came to believe very strongly that all that this was done to her in what is known in circles as a 'curse' or in the Cree Aboriginal context 'bad medicine'. What ever it is, it is a reality for Lotte.

Case Studies

From the cohort group nine subjects succumbed to cervical cancer. The following are a few of the interviews, reflecting the relationships that this researcher has had with the cohort of that school at Goodfish Lake Alberta, since 1984 when the first death occurred. The depth of each relationship has developed as a result of silent group suffering over 37 years since the school closed its door.

Deline

Deline suffers from three types of cancer, cervical, breast, and brain cancer, and has had brain surgery. She is 45 years old. Her first battle was with the brain tumor that was removed in 1988. Then she had breast cancer, which was treated with chemotherapy in 1990, and cervical cancer, which continues today. In

addition she has rheumatoid arthritis which keeps her busy just trying to remain positive with the thought that a higher power had designed this ordeal for her alone. She wishes to pass on this message “that she did not succumb to all these medicines”. Her Kohkom (grandmother) raised her; therefore she understands the diseases as “big medicine”. She currently is enrolled in a palliative care program, perhaps adding strength to a program she can teach herself. Deline was also one of the first in the community to attain a university degree in education and has taught Cree in the Native Studies program at the University.

At the time of her Kohkom’s death at 115 years of age, Deline was already in poor health with a brain tumor. Her husband had abandoned her, leaving her to take care of her two children, although she was almost paralyzed. The ‘big medicine’ was to be her nemesis for the next 15 years. When one confronts an illness, ‘medicine which was meant for you’ kih mahs kih keym, it becomes ‘your own’ medicine’. Aboriginal healers were able to diagnose and arrest a disorder because they had knowledge of its base and weakness, therefore developing a relationship with the disease to remove it from the host body. It is this same pattern by which medical geneticists are able to determine the origin and the cellular structure of microorganisms that inhabit the human body (cell breakdown or cell replication).

The late Peter Shirt said that, “breakdown of the human cell” (probably Helper T-cells) is often the cause of disease. The only way to “heal” a person was to persuade these cells to reconstruct their true patterns, although some of

the markers were very stubborn to do so (personal communication in June 21, 1976); hence my personal interest in genetics.

It was only in the mid 1900s that the understanding arose of the four main proteins (nucleotides) that are responsible for the development of all cellular structure and that each cell base had a formula (i.e. a=ACTTTCAGACC) that constituted the basis of the double helix (Watson & Crick, 1983). An abstract developed in 1953 detailed their novel findings of Deoxynucleotides (DNA) at a time when science needed new developments. The four proteins they screened were Cytosine (C), Guanine (G), Thymine (T) and Adenine (A) (Hames & Hooper, 1997). Basically they were the four main protein bases that constituted the human genome in many variations.

Esther

Esther needed me in the year of 1992 to help in the “healing” of cancer that had spread throughout her body. Cervical cancer (stage IV) would consume her by the end of the year and she would pass on to the other side in the fall of 1992.

Since the diagnosis came early in the year of 1992, little could be done, due to the frozen ground, to construct a “sweatlodge” healing-lodge ceremony. Cree Medicinal Therapy was administered to the woman but later she resorted to chemotherapy as a means of arresting the sickness. When the snow had melted, the husband and family members assisted in the building of the lodge (after waiting for the first thunder to sound its blessing). She was the first to be treated

that year for cancer and was the last. (After the Indian Summer and the first fall of snow.)

In the end of June, 1992 the doctors at the Cross-Cancer Centre told her that the cancer was in complete remission. Although at that stage IV the cancer itself is usually irreversible for a period of two months she had no visits to the physician or the healer until she called me up in San Diego to tell us to come home from our summer vacation. With intensive healing and using the services of several healer assistants, she still ended up in the hospital again in September 29, 1992. This time her immediate response was to get her ready for the departure to the next world, realizing that the acceptance of the disease was at hand. True to format of disease and dying, a full circle was complete. She left to the other side in November of that year (1992).

Lotte

Lotte was born in 1963; she went to the small school as a grade one student. She was enrolled at the same time and period as this researcher (1959-1960) in grade one. She excelled in all subjects and was called the teacher's pet. Hardworking students are often referred to as pets and therefore tended not to work as hard as others. In 1986 she developed a tumor of the brain which was removed immediately, but soon the tumor came back and she had further surgery in 1988 for the same type of tumor. The tumor was malignant but she was told originally that it was benign.

By 1995 the patient had turned to traditional Cree healing, although her family (clan) membership had no immediate connection to the traditional mores.

It had become a last resort and as a result she was ostracized from her immediate family. Through the systems of Cree Traditional Healing Methodology one becomes either a member whose ties must be linked with history or else an initiate through various rituals and ceremonialism. A traditional family would have to sponsor her. Her membership came through the Sundance clan where she was adopted, first as a sister then a lover of the leader. After going through the different ceremonies designated for her, she developed an antisocial mentality. Her psychosocial state deteriorated to a point where she became a recluse. She secluded herself, not allowing anyone connected to her past to see her.

Today she lives a life of a reclusive, scared, scarred, and endlessly angry person, seldom coming out of her apartment other than to get her medication.

When interviewing the group for this study I managed to get an agreement from her to tell her story in a manner suitable. (The cohort now thinks I am progressive enough to help design a suitable cause and effect hypothesis for the demons that affected us all as children.)

Through the interviews I found the nurse aide's, Dela, knew about the sugar cubes she had given us every three months, as well as the needles for small pox, measles and polio. (The Sabin Vaccine was an oral vaccine, requiring sugar cubes to be used.) In addition, the oral vaccine was cheaper to make in part because it does not require careful treatment with formalin (a virus killer). However the disadvantage was its tendency to spoil when exposed to prolonged temperate heat. In fact, maintaining a "cold chain", that is, keeping the vaccine refrigerated throughout its journey from manufacturing, distribution and

administration, has been one of the principal hurdles for immunization programs (Aggarwal & Singh, 1995).

Viola C.

This research has been subjected to methods using in an insider's approach. Very little attention to development of one-on-one, across-the-desk rapport has been needed because of the unique relationship the researcher has developed with the entire subject. The interview process with Viola occurred over a period of two days where visits (6) were exchanged to complete the data collection. Viola did remember more than I did, perhaps because that school was a way out of the adverse poverty she lived in. In addition, her mother had abandoned her seven children in 1962, leaving her and her oldest sister to care for the youngest. Therefore school was important to her as well as framing a clear chain of events in her life. The following is part of the dialogue this researcher had with her in May, 2000.

Commentary by a Cohort Member:

In the school you're talking about, I remember our teacher used to give us these sugar cubes and I always thought that was one reason many of us got sick. You know there are not many of us that are alive today. I use to pretend I took them, but I use to put them in my pocket to show my dad. He would give them to my baby brother. [Researcher notes: *The brother she mentions is 27CT in Appendix 1B, a member of the cohort. He died from suicide, having experienced headaches which he said he could not endure. I recall his efforts to rid himself of the headaches, participating in*

the ceremonies that comprise healing practices, but in the end he eliminated the problem for himself. I understand it subjectively, from personal experience before brain surgery, when cognition is low.]

The comments she made were not in any way connected to a discussion on the topic, 'day-schools during the residential school era': when she brought up the subject of the sugar cubes, especially in connection with her younger brother's excruciating headaches, it was almost like finding a piece of a puzzle at a frustrating time in the research project, when it was tempting to question the validity of the possibility of connection between the cohort's health and mortality, and the special school,. Someone else remembered the use of sugar cubes, but only in terms of establishing that sugar cubes were used at the school to provide medication as she suggested. Until recently she was healthy.

The Other Two Survivors

The remaining two survivors appeared to have been healthy when this project was being completed. It might have been possible to interview them to include their perspectives as healthy survivors. Unfortunately, during the last stage of the project, both were diagnosed with cancer and were beginning treatment . It would not have been appropriate to request interviews with them at the time. Their illnesses brought the morbidity rate of the cohort to 100%.

Chapter IV. Contemporary Health in Goodfish Lake Community

Health Determinants From an Aboriginal Perspective

Although large numbers of First Nations people live outside reserves, there is still a great divide between populations. Many Aboriginal people, to this day, have little or no lived-experience in the outside world, the world of the “white man”. Though a large number live off-reserve, there remains a social division between the communities, which may be based on either (or both) perceptions of racial difference or socio-economic status. The Grand Chief of Saskatchewan, on November 15, 1999, said that the welfare rate of aboriginal people is between 80% and 98%: it can be said that many Aboriginal people live below the national poverty level, but do not, themselves, think in those terms. On average, the Aboriginal annual income across Canada is \$7,000, while the national poverty level is \$14,000. Poverty is a disease, and from a social standpoint, may be expected to increase (McKnight, 1995).

The assumption of culture (or culture change) as a determinant of health, as defined in many epidemiological studies, does not have much explanatory value. Socioeconomic Status (SES), has been said to be the most powerful and consistent epidemiological risk factor. Socio-economic status is an important correlate of race in many populations; it is inadequate to present data by race without controlling for SES. Researchers frequently find that adjusting their results for SES substantially reduces, or even eliminates racial disparities in health (Amick et al., 1995).

This research includes a current socio-economic indicator (i.e., employment) in a house to house survey of 100 individuals in the community, focusing on community attitudes about health care. The survey was completed in April of 2000. The objective is to set the cohort study into a current setting, the community of the survivors. The results are tabulated below.

Results from the Socio-economic survey

Question 1. Quality of care. Judging from community discussions and the discourse of Elders, the main issue would not appear to be the quality of health care, but the quantity—being able to access health care with relative ease. Yet with this question the 100 community members showed disparity between the modal response of Poor (41) and the least frequent response of Excellent (5). Just less than one third of the respondents thought that the quality of health care provided by physicians, hospitals, and health centers during the past year was “good” or better. There is a very widespread judgment in the community that the quality of medical care is not good.

Question 2. Comparison: Family health status, relative to community. Evaluating the health status of your own family is a personal matter. Humility may play a role here, as a cultural norm for Aboriginal people would have most people tend to rate themselves as low as possible; it would not have been surprising to find a large number who answered Fair or Poor, though less than one third did so, and the rest rated themselves from Good to Excellent. This is a response area that cannot be interpreted at face value because of the semantics of the terms, as well as cultural norms involving public self-evaluation, relative to others

Questions	Excellent	Very Good	Good	Fair	Poor	
1. Rate the quality of care received this year: Physicians, as well as Hospitals & Health Centres.	5	13	14	27	41	
2. Rate your own family's health status in relation to the rest of the community.	33	21	17	3	26	
3. The community's health status according to your view is?	21	27	36	7	9	
4. Rate your employment status for the whole of the past year.	Unemployed	Part-time	Seasonal	Full-time	Careers	
	53	9	14	15	9	
5. How many times in the course of one year were you in a situation where you had to make an appointment to see a physician?	Weekly	Bi-Weekly	Monthly	Never		
	65	23	11	1		
6. Identify the type of healthcare you accessed in 1999	Physicians	Specialists	Alternative Treatment	Traditional Healers		
	38	19	20	23		
7. Indicate the possible cause of poor health in the Community, including all factors	Water	Food	Drugs	Contaminants	Lifestyle	Addictions
	30	41	10	2	4	7

Survey sample size N=100. Conducted by Clifford Cardinal at Whitefish Lake First Nation #128, April 2000

Table 1. Aboriginal People's Attitudes Towards Health Care

Question 3. Community health status. Rating one's own community involves some of the same issues as Question 2. It portrays perceptions of the community, and is based on a feeling of identification and a sense of community

belonging, where one stands in the community. This concept of belonging to a community may be related to the development of what we view as bands. Only one sixth of the respondents had essentially negative evaluations of community health (e.g., Fair (7) and Poor (9)). Again, the responses to this question can only be tentatively accepted at face value. One has only to look at the frequency with which community members seek out health care providers to see that there is a contradiction between this self-evaluation and the kind of self-assessment that results in action: seeking medical attention.

Question 4. Employment status. Question 4 marks the economy as an indicator of health. Employment as indicated, is implying that SES is factored into any health index. The 100 respondents were a mixed group of people, whose ages ranged from between 20 and 60 years of age; 63 were female and 37 were male. The community has an unemployment rate of 82% as of 1997. This mini-survey revealed that the unemployed (53) made up over half of the community's economically distressed, while the seasonally employed was at a modest 14%. The seasonally employed were mainly fire fighting for 30 days a year on the average. Other part-time work includes welfare work programs in the community.

Question 5. Frequency of physician appointment. This question was motivated by the discussions on the overuse of healthcare services by Aboriginal people in Alberta, a statement made over and over again in the now renowned National Forum on Health (1997). Included are the amounts and times of use of health services by individuals in the community of Goodfish Lake, Alberta, within a one-year period. From the survey, 65 of 100 sought appointments weekly, while only one person indicated to have never visited a doctor or a hospital.

(Further ethnographic or policy research is motivated by this figure. On the face of it, the figure appears to indicate overuse. This probably reflects peculiarities in patterns of access (or constraints to access), relative to frequency, continuity, and repetition of itinerant physicians' clinics; economies of scale in providing for visiting physicians; and communications problems between health care practitioners and community members.)

Question 6. Type of health care accessed. This particular question is a contingency question, relating to the previous question. It also serves as an indicator of the type of service that the Aboriginal people at Goodfish Lake prefer. Overall there was an interesting sentiment in regard to preferences of treatment of the disease by the sick people. The following is the preference-spread by the subjects in the event they were ill: Physicians (38), Specialists (19), Alternative Treatment (20), and Healers (23). This indicated a general spread of the types of help available today locally. It also implies Aboriginal people are relying on both alternative treatment and healers as their own personal electives, and that personal expense is not an issue when one becomes ill. One person stated that, "as a last resort he would turn to traditional healing, because it was costly". Traditional healers make (if one was going to apply costs) up to \$1,000.00 for cancer treatment, but cost is not mentioned, because to do so is to jeopardize one's own healing factors. A traditional healer well versed in the art of treating cancer can treat up to 10 patients a day, all year. This of course depends on the reputation of the healer in the Aboriginal community.

Question 7. Causes of poor health. This was a free choice response. It was interesting to find what the individuals felt were the causes of ill health within

the community. There appears to be a disparity between the individual's perception and the community's as an aggregate. Knowing what the community feels at this point appears to confound the results taken from individual interviews. Community attitudes affected individual's responses. It could be taken that the community has a direct or an indirect effect on health behaviours within the overall community as well as in individual health outcomes. Aside from the fact that other people had completed the interview surveys in a period of two weeks, the answers to these questions were generally what I had related to and anticipated from an Aboriginal perspective. Generally, health outcomes result from the expected behaviour of a disease. Personal rationales for individual health status are another aspect of personal will and are viewed as an ongoing overall characteristic of the health status of people in Goodfish Lake. However, blaming others from outside the community in regard to personal health status also arose.

The social components from within the existing Aboriginal cultural paradigms are not easily understood for Eurocentric mindsets. Developing causal models in keeping with the determinants of health model requires both a theoretical view and empirical testing of the theory. The one element that must be added is the contextual mindset of researchers, "increased concentration on relative deprivation or social inequalities as a means of exploring community determinants of health" (Amick et al., 1995).

Community as a Determinant of Health

The community of Goodfish is an excellent example of homogeneity and the community is perhaps the greatest single determinant of health from within. Although there exist factions within the community, a person has to fit in order to be a part of that collective community. It is always important to note that many Aboriginal people still feel that “something” was wrong in those years indicated in this study (1959-1963) but that nothing was ever done to explore what really happened.

Psychosocial behaviors that appear rampant in the community clearly include suicides committed by the cohort group during the years marked in the retrospective study period. It included four suicides from the group of 38 subjects during the 16-year period (beginning with 1984, the suicide rate was at 12%). One could easily suggest these cases to imply the subjects lived a high-risk lifestyle, as is the case with most Aboriginal communities in Alberta, but the element of changed behaviour centered on the activity of that ‘special school’ which seemed to prevail in all instances of the interviews. There were no murders, as are often associated with high-risk behaviours in the communities. On the contrary, there was a sense of camaraderie that was student-specific, due perhaps to the context of communal living (the people of Goodfish were well aware that the subjects went to that school). Overall the mortality issue was not an easy topic in many instances during the interviews as one person stated, ‘why do we need to bring something up that is not a problem today’. In Aboriginal communities it is not proper to discuss the dead unless it is seen in the context of good history, implying those deeds that were accomplished by great men.

Always in the minds of the cohort group who felt that discussions around those that have passed on to the other side (death) might cause more bad than good for all of us. It is therefore important to note at this point further research on what has occurred already is often seen as being wrong (taboo).

Table 2. Attitudes Regarding Death: Personal Observations

<ul style="list-style-type: none">• Funerals in Aboriginal communities are social events, a complete celebration of life, and a ceremony of life's closure. They are an important element of social interaction and structure. (Bill Reid: CBC's Documentary of a Haida's own Funeral Design)• Towards personal reality, people often discuss who should be present at their own funerals, calling upon certain Elders to preside over the arrangements they made prior to death.• To the many Aboriginal people, dying is much easier and more viable than dealing with the miseries in life and should be anticipated as well as celebrated to such extents as to what was lacking in life.• To the Cree traditions, cults know as 'dog soldiers' were in reality suicide squads. They staked themselves in the ground with ropes tied around their waists, waiting for the charging enemy to get within range of their bullets or arrows, thus giving time for the others to flee from the battle scene. This society still exists today; their stories told in Pow Wows and other Wellness Gatherings and heard by all whom attend most Aboriginal gathering places.

Chapter V. Conclusion

As we enter the Millennium we have visions that the Cree will change so that each and every member can attain autonomy from within. If we minimize our objective to alter or change the views of a group of people who have refused to change except in their own terms, we soon realize that maybe the approach is wrong. Intervention programs and health outcomes may not reduce the high mortality and morbidity rates in Aboriginal communities in Alberta. The public and policy definition of the issues has been articulated outside the community.

Instead risk factors may need to be expressed by the people who live in those high-risk situations. The many people who have no concept of poverty and the effects of an empty stomach should consult freely and openly with those who have lived experience. Decision-makers need to consult more freely with those living the traditional life of the Cree.

Health care, as an abstract concept of the Aboriginal people, has long been viewed in terms of practices that were decreed by a long line of medical practitioners (healers), designed by nature, nurtured by tradition and ordained by way of divine intervention. The outcome was curing, rather than treatment of disease. Treatment methodology, more recently, has offered a distinction between the healer and the community, whereby disease treatment is often provided by medical doctors.

As we review the reform strategies of the government today for the indigenous people, we see the impact it has had on their cultural integrity. Aboriginal input in decision-making is often lacking in the development of policies

that affect them. Instead token positions are often provided in the form of board memberships and honorariums, or Elders are included, usually to formally open meetings. Furthermore the inability of the leaders to articulate their needs has often resulted in ambiguity of policy statements. Health determinants in the Aboriginal context include those mentioned by health care researchers, such as poverty and socio-economic stresses, but should also include the mass break up of a cultural complex by oppressing cultures.

Epidemiological research has been increasingly concerned with mechanisms by which key determinants of health promote health and cause disease (Amick et al., 1995). Their studies deal with complexities by means of three or more variables at a time to reconstruct health-promoting factors, or the etiology of disease.

When building upon other larger assumptions such as regressive studies, we begin to validate the very context by which these "First Nations" were built. Indeed First Nations were oppressed. Yes, perhaps the oppression is based on current and recent racism, but Aboriginal leaders and the stakeholders alike at some point need to put aside those cultural disparities and declare the desire to work together. This is perhaps where the benefit lies with the cohort from Goodfish Lake, by providing a clear focus for continuing collaborative research.

Very little concern has been put into investigating the nature of the vaccines that were common in the period of time when polio was pandemic. There was too much pressure to manufacture a vaccine that could arrest polio. Perhaps the same pressure was seen by our eyes not too many years ago in the struggle to combat HIV-AIDS in Alberta. In a bigger reality both vaccines (Salk

and Sabin) offered the world a great reprieve with the introduction of vaccines that were efficient with few side effects. Data revealed that opportunistic infections from vaccines pointed to the contaminated titers of polio vaccines and recombined in their own genes to create monkey-human hybrid viruses.

Summarizing something that is almost sacred to the people is a very difficult task especially if one had shared the sum of one lifetime as a subject in the topic of choice. More difficult is the inability to articulate some of the trauma that was expressed by some of the members of the community where this research took place.

I thank the higher power that has given me one last chance to tell people what really happened in that little school house nearly 40 years ago. I recall those that have left before me. Thirty-one people. Not only were they people but they were comrades that left a piece of their precious lives with me.

The discretionary description is a heavy burden in the study; I see no rationale at the moment why the mortality of the cohort was so high, or why nothing was ever done except to keep a tabulation of the high mortality rates of Aboriginal people at the time.

This work documents an unusual rate of morbidity and mortality in a specific small age and social cohort in a small Aboriginal community, rates that now comprise 100% of the cohort. By any measure, that situation is unusual and worthy of clinical investigation. This work demonstrates that as community members attempt to account for the pain and suffering that those rates represent, the members of the cohort themselves, and other community members, raise as an incidental concomitant—not a cause—the common experience of the cohort's

attendance at an unusual school over a three-year period, 40 years ago. There are, conceivably, other common factors that might be implicated as contributing to mortality and morbidity.

We will continue to wonder what it was that led to the high mortality rates of the cohort group and whether or not SV40 was responsible. The kind of clinical work that would substantiate the implication of the vaccine in mortality and morbidity is beyond the scope of this study. The reality of coming so close to triangulating clinical evidence, with historical documentary evidence and ethnographic evidence is a mixed blessing. With new methods that are now available in molecular medicine, even a small number of blood-dot samples might be one step toward confirming the implication of the vaccine, or raise new questions.

My goal in this study has been to learn how to do research in a community, fitting myself with the right tools to construct a possible investigation in the future to improve the health of Aboriginal people. This study has included an integration of interviews and conversations with the Elders, with the nursing staff from the school, and with the survivors within the cohort. The data have been organized and discussed, rather than dissected, as it was the wish of the Elders and the survivors that the stories themselves be the data. Indigenous people are increasingly developing their own approach to research, an approach that reflects the past, and provides an opportunity to hear voices of those who have not traditionally been heard in the halls of research institutions (Alfred, 1999; Smith, 1999). This study includes my own voice, as well as the others in these pages.

There are many determinants of health and illness on aboriginal reserves. I have raised some of these in relation to Goodfish Lake: geographic location; politics; educational practices and belief; aboriginal health beliefs; healing practices; culture, and most important of all to the surviving cohort, community. We may never fully understand what happened to our cohort at that special school. We know, however, that in our community is our source of support and healing.

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Appendix 1A. Comparison Group

Mortality and Morbidity for 1989 to 1999 in the
(7-13 years) Goodfish Cohort
Protestant Comparison Group

Protestant Comparison Group born between 1949 to 1957
 (Status of all residents in community is common knowledge since kinships must be known at all times by Healers)

<u>Coding</u>	<u>Date of Birth</u>	<u>Status</u>	<u>Disease & Condition</u>
1CM	1949	Alive	Healthy (Alcoholism)
2CM	1949-1990	Deceased	Cirrhosis
3CM	1949	Alive	Healthy
4CM	1949-1989	Deceased	Car Accident
5CM	1949	Alive	Healthy (Morbidity)
6CM	1949	Alive	Healthy
7CM	1953	Alive	Had Cancer (Therapy)
8CM	1954-1989	Deceased	Throat Cancer
9CM	1956	Alive	Health (Alcoholism)
10CM	1952	Alive	Healthy
11CM	1952	Alive	Had Cancer
12CM	1950	Alive	No Known Disease
13CM	1953	Alive	Healthy
14CM	1954-1987	Deceased	Lost in Wilderness
15CM	1956	Alive	Throat Cancer
16CM	1952	Alive	Healthy
17CM	1953	Alive	Healthy (Alcoholism)
18CM	1954	Alive	Drug Abuse
19CM	1949	Alive	Healthy
20CM	1954-1990	Deceased	Drowned
21CM	1950-1992	Deceased	Car Accident
22CM	1953-1988	Deceased	Murdered
23CM	1953-1990	Deceased	Unknown (died in bed)
24CM	1955	Alive	Healthy
25CM	1954	Alive	Healthy
26CM	1952	Alive	Healthy
27CM	1950-1990	Deceased	Cervical Cancer
28CM	1854-1987	Deceased	Brain Cancer
29CM	1953	Alive	Unknown Status
30CM	1954	Alive	Healthy
31CM	1952-1989	Deceased	Suicide
32CM	1952-1989	Deceased	Murdered
33CM	1954-1989	Deceased	Died from Overdose
34CM	1949	Alive	Health
35CM	1957-1990	Deceased	Car Accident
36CM	1950-1993	Deceased	Liver Cancer
37CM	1952-1992	Deceased	Suicide
38CM	1952-1994	Deceased	Car Accident

Appendix 1B. Cohort Group

Mortality and Morbidity for 1989 to 1999 in the
(7-13 years) Goodfish Cohort

**Mortality and Morbidity Rates for 1984 to 1998 in
the (7-13 years) Goodfish Cohort
Roman Catholic Children born between 1949 to 1956**

<u>Code</u>	<u>Date of Birth</u>	<u>Status</u>	<u>Disease &</u>
1CT	1949-1984	Deceased	Car Accident
2CT	1949-1984	Deceased	Lung Cancer
3CT	1949-1984	Deceased	Liver Cancer
4CT	1949-1995	Deceased	Cervical Cancer
5CT	1949-1990	Deceased	Cervical Cancer
6CT	1949-1988	Deceased	Cervical Cancer
7CT	1949-1991	Deceased	Bone/Brain Cancer
8CT	1949-1985	Deceased	Brain Cancer
9CT	1950-1987	Deceased	Liver Cancer
10CT	1950-1989	Deceased	Suicide (due to pain)
11CT	1950-1986	Deceased	Liver Cancer
12CT	1950-1994	Deceased	Suicide
13CT	1950-1992	Deceased	Liver Cancer
14CT	1950-1990	Deceased	Brain Cancer
15CT	1950-1985	Deceased	Brain Cancer
16CT	1951-	Alive	Cervical Cancer
17CT	1951-1985	Deceased	Brain Cancer
18CT	1951	Alive	Cervical Cancer
19CT	1952-1987	Deceased	Brain Cancer
20CT	1952	Alive	Brain/Cervical Cancer
21CT	1952-1985	Deceased	Car Accident
22CT	1952-	Alive	Brain Tumor
23CT	1952-1990	Deceased	Liver Cancer/Car
24CT	1952-	Alive	Brain Tumor removed
25CT	1952-1990	Deceased	Cervical Cancer
26CT	1953-1990	Deceased	Brain Tumor
27CT	1953-1988	Deceased	Suicide (due to pain)
28CT	1853-1998	Deceased	Brain Tumor
29CT	1954-1989	Deceased	Mammary Cancer
30CT	1954-1987	Deceased	Liver Cancer
31CT	1954-	Alive	Cervical Cancer
32CT	1955-1985	Deceased	Liver Cancer
33CT	1955	Alive	Cervical Cancer
34CT	1955-1989	Deceased	Brain Cancer
35CT	1955-1995	Deceased	Suicide (personal)
36CT	1956-1990	Deceased	Cervical Cancer
37CT	1956-1995	Deceased	Liver Cancer
38CT	1956-1996	Deceased	Liver Cancer

Appendix 2. Treaty No. 6

TREATY No. 6

BETWEEN
HER MAJESTY THE QUEEN
AND THE PLAINS AND WOOD CREE INDIANS
AND OTHER TRIBES OF INDIANS
AT FORT CARLTON, FORT PITT AND BATTLE RIVER WITH ADHESIONS

Roger Duhamel , F.R.S.C.
Queen's Printers and Controller of Stationary
Ottawa, ON, 1964
Cat. No. R33-0664
IAND Publication No. QS-0574-000EE-A-1

(without adhesions)

ARTICLES OF A TREATY made and concluded near Carlton on the 23rd day of August and on the 28th day of said month, respectively, and near Fort Pitt on the 9th day of September, in the year of Our Lord one thousand eight hundred and seventy-six, between Her Most Gracious Majesty the Queen of Great Britain and Ireland, by Her Commissioners, the Honourable Alexander Morris, Lieutenant-Governor of the Province of Manitoba and the North-west Territories, and the Honourable James McKay, and the Honourable William Joseph Christie, of the one part, and the Plain and Wood Cree and the other Tribes of Indians, inhabitants of the country within the limits hereinafter defined and described by their Chiefs, chosen and named as hereinafter mentioned, of the other part.

Whereas the Indians inhabiting the said country have, pursuant to an appointment made by the said Commissioners, been convened at meetings at Fort Carlton, Fort Pitt and Battle River, to deliberate upon certain matters of interest to Her Most Gracious Majesty, of the one part, and the said Indians of the other.

And whereas the said Indians have been notified and informed by Her Majesty's said Commissioners that it is the desire of Her Majesty to open up for settlement, immigration and such other purposes as to Her Majesty may seem meet, a tract of country bounded and described as hereinafter mentioned, and to obtain the consent thereto of Her Indian subjects inhabiting the said tract, and to make a treaty and arrange with them, so that there may be peace and good will between them and Her Majesty, and that they may know and be assured of what allowance they are to count upon and receive from Her Majesty's bounty and benevolence.

And whereas the Indians of the said tract, duly convened in council, as aforesaid, and being requested by Her Majesty's said Commissioners to name certain Chiefs and Headmen, who should be authorized on their behalf to conduct such negotiations and sign any treaty to be founded thereon, and to become responsible to Her Majesty for their faithful performance by their respective Bands of such obligations as shall be assumed by them, the said Indians have thereupon named for that purpose, that is to say, representing the Indians who make the treaty at Carlton, the several Chiefs and Councillors who have subscribed hereto, and representing the Indians who make the treaty at Fort Pitt, the several Chiefs and Councillors who have subscribed hereto.

And thereupon, in open council, the different Bands having presented their Chiefs to the said Commissioners as the Chiefs and Headmen, for the purposes aforesaid, of the respective Bands of Indians inhabiting the said district hereinafter described.

And whereas, the said Commissioners then and there received and acknowledged the persons so presented as Chiefs and Headmen, for the purposes aforesaid, of the respective Bands of Indians inhabiting the said district hereinafter described.

And whereas, the said Commissioners have proceeded to negotiate a treaty with the said Indians, and the same has been finally agreed upon and concluded, as follows, that is to say:

The Plain and Wood Cree Tribes of Indians, and all other the Indians inhabiting the district hereinafter described and defined, do hereby cede, release, surrender and yield up to the Government of the Dominion of Canada, for Her Majesty the Queen and Her successors forever, all their rights, titles and privileges, whatsoever, to the lands included within the following limits, that is to say:

Commencing at the mouth of the river emptying into the north-west angle of Cumberland Lake; thence westerly up the said river to its source; thence on a straight line in a westerly direction to the head of Green Lake; thence northerly to the elbow in the Beaver River; thence down the said river northerly to a point twenty miles from the said elbow; thence in a westerly direction, keeping on a line generally parallel with the said Beaver River (above the elbow), and about twenty miles distant therefrom, to the source of the said river; thence northerly to the north-easterly point of the south shore of Red Deer Lake, continuing westerly along the said shore to the western limit thereof; and thence due west to the Athabasca River; thence up the said river, against the stream, to the Jasper House, in the Rocky Mountains; thence on a course south-easterly, following the easterly range of the mountains, to the source of the main branch of the Red Deer River; thence down the said river, with the stream, to the junction therewith of the outlet of the river, being the outlet of the Buffalo Lake; thence due east twenty miles; thence on a straight line south-eastwardly to the mouth of the said Red Deer River on the south branch of the Saskatchewan River; thence eastwardly and northwardly, following on the boundaries of the tracts conceded by the several treaties numbered four and five to the place of beginning.

And also, all their rights, titles and privileges whatsoever to all other lands wherever situated in the North-west Territories, or in any other Province or portion of Her Majesty's Dominions, situated and being within the Dominion of Canada.

The tract comprised within the lines above described embracing an area of 121,000 square miles, be the same more or less.

To have and to hold the same to Her Majesty the Queen and Her successors forever.

And Her Majesty the Queen hereby agrees and undertakes to lay aside reserves for farming lands, due respect being had to lands at present cultivated by the said Indians, and other reserves for the benefit of the said Indians, to be administered and dealt with for them by Her Majesty's Government of the Dominion of Canada; provided, all such reserves shall not exceed in all one square mile for each family of five, or in that proportion for larger or smaller families, in manner following, that is to say: that the Chief Superintendent of Indian Affairs shall depute and send a suitable person to determine and set apart the reserves for each band, after consulting with the Indians thereof as to the locality which may be found to be most suitable for them.

Provided, however, that Her Majesty reserves the right to deal with any settlers within the bounds of any lands reserved for any Band as She shall deem fit, and also that the aforesaid reserves of land, or any interest therein, may be sold or otherwise disposed of by Her Majesty's Government for the use and benefit of the said Indians entitled thereto, with their consent first had and obtained; and with a view to show the satisfaction of Her Majesty with the behaviour and good conduct of Her Indians, She hereby, through Her Commissioners, makes them a present of twelve dollars for each man, woman and child belonging to the Bands here represented, in extinguishment of all claims heretofore preferred.

And further, Her Majesty agrees to maintain schools for instruction in such reserves hereby made as to Her Government of the Dominion of Canada may seem advisable, whenever the Indians of the reserve shall desire it.

Her Majesty further agrees with Her said Indians that within the boundary of Indian reserves, until otherwise determined by Her Government of the Dominion of Canada, no

intoxicating liquor shall be allowed to be introduced or sold, and all laws now in force, or hereafter to be enacted, to preserve Her Indian subjects inhabiting the reserves or living elsewhere within Her North-west Territories from the evil influence of the use of intoxicating liquors, shall be strictly enforced.

Her Majesty further agrees with Her said Indians that they, the said Indians, shall have right to pursue their avocations of hunting and fishing throughout the tract surrendered as hereinbefore described, subject to such regulations as may from time to time be made by Her Government of Her Dominion of Canada, and saving and excepting such tracts as may from time to time be required or taken up for settlement, mining, lumbering or other purposes by Her said Government of the Dominion of Canada, or by any of the subjects thereof duly authorized therefor by the said Government.

It is further agreed between Her Majesty and Her said Indians, that such sections of the reserves above indicated as may at any time be required for public works or buildings, of what nature soever, may be appropriated for that purpose by Her Majesty's Government of the Dominion of Canada, due compensation being made for the value of any improvements thereon.

And further, that Her Majesty's Commissioners shall, as soon as possible after the execution of this treaty, cause to be taken an accurate census of all the Indians inhabiting the tract above described, distributing them in families, and shall, in every year ensuing the date hereof, at some period in each year, to be duly notified to the Indians, and at a place or places to be appointed for that purpose within the territory ceded, pay to each Indian person the sum of \$5 per head yearly.

It is further agreed between Her Majesty and the said Indians, that the sum of \$1,500.00 per annum shall be yearly and every year expended by Her Majesty in the purchase of ammunition, and twine for nets, for the use of the said Indians, in manner following, that is to say: In the reasonable discretion, as regards the distribution thereof among the Indians inhabiting the several reserves, or otherwise, included herein, of Her Majesty's Indian Agent having the supervision of this treaty.

It is further agreed between Her Majesty and the said Indians, that the following articles shall be supplied to any Band of the said Indians who are now cultivating the soil, or who shall hereafter commence to cultivate the land, that is to say: Four hoes for every family actually cultivating; also, two spades per family as aforesaid: one plough for every three families, as aforesaid; one harrow for every three families, as aforesaid; two scythes and one whetstone, and two hay forks and two reaping hooks, for every family as aforesaid, and also two axes; and also one cross-cut saw, one hand-saw, one pit-saw, the necessary files, one grindstone and one auger for each Band; and also for each Chief for the use of his Band, one chest of ordinary carpenter's tools; also, for each Band, enough of wheat, barley, potatoes and oats to plant the land actually broken up for cultivation by such Band; also for each Band four oxen, one bull and six cows; also, one boar and two sows, and one hand-mill when any Band shall raise sufficient grain therefor. All the aforesaid articles to be given once and for all for the encouragement of the practice of agriculture among the Indians.

It is further agreed between Her Majesty and the said Indians, that each Chief, duly recognized as such, shall receive an annual salary of twenty-five dollars per annum; and each subordinate officer, not exceeding four for each Band, shall receive fifteen dollars per annum; and each such Chief and subordinate officer, as aforesaid, shall also receive once every year, a suitable suit of clothing, and each Chief shall receive, in recognition

of the closing of the treaty, a suitable flag and medal, and also as soon as convenient, one horse, harness and waggon.

That in the event hereafter of the Indians comprised within this treaty being overtaken by any pestilence, or by a general famine, the Queen, on being satisfied and certified thereof by Her Indian Agent or Agents, will grant to the Indians assistance of such character and to such extent as Her Chief Superintendent of Indian Affairs shall deem necessary and sufficient to relieve the Indians from the calamity that shall have befallen them.

That during the next three years, after two or more of the reserves hereby agreed to be set apart to the Indians shall have been agreed upon and surveyed, there shall be granted to the Indians included under the Chiefs adhering to the treaty at Carlton, each spring, the sum of one thousand dollars, to be expended for them by Her Majesty's Indian Agents, in the purchase of provisions for the use of such of the Band as are actually settled on the reserves and are engaged in cultivating the soil, to assist them in such cultivation.

That a medicine chest shall be kept at the house of each Indian Agent for the use and benefit of the Indians at the direction of such agent.

That with regard to the Indians included under the Chiefs adhering to the treaty at Fort Pitt, and to those under Chiefs within the treaty limits who may hereafter give their adhesion thereto (exclusively, however, of the Indians of the Carlton region), there shall, during three years, after two or more reserves shall have been agreed upon and surveyed be distributed each spring among the Bands cultivating the soil on such reserves, by Her Majesty's Chief Indian Agent for this treaty, in his discretion, a sum not exceeding one thousand dollars, in the purchase of provisions for the use of such members of the Band as are actually settled on the reserves and engaged in the cultivation of the soil, to assist and encourage them in such cultivation.

That in lieu of waggons, if they desire it and declare their option to that effect, there shall be given to each of the Chiefs adhering hereto at Fort Pitt or elsewhere hereafter (exclusively of those in the Carlton district), in recognition of this treaty, as soon as the same can be conveniently transported, two carts with iron bushings and tires.

And the undersigned Chiefs on their own behalf and on behalf of all other Indians inhabiting the tract within ceded, do hereby solemnly promise and engage to strictly observe this treaty, and also to conduct and behave themselves as good and loyal subjects of Her Majesty the Queen.

They promise and engage that they will in all respects obey and abide by the law, and they will maintain peace and good order between each other, and also between themselves and other tribes of Indians, and between themselves and others of Her Majesty's subjects, whether Indians or whites, now inhabiting or hereafter to inhabit any part of the said ceded tracts, and that they will not molest the person or property of any inhabitant of such ceded tracts, or the property of Her Majesty the Queen, or interfere with or trouble any person passing or travelling through the said tracts, or any part thereof, and that they will aid and assist the officers of Her Majesty in bringing to justice and punishment any Indian offending against the stipulations of this treaty, or infringing the laws in force in the country so ceded.

IN WITNESS WHEREOF, Her Majesty's said Commissioners and the said Indian Chiefs have hereunto subscribed and set their hands at or near Fort Carlton, on the days and year aforesaid, and near Fort Pitt on the day above aforesaid.

Signed by the Chiefs within named in presence of the following witnesses, the same having been first read and explained by Peter Erasmus, Peter Bullendine and the Rev. John McKay.

ALF. JAMES, M.D.

JAS. WALKER, N.W.M.P.

J. H. McLELLER, N.W.M.P.

PIERRE LEVAILLER, X
his mark.

ISADORE DEMOND, X
his mark.

JEAN DUMOND, X
his mark.

PETER HOURIE,

F. GINGRAS,

J. B. MITCHELL, Staff Constable
N.W.M.P.

E. H. PRICE, Hospital Steward
N.W.M.P.

XAVIER LETANGER, X
his mark.

WILLIAM SINCLAIR.

ALEXANDER MORRIS,
L. G. N.W.T.

JAMES MCKAY, Indian Commissioner.

W. J. CHRISTIE, do

MIS-TO-WA-SER, X
his mark.

ACC-TO-K-EM-SONG, X
his mark.

DEE-YAK-KAH-NICHE-OO-SIT, X
his mark.

AI-YAH-TOA-KEM-EM-AM, X
his mark.

KEE-TOO-WA-HAW, X
his mark.

CHA-NAS-TO-PAY-SIN, X
his mark.

JOHN SMITH, X
his mark.

JAMES SMITH, X
his mark.

CHINKE-WAYAN, X
his mark.

MASS-AN, X
his mark.

PIERRE CADEN, X
his mark.

KOS-TAH-TIK-WAH-PHEE, X
his mark.

MAHE-KEE-TO-FIX-AN, X
his mark.

Head Chiefs of the
Carlton Indians.

Chiefs.

Councillors of
Mis-to-wa-ser.

A. R. KENNEDY,
 R. I. PRITCHARD,
 L. CLARK,
 W. MCKAY,
 W. D. JARVIS, Inspector, N.W.
 M.P.

SAN-SAN-KOO-MOOS, X	his mark.	} Councilors of Aa-tak-uk-koop.
BENJAMIN, X	his mark.	
MEE-NOW-AH-CHANE-WAY, X	his mark.	} Councilors of Per-guh-uh-uhk-co-sit.
KHE-UK-OW-AR-IE, X	his mark.	
PEE-TOOR-AH-HAN AP-EE-GIV-ZW, X	his mark.	} Councilors of Per-guh-uh-uhk-co-sit.
PEE-AY-CHEW, X	his mark.	
TAM-WAH-JUSE EE-KAUF-TOW, X	his mark.	} Councilors of Kee-oh-uh-uhk.
AHS-KOOS, X	his mark.	
PET-Z-QUA-CAY, X	his mark.	} Councilors of Kee-oh-uh-uhk.
JEAN BAPTISTE, X	his mark.	
ISADORE WOLPE, X	his mark.	
KEE-KOO-HOOS, X	his mark.	
OO-SAHN-US-KOO-NRE-NIK, X	his mark.	} Councilors of Alo-yuh-tuh-kum-ik-in-un.
FAY-EAH-YOO-WAY, X	his mark.	
LEO-SOH-AM-EE-KNAEN, X	his mark.	
NEZ-WAH-YAK-EE-NAH-KOOS, X	his mark.	
KAK-TU-N-KOW-AHY, X	his mark.	} Councilors of Che-ke-ay-ay-sin.
KAH-RUN-EE-KNAH-AHS-LUM, X	his mark.	
NAN-PACH, X	his mark.	
MUS-IN-AM-WE-KIM-AHKS, X	his mark.	

WILLIAM BADGER, his
 BENJAMIN JOYFUL, x mark.
 JOHN BADGER,
 JAMES BRAS,
 BERNARD CONSTANT,
 HENRY SMITH, his
 x mark.
 MA-TWA-ABS-TIN-OO-WIGON, his
 x mark.
 JACOB McLEAN, his
 x mark.
 NAA-POO-CHER-CHERS, his
 x mark.
 WAH-WIS, his
 x mark.
 KAK-PAN-PAN-NAH-CHESTIK-WAY, his
 x mark.
 KAK-NEU-AM-TEAH-PAN-WAIT, his
 x mark.

Councillors of
 John Smith.
 Councillors of
 James Smith.
 Councillors of
 Chippewagon.

Signed by the Chiefs and Headmen of
 the Willow Indians near Fort Carlton,
 this 28th day of August, A.D. 1876, the
 same having been first read and ex-
 plained by the Hon. Jas. McKay and
 by Peter Erasmus, in the presence of
 the undersigned witnesses:

A. G. JACKES, M.D.,
 JOSEPH GENTON,
 JOHN A. KERR,
 PIERRE X LAVELLEE,
 W. D. JARVIS, Ins. N.W.M.P.

WASS-WEE-KAH-OO-TAN-MAH-HOTE, his
 x mark.
 (TOTEM,) (OF MEN-CHU-AW-ANIS),
 SER-SEE-QUAN-IRH, his
 x mark.
 WEE-TEE-KOO-WEE-ZAH-NAW-OO, his
 x mark.
 KAH-MER-NIN-TOO-WAY-TIT, his
 x mark.
 KAH-PAY-YAK-WAISEK-OO-KEM, his
 x mark.
 SEE-SEE-KWAN-IS, his
 x mark.
 Joint Chiefs of the Willow Indians.
 KAH-NAH-LAH-SKOW-WAIT, his
 x mark.
 KAH-NAH-YEE-KOO-WEN, his
 x mark.
 KAH-SAH-MAN-CHEW, his
 x mark.
 MOON-ED-YAHS, his
 x mark.
 OUMIN-AH-KAW, his
 x mark.
 OOTEH-HOO-PAB-KAH-MAY-TOW-WAY-TIT, his
 x mark.
 Councillors of Willow Indians.

Signed by Her Majesty's Commissioners and by the Chiefs and Headmen hereafter subscribing hereto, the same having been first read and explained to the Indians by the Honourable James McKay and Peter Erasmus, near Fort Pitt, this 9th day of September, A.D. 1876, in the presence of the undersigned witnesses.

A. G. JACKES, M.D.
 JAS. McLEOD, Commr. N.W.M.P.
 JAS. E. WALSH, Inspector N.W.M.P.
 +VITAL J., Bishop St. Albert, O.M.I.
 E. DALRYMPLE CLARK, Adj. N.W.M.P.
 CONSTANTINE SOULAS, Pres., O.M.I.
 JOHN McDUGALL, Meth. Missionary.
 JOHN McELVEY,
 W. E. JONES.
 PETER C. PALMERON,
 A. R. KENNEDY,
 PETER ERASMUS,
 THOMAS MCKAY,
 JAMES SIMPSON,
 ELIZA HARDISTY,
 MARY MCKAY.

ALEXANDER MENAS, L.G., N.W.T.
 JAMES MCKAY, Indian Commr.
 W. J. CHRISTIE, Indian Commr.

WEE-KAS-KOO-KEE-KAF-YIN, x
 his mark.

PEE-YAS-EE-WAH-KAH-WE-CHA-KOOT, x
 his mark.

JAMES SZENZEL, x
 his mark.

OC-NAH-TAN-MRE-NAH-HOOS, x
 his mark.

SEE-KAHN-ROOYCH, x
 his mark.

TUB-TUE-EE-SHWANES, x
 his mark.

PEE-KAY-SES, x
 his mark.

KAC-YE-WIN, x
 his mark.

Cree Chiefs.

KIN-OO-SAY-OO, x
 his mark.

Chipewyan Chief.

SHE-WAS-EWAR, x
 his mark.

WAY-WAY-EEE-POO-WE-YEK, x
 his mark.

Councillors to Wee-kus-luo-ko-ay-yir.

TYP-ES-SLOW-AH-CHAK, x
 his mark.

PAT-PAT-SEE-SER-HOO, x
 his mark.

ON-NOW-AK-ER-PAN-CHAS, x
 his mark.

MY-GE-WAY-SERS, x
 his mark.

Councillors to Wee-kus-luo-ko-ay-yir.

CAKE-CAKE, his
 x
 mark.

KAY-OO-WOK, his
 x
 mark.

AH-SIS, his
 x
 mark.

Councillor to Councillor to
Sec. Kaya-Koyoh, James Bessam. Oem-pak-mus-jin-a-hoo.

Recorded 24th February, 1877.
Lib. 27, Fol. 352.
L. A. CATELLIER,
Deputy Registrar-General of Canada.