

**First Nations Peoples' Perspectives  
and  
Experiences with Cancer**

by  
Fjola Hart-Wasekeesikaw

A Thesis  
submitted to the  
Faculty of Graduate Studies  
in partial fulfilment of the  
requirements for the degree of

Master of Nursing

Faculty of Nursing  
University of Manitoba  
Winnipeg, Manitoba

© June 11, 1996



National Library  
of Canada

Acquisitions and  
Bibliographic Services Branch

395 Wellington Street  
Ottawa, Ontario  
K1A 0N4

Bibliothèque nationale  
du Canada

Direction des acquisitions et  
des services bibliographiques

395, rue Wellington  
Ottawa (Ontario)  
K1A 0N4

*Your file* *Votre référence*

*Our file* *Notre référence*

The author has granted an irrevocable non-exclusive licence allowing the National Library of Canada to reproduce, loan, distribute or sell copies of his/her thesis by any means and in any form or format, making this thesis available to interested persons.

L'auteur a accordé une licence irrévocable et non exclusive permettant à la Bibliothèque nationale du Canada de reproduire, prêter, distribuer ou vendre des copies de sa thèse de quelque manière et sous quelque forme que ce soit pour mettre des exemplaires de cette thèse à la disposition des personnes intéressées.

The author retains ownership of the copyright in his/her thesis. Neither the thesis nor substantial extracts from it may be printed or otherwise reproduced without his/her permission.

L'auteur conserve la propriété du droit d'auteur qui protège sa thèse. Ni la thèse ni des extraits substantiels de celle-ci ne doivent être imprimés ou autrement reproduits sans son autorisation.

ISBN 0-612-16153-6

**Canada**

THE UNIVERSITY OF MANITOBA  
FACULTY OF GRADUATE STUDIES  
COPYRIGHT PERMISSION

FIRST NATIONS PEOPLES' PERSPECTIVES AND  
EXPERIENCES WITH CANCER

BY

FJOLA HART-WASEKEESIKAW

A Thesis/Practicum submitted to the Faculty of Graduate Studies of the University of Manitoba in partial fulfillment of the requirements for the degree of

MASTER OF NURSING

Fjola Hart-Wasekeesikaw © 1996

Permission has been granted to the LIBRARY OF THE UNIVERSITY OF MANITOBA to lend or sell copies of this thesis/practicum, to the NATIONAL LIBRARY OF CANADA to microfilm this thesis/practicum and to lend or sell copies of the film, and to UNIVERSITY MICROFILMS INC. to publish an abstract of this thesis/practicum.

This reproduction or copy of this thesis has been made available by authority of the copyright owner solely for the purpose of private study and research, and may only be reproduced and copied as permitted by copyright laws or with express written authorization from the copyright owner.

## TABLE OF CONTENTS

	Page
ABSTRACT . . . . .	viii
ACKNOWLEDGEMENTS . . . . .	x
DEDICATION . . . . .	xiii
LIST OF TABLES . . . . .	xiv
LIST OF FIGURES . . . . .	xv
CHAPTER 1: STATEMENT OF THE PROBLEM . . . . .	1
Cancer and First Nations People . . . . .	3
Understanding the Cancer Experience Among First Nations People: Epidemiological Perspectives . . . . .	5
Retrospective Studies: The Changing Profile of Cancer in First Nations People . . . . .	7
Risk Factors And Cancer Among First Nations People . . . . .	11
Beyond Statistics: The Experience of Cancer Among First Nations . . . . .	12
Research Questions . . . . .	15
Purpose . . . . .	16
Assumptions . . . . .	16
Conceptual Framework . . . . .	17
Health and Sickness . . . . .	17
Traditional Healer . . . . .	19
The Medicine Wheel . . . . .	19
Summary . . . . .	26
CHAPTER 2: LITERATURE REVIEW . . . . .	27
Cancer and First Nations People: Epidemiology and Social Science Research . . . . .	27
Native People of the Northwest Territories, Alaska and Greenland . . . . .	31
Modern Cancer Sites for Arctic Inuit and Eskimo . . . . .	34
Summary: The Native People of the Northwest Territories, Alaska and Greenland . . . . .	43
Native People of Western Washington, Saskatchewan, Manitoba, Ontario, Dakotas, New York State, and New Mexico . . . . .	46
Native American People in Western Washington State . . . . .	46
First Nations People of Saskatchewan . . . . .	48
First Nations People of Manitoba . . . . .	51
First Nations People of Ontario . . . . .	53
Indian People of the Dakotas . . . . .	55

Indian People of New York State . . . . .	58
Indian People of New Mexico State . . . . .	58
Discussion: Native People of Manitoba, Ontario, Saskatchewan, Western Washington, Dakotas, New York State and New Mexico . . . . .	62
Specific Cancer Sites: The Aboriginal Population . . . . .	64
Nasopharynx . . . . .	64
Salivary Gland . . . . .	66
Esophagus . . . . .	67
Kidney . . . . .	68
Choriocarcinoma . . . . .	69
Gallbladder . . . . .	69
Lung . . . . .	70
Cervix . . . . .	73
Breast . . . . .	80
Colon and Rectum . . . . .	83
Stomach . . . . .	85
Liver . . . . .	85
Urinary Bladder and Prostate . . . . .	85
Melanoma . . . . .	87
Summary: Specific Cancer Sites . . . . .	88
Survival . . . . .	94
Mortality . . . . .	95
Cancer Prevention . . . . .	96
Early Detection and Screening . . . . .	98
Conclusion . . . . .	99
CHAPTER 3: METHODOLOGY . . . . .	101
Study Design . . . . .	102
Participants . . . . .	102
Participant Access . . . . .	103
Community Response . . . . .	105
Data Collection Methods . . . . .	107
Data Analysis . . . . .	111
Establishing Trustworthiness in the Study . . . . .	115
Credibility . . . . .	115
Transferability . . . . .	119
Dependability . . . . .	120
Confirmability . . . . .	120
Fairness . . . . .	121
Ethical Considerations . . . . .	121
Limitations of the Study . . . . .	122
Conclusion . . . . .	124

CHAPTER 4: CAUSATION AND CANCER METAPHOR . . . . .	125
The Participants . . . . .	125
The Stranger As Metaphor . . . . .	126
The Presence of a Stranger: The Elders Speak . . . . .	128
Prevention of Cancer: Traditional Ways . . . . .	130
Where the Stranger Comes From: An Overview . . . . .	132
The Elders Speak . . . . .	132
Cancer Patients Speak . . . . .	134
Family Members Speak . . . . .	135
Community Members Speak . . . . .	135
The Stranger From The North . . . . .	137
The Impact of Progress on Food Consumption . . . . .	138
Teaching from an elder . . . . .	138
A health services administrator's perspective . . . . .	139
The Impact of Progress on The Nature of Food . . . . .	139
Chemicals and additives in food . . . . .	140
Canned foods . . . . .	141
Junk food . . . . .	142
Domestic meat . . . . .	143
Progress: Chemicals in the Water . . . . .	143
Ella's cancer . . . . .	144
Jacob's cancer . . . . .	144
Smoking Cigarettes . . . . .	145
Ebenezer's Cancer . . . . .	145
Sylvia's Cancer . . . . .	145
Physical Injury . . . . .	146
Jacob's Cancer . . . . .	146
Sylvia's Cancer . . . . .	147
Infection . . . . .	147
Samuel's Cancer . . . . .	148
Isabel's Cancer . . . . .	148
Onjine . . . . .	148
Joanne's Cancer . . . . .	149
Destiny . . . . .	149
Ebenezer's Cancer . . . . .	149
Summary: Where The Stranger Comes From . . . . .	150
Manitoch Metaphor: The Stranger As Worm . . . . .	151
Manitoch in the Body: A Difficult Cure . . . . .	154
Manitoch: A Case Study of Roberta's Cancer . . . . .	156
The Surgery . . . . .	158
The Recovery . . . . .	159
Modern Metaphors: Manitoch-As-Cancer-Cell . . . . .	159
Other Metaphors . . . . .	161
Summary: Manitoch Metaphor . . . . .	162

Conclusion . . . . .	163
<b>CHAPTER 5: THE CANCER EXPERIENCE . . . . .</b>	<b>165</b>
An Overview of The Informants . . . . .	166
Becoming Aware: The Stranger in the Body . . . . .	168
Sylvia's Awareness . . . . .	169
Kathy's Awareness . . . . .	170
Roberta's Awareness . . . . .	171
Summary: Becoming Aware . . . . .	172
Becoming A Stranger: Leaving the Community . . . . .	173
Finding the Cancer . . . . .	173
Sylvia's Journey . . . . .	174
Kathy's Journey . . . . .	176
Treating the Cancer: Emphasizing the Stranger . . . . .	176
Sylvia's Experience . . . . .	179
Summary: Becoming A Stranger . . . . .	181
The Stranger Apparent . . . . .	184
Seeing The Stranger As Death . . . . .	184
Isabel Sees Cancer As Death . . . . .	186
The Stranger As Always Present . . . . .	188
The Stranger Calls Again: A Case Study . . . . .	189
Silence . . . . .	191
Personal Silence . . . . .	191
Sylvia's cancer . . . . .	191
Family Silence . . . . .	192
Ruby's cancer . . . . .	192
Community Silence . . . . .	194
Silence in the Community of The Nesting Eagles . . . . .	194
Silence in the Community of The Silent Eagle . . . . .	195
Silence in The Community of The Raven . . . . .	196
Summary: The Stranger Apparent . . . . .	196
Learning To Live With Cancer: A Stranger No More . . . . .	199
Beyond Cure: The Need for Healing . . . . .	199
Indian Medicine . . . . .	200
Ebenezer's healing . . . . .	200
Suzanne's healing . . . . .	201
Roberta's healing . . . . .	202
Christianity: Having Faith . . . . .	203
Test of faith . . . . .	203
Physician as healer . . . . .	205
The gift . . . . .	205
Summary: Learning To Live With Cancer . . . . .	206

CHAPTER 6: THE COMMUNITY EXPERIENCE . . . . .	208
An Overview of The Informants . . . . .	208
Silence Surrounds The Stranger . . . . .	209
Community Silence . . . . .	210
The Silence of Health Care Providers . . . . .	213
Community of The Raven . . . . .	214
Community of The Silent Eagle . . . . .	214
Community of The Nesting Eagle . . . . .	215
Summary: Silence Surrounds The Stranger . . . . .	215
Making The Stranger Known: The Healing Journey . . . . .	216
Traditional Indian Medicine: Finding the Spiritual Pathway . . . . .	217
Spirituality . . . . .	217
The Community of The Raven . . . . .	219
The Elders in The Community of The Raven Speak . . . . .	219
The Community of The Silent Eagle . . . . .	221
The Community of The Nesting Eagle . . . . .	222
The Community of The Medicine Eagle . . . . .	222
Summary: Making The Stranger Known . . . . .	224
CHAPTER 7: DISCUSSION AND RECOMMENDATIONS . . . . .	227
Relationship of Findings to the Literature . . . . .	227
Overview of Findings in the Literature . . . . .	227
Cancer: A New Disease . . . . .	228
Cancer Causation . . . . .	228
Food: An Origin of Cancer . . . . .	229
Other Sources of Cancer . . . . .	233
Cancer As A Metaphor . . . . .	235
Traditional Healers: Caring and Healing . . . . .	240
Traditional Healers and Elders . . . . .	244
Accessing Traditional Healers . . . . .	244
Elders: Role in Community Development . . . . .	246
Cancer: A Mark of Disgrace . . . . .	248
Overview of Findings Beyond the Literature . . . . .	249
Spiritual Visions and Dreams . . . . .	249
Silence: Cancer Prevention and Early Detection of Cancer . . . . .	250
Relationship of Findings to the Conceptual Framework . . . . .	252
Reflection and Reflexivity . . . . .	254
Making A Quilt: The Storyteller's Gift and The Listener's Burden . . . . .	257
Recommendations . . . . .	259
Recommendations for Nursing Research . . . . .	259
Recommendations for Nursing Education . . . . .	260
Recommendations for Nursing Practice . . . . .	261
Message to First Nations People . . . . .	262



References ..... 264

Appendices

A. Approval Form ..... 279  
B. Letter To Chief and Council ..... 280  
C. A Letter of Invitation to Participate in a Study ..... 281  
D. A Letter of Invitation to Participate in a Study ..... 282  
E. A Letter of Invitation to Participate in the Study ..... 283  
F. Consent Form For Participants Diagnosed With Cancer ..... 284  
G. Consent Form For Family Members of Participants With Cancer . 286  
H. Consent Form For Traditional Elders and Healers ..... 288  
I. Consent Form For Community Members ..... 290  
J. Interview Guide For Participants With Cancer ..... 292  
K. Interview Guide For Family Members of Participants With Cancer 293  
L. Interview Guide For Community Members ..... 294

## ABSTRACT

First Nations People have recently become concerned about the rising incidence of cancer in their communities. However, knowledge about First Nations Peoples' experiences with cancer is fragmented and limited in scope. To date, it is understood statistically; the psycho-social aspect of the cancer experience is absent. The purpose of this descriptive, ethnographic study was to explore the experiences of First Nations People diagnosed with cancer and Elders' perceptions of cancer.

The Medicine Wheel was the conceptual guide for this study. Forty six informants living in four Anishinaabe communities were interviewed using semi-structured interview schedules. Content analysis of First Nations experiences with cancer occurred at various levels using three data sets: the individual with cancer, her/his family and community.

The cancer experience was metaphorically characterized by "the stranger." Some examples of the themes are presented. In "The Presence of a Stranger: The Elders Speak," the Elders provided a historical perspective of the development and prevention of cancer in First Nations communities. "Becoming Aware: The Stranger in the Body" describes the informants' experiences when they sensed they had cancer. In the theme "Making The Stranger Known: The Healing Journey," the informants identified traditional Indian medicine as one way to manage cancer in their communities.

Some of the findings revealed that cancer is thought to be a new disease affecting Anishinaabe. Food is considered to be the primary cause of cancer and the

loss of traditional values is at the core of cancer in First Nations communities. A range of metaphors reflected First Nations Peoples' understanding about cancer. The most common metaphor used by the Anishinaabe in this study was "manitoch" which, in the Ojibwa language, Sauteaux, means cancer-as-worm. Informants suggested that Western medicine is limited in its ability to cure cancer. First Nations People with cancer consulted one or more Indian medicine healers before, during, or after obtaining medical cancer treatment. Spiritual visions and dreams were important to First Nations People. Recommendations are provided for future nursing research, education and practice.

## ACKNOWLEDGEMENTS

I was guided in this thesis work by my dreams, insight I gained during the early, quiet morning hours, and the words of many teachers.

I am grateful to my thesis committee for supporting me while I completed this project from my understanding as a First Nations person. I felt confident about this exploration because I was learning from a committee of researchers who were knowledgeable, experienced and passionate about their work. Each contributed to my learning.

Thank you Dr. David Gregory for chairing my thesis committee. We travelled a long distance together on this journey of discovery. Many times you walked beside me. We discussed many things and often we laughed. Other times we walked in silence. Sometimes I walked alone. But, you were ready to join me when the time was right. David, your patience, honesty and kindness were greatly appreciated as was your critique of my work in progress.

Thank you Dr. Linda Kristjanson for your patience and understanding. When I was about to collect the data for this project, the fears I had about doing research resurfaced. Linda helped me understand how an ethically sound research project addressed many of my fears. Also, she helped me gain insight into my data analysis

when I became bogged down with a large number of themes. Linda, thank you for your encouragement.

I appreciated Dr. John O'Neil's questions and comments for my consideration. They were thought provoking and helpful in my thesis work. Thank you, John, for inviting me to make a presentation before colleagues at the Department of Community Health Sciences, University of Manitoba. The presentation helped to prepare me for my thesis defense.

I want to acknowledge Elder Eddie Belrose who, nineteen years ago, told me about the Circle of Life. Since then I have referred to the Medicine Wheel in every aspect of my life.

I am grateful, Ms. Sherry Ripak, my transcriber, for your patience and generosity. Thank you Lai Chun Mamaril for your help.

To the wisdom and understanding of my friends. Ms. Diane Clare who understood what it was like to be in "thesis land." I appreciated the many times we talked about the mystery and humour in life. Kathy Bird with whom I share an understanding which surpasses words.

I received much strength from my family: my daughter, Kim, my brother, Michael, and my mother, Vivian.

This research was supported by the following: Eleanor Jean Martin Award, Canadian Nurses Foundation; Manitoba Association of Registered Nurses; Margaret R. Francis Award, University of Manitoba; Maurice Legault Clinical Cancer Nursing Fellowship, Canadian Cancer Society; and the Northern Health Research Unit, Department of Community Health Sciences, University of Manitoba.

All my relations

**DEDICATION**

To the Anishinaabeg

## LIST OF FIGURES

	<b>Page</b>
Figure 1. Elements of the Medicine Wheel . . . . .	22
Figure 2. Life Cycle of the Medicine Wheel . . . . .	23
Figure 3. Individual, Family and Community in the Medicine Wheel . . . . .	25
Figure 4. Aspects of the Individual, Family and Community . . . . .	25
Figure 5. Topics of Cancer and First Nations People: Epidemiology and Social Science Research . . . . .	27
Figure 6. Cancer Causation and Metaphor Topics . . . . .	127
Figure 7. Cancer Experience Topics . . . . .	166
Figure 8. Community Experience Topics . . . . .	208



## CHAPTER 1

### STATEMENT OF THE PROBLEM

To determine the future of their communities, First Nations People are reclaiming an active role in defining and managing their health care. At the core of this movement is an exploration of cultural roots and the affirming of identity. First Nations People know that attaining health is interwoven with identity. Preserving identity fosters confidence in determining health from a First Nations Peoples' perspective. Health and disease are not simply defined by universal parameters. Rather, within a community, culture and its history define health and disease. They are the actions necessary for healing to take place. First Nations communities are now asserting their health priorities. They are developing and implementing health and healing approaches that account for culture, history, and identity.

First Nations People have identified that the management of health includes programs that reflect a holistic view of health in their communities. While cultural survival and renewed understanding of the laws of nature and health are inherent to First Nations health programming, the integration of employment and socio-economic development, revival of traditional therapies, decreased dependence upon western medicine, and the presence of First Nations health care providers are equally important (Alberta Health, 1995; Ontario Ministry of Health, 1994).

Increasingly, First Nations communities are developing and delivering health care programs that are specific to their communities and that incorporate traditional healing systems to promote healthy lifestyles. Traditionally, First Nations People

viewed themselves as healthy. The community and its members existed in a state of harmony with both the material and spiritual environment. In defining health and health care needs, First Nations People are now remembering the values and practices of the "old ways." People are examining contemporary health care methods and they are considering how these two ways of healing can be used to maximize the health of community members.

First Nations People are requesting culturally sensitive health care, seeking input into the development of various health prevention programs, and including traditional healing practitioners in the delivery of health care services. Effective health care services and prevention programs are understood by those whom they are intended to serve and relate to the needs identified by those being served (The Indian Tribes of Manitoba, 1971, p. 173). The challenge to provide meaningful health care services by nurses and other health care providers is not new; it is an ongoing process as improved communication and increased understanding between the First Nations communities and health care providers develops.

As First Nations communities evolve in the management of their health care, nurses and physicians are also learning how to provide culture specific care for aboriginal people. The expectation is that health care practitioners provide programs, services, and interventions that are culturally sensitive and culturally appropriate. First Nations People are using not only contemporary curing and healing practices, but they are also remembering their cultural roots and revivifying traditional healing practices. Therefore, nurses and other health care providers require knowledge about

how diseases are experienced from an aboriginal perspective.

### Cancer and First Nations People

Recently, First Nations People have become concerned about the rising incidence of cancer in their communities. The nature of this concern has not been studied. Furthermore, beliefs about the origins of cancer among Native people has not been explored. First Nations People have requested that studies be conducted to identify cancer risk factors (Edge, 1988; Sprott, 1988). Perspectives held by First Nations People about the prevention, causation and treatment of cancer have not been documented. The experience of cancer, as lived by First Nations People remains relatively unknown.

Knowledge about cancer in First Nations communities is fragmented and limited in scope. Describing the cancer experiences and identifying comprehensive cancer patterns among Native people has not received the consideration accorded to other diseases such as diabetes or hypertension. Historically, infectious diseases and their impact on the life expectancy of the aboriginal people received investigative attention. Health issues such as accidental injuries, alcoholism, diabetes, mental health and infectious diseases have been the primary focus of attention in the contemporary First Nations population (Joe & Justice, 1992, p. 10). The prevailing assumption that aboriginal people do not develop cancer may have also limited cancer research among First Nations People.

The contemporary aboriginal explanation of cancer is absent. This may be partly due to the emphasis placed on finding a cure for cancer. When cure is stressed,

attention is primarily on the physical aspects of the person. Other equally important elements of a being, the emotional, social and spiritual are largely ignored.

To affirm that cancer can be beaten assumes that biomedical management and disease cure are the only choices for cancer patients. The search for a cure has limited how health care providers relate to people diagnosed with cancer. By focusing on the disease, cancer care has focused on the physical aspect of the person. Two postulates have been forgotten in the quest for a cure for cancer: Each person relates to the disease as a spiritual, emotional, social and physical being, and each community relates to its members with cancer in a culturally bound manner. While indicators from the biomedical model contribute to formulating the idea of cancer, they are not the only sources for understanding its ramifications. Broadening the field of understanding to include the cultural realm will redirect attention to the person diagnosed with cancer.

Identifying the incidence of cancer among Native people is often difficult given the absence of a national aboriginal cancer registry. If "ethnicity" is not recorded in a cancer registry then the national and provincial cancer rates among First Nations People remains unknown. In Canada, research studies requiring an aboriginal data base generally reflect the Inuit people and registered Indian people (status Indian) living on reserves. Additionally, it is problematic to access First Nations People who do not live on the reserves. The Métis and other aboriginal people who are not of the registered Indian population are impossible to locate without being identified by ethnic origin.

The Manitoba Cancer Treatment and Research Foundation (MCTRF) 1992 registry does not contain the identity of people by ethnicity. The registered Indian population is not indicated in the registry. Consequently, accurate cancer incidence rates are not available for the First Nations People in Manitoba.

### Understanding the Cancer Experience Among First Nations People:

#### Epidemiological Perspectives

To date, the knowledge and understanding of First Nations' cancer experience is understood statistically; the psycho-social aspect of the cancer experience is absent. Generalizations cannot be made about aboriginal people and cancer. Two reasons for this exist. First, aboriginal people are not homogenous. They have varying cultural and historical backgrounds which are linguistic in origin. These factors may affect their cancer experiences. Second, without the focus of research on particular aboriginal groups, contrasting and comparing these groups is impossible. Most of the epidemiological studies describe the incidence of cancer according to geographical regions: The Native people of Alaska and Northwest Territories; Washington State; Saskatchewan, Ontario and Manitoba; New York State; and, the Native people of New Mexico and Arizona. Describing aboriginal people and cancer in this manner aggregates the different linguistic aboriginal groups. For example, a study of First Nations People who reside on reserves in Manitoba would include the following linguistic groups: Cree, Ojibwa and Oji-Cree (Algonkian), Dakota (Sioux), and Dene (Athapaskan).

The cancer pattern for each aboriginal group is unique. The Inuit people living

in the Northwest Territories and Alaskan Eskimo people are similar in that cancer of the esophagus and salivary gland are the predominant types of cancer (Hildes & Schaefer, 1984; Lanier, Bulkow & Ireland, 1989; Schaefer, Hildes, Medd & Cameron, 1975). These types of neoplasms are also predominant in the Greenlandic Eskimo (Nielsen, 1986). This particular cancer pattern among the Inuit of Canada, and the Eskimo of Alaska and Greenland may be influenced by genetics and related to arctic temperatures and diet.

Another example of unique cancer patterns among aboriginal groups is evidenced in the Oglala Lakota Sioux of the northern plains and the Tohono O'odham in the southwestern United States. In this study which was conducted from 1970 to 1979, Oglala men have a higher incidence of lung cancer at 46.9 per 100,000 (age-adjusted) than Tohono O'odham men (13.7 per 100,000). Tohono O'odham men have proportionately more stomach cancer (38 per 100,000) than Oglala men at 16.6 per 100,000 (Justice, 1988). Data on specific American Indian groups are limited as only the New Mexico Surveillance, Epidemiology and End Results program of the National Cancer Institute in the United States contains cancer rates for American Indian groups.

In Canada, data on Indian groups are not as readily available as they are in southwestern United States. This is largely because there is no national aboriginal cancer registry. The prevalence of primary cancer sites among aboriginal people have been identified according to regions. For example, Young and Frank (1983) conducted a study of Cree and Ojibwa registered Indian people residing in

northwestern Ontario from 1972 to 1981. No stomach cancers were reported. In this region, kidney cancer was of primary concern for men while women were at greatest risk for cancer of the gallbladder.

The few epidemiological studies which compare aboriginal groups' cancer experiences suggest each group has its own cancer pattern. These cancer patterns are influenced by the lifestyles and environment in which the aboriginal groups live. Linguistic in origin, these aboriginal groups have changed over time as a result of influences of non-aboriginal cultures.

#### Retrospective Studies: The Changing Profile of Cancer in First Nations People

Retrospective studies indicate that cancer sites are changing among aboriginal groups over time. The incidence for all cancer sites is increasing as aboriginal people develop cancers common to affluent industrialized societies ie: breast, cervix, colon and rectum, lung, and prostate. Cigarette smoking, alcohol intake, high fat and low fibre diet are associated with these cancers. Possible lifestyle changes such as sexual intercourse, pregnancy, childbirth and lactation practices are important considerations. Underestimation in early periods of cancer studies, exposure to environmental influences, low socio-economic status, access to, and utilization of cancer screening may also explain increasing incidence of these cancers. Among aboriginal people, some of the "acculturation" cancers are comparable to, or exceed the rates for the same cancers found in the general population. The trend of increasing incidence of breast, cervical, colorectal, lung, and prostate cancers is affecting the incidence for all cancer sites among aboriginal people.

American Native and Canadian Indian people have lower rates of cancer than other groups in their respective countries. Incidence rates for all cancer sites in the American Native population are generally less than age and sex adjusted rates for Caucasian or Blacks in the United States. Indian people living on reserves in Canada were at lower risk of developing cancer than the provincial rates from 1979 to 1983 (Young, Orr, McNichol, & Katz, 1991, p. 6). In Saskatchewan, for both men and women combined, and for men only, the incidence of cancer for registered Indians and northerners was significantly below the cancer rates of the province during a twenty year period from 1967 to 1986 (Irvine et al., 1991). In Manitoba, from 1970 to 1979, the overall risk of developing cancer among Indian people living on reserves was significantly lower when compared to the general population (Young & Choi, 1985).

Tumours of the cervix, colon and rectum, and lung increased in incidence reflecting changes in the acculturation patterns of the Inuit and gradually replaced "traditional" tumours (Hildes & Schaefer, 1984). From 1950 to 1966, cancers of the salivary gland, nasopharynx, and kidney became known as the "traditional" tumours because they occurred most frequently in the Inuit when compared to other native populations in Canada. Genetics, exposure to infectious agents in the arctic environment and traditional Inuit lifestyle ie: the chewing and salivation required to work leather, and the consumption of raw frozen meat and fish were thought to contribute to the development of salivary gland tumours. From 1974 to 1980, salivary gland cancer decreased from 25 to 5 per cent; nasopharynx from 10 to 5 per cent;



and, kidney from 11 to less than 5 per cent.

The rates of incidence for cancer of the cervix, colon and rectum, and lung among some aboriginal groups are comparable to, or exceed, the rates of the general population. Aboriginal women in Canada and the United States experience cervical cancer more often than other women in their country. American Indian women living in New Mexico and Arizona have over twice the incidence of cervical cancer, 20.5 per 100,000 (age-adjusted) than American White women from 1977 to 1983 (Burhansstipanov & Dresser, 1993). Similarly, Indian women residing on Manitoba reserves experienced cervical cancer one and one half times as often as all women in the Province (Young & Choi, 1985). From 1970 to 1984, cervical cancer occurred three times as often in Canadian Inuit women than in the Canadian population (Gaudette, Dufour, Freitag, & Miller, 1991). However, cervical cancer rates among Canadian Inuit women are stabilizing: 33 per 100,000 in 1970-74, 42 per 100,000 in 1975-79, and 26 per 100,000 in 1980-84. Unlike the Canadian Inuit women, registered Indian women in northern Saskatchewan are not only at a greater risk of developing cervical cancer than women of northern Saskatchewan but the incidence of cervical cancer among registered Indian women has increased by 52% (changing from 34 to 52 per 100,000) during the period from 1967-71 to 1982-86.

Colon and rectum cancer rates among the Canadian and American Alaskan Native people are comparable to, or exceed, the rates of their comparison populations. Among Canadian Inuit, colorectal cancers occurred at the expected rate of Canadian people from 1970 to 1984 (Gaudette et al., 1991). Alaskan Native People

experienced a greater risk of developing colon and rectum cancer. Their rate of incidence (age-adjusted) was 63 per 100,000 compared to other racial groups in the United States which was 53 per 100,000 (Burhansstipanov & Dresser, 1993).

In Saskatchewan, there was a deficit in the incidence of lung cancer among Indian women from 1972 to 1981 when compared to the provincial female population. However, during this same time period, the gap between Indian women and provincial women narrowed. During 1982 to 1988, Indian women lung cancer rates, although not statistically significant, exceeded the rates of provincial women (Irvine et al., 1991). For the Canadian Inuit female lung cancer occurs six times more frequently when compared with the general population. The Canadian Inuit male is at twice the risk (Gaudette, Gao, Freitag & Wideman, 1993).

Increases in breast, cervical and lung cancer incidence among registered Indian people in Saskatchewan have influenced a four-fold increase, for all cancer sites, in cancer age-standardized incidence per 100,000 from 1967 to 1986 (Irvine et al., 1991). In the same study, northerners, which consisted of 50 per cent registered Indians, 30 per cent Métis and 20 per cent other ethnic groups, experienced a two-fold increase. The greatest increase in incidence occurred during the first five years among the northerners and during the last decade of the study in the Indian population.

When compared to the general Canadian population, trends suggest that lower incidence for all cancer sites in First Nations People is changing as aboriginal people develop cancers which reflect acculturation. Influenced by other Canadian cultures,

some First Nations are experiencing increased incidence of breast, cervix, colon and rectum, and lung cancers. Indeed, the incidence of cervical and lung cancers among First Nations women are comparable to, or exceeded, the rates of other women in their provinces. For example, the incidence of cervical cancer among registered Indian women residing in Saskatchewan has exceeded the incidence of cervical cancer among women in Saskatchewan during a twenty year period (1967-71 to 1982-86). While the incidence of cervical cancer among women in Saskatchewan has declined from 15 to 8 per 100,000, the incidence of cervical cancer among First Nations women increased from 34 to 52 per 100,000. These trends are also occurring in American Native people in the United States.

#### Risk Factors And Cancer Among First Nations People

The incidence of certain cancer types are associated with certain risk factors. Navajo, uranium mining and lung cancer; Inuit and hepatitis B virus, Alpha-fetoprotein screening for early detection of hepatocellular carcinoma in HBsAg carriers, and hepatitis viral vaccination of susceptible populations; Epstein-Barr virus is connected with salivary gland carcinoma.

Survival rates among American Native and Canadian Indian people are lower than other ethnic groups in their respective countries. Native women of North Carolina die at twice the rate from cervical cancer that the caucasian women of the state. Saskatchewan northerners and registered Indians have significantly poorer survival rates than the province as a whole. Fifty-four per cent of northerners survived five years from the time of diagnosis; 56 per cent of registered Indians

survived five years after cancer diagnosis while 60% of the Saskatchewan population survived five years after cancer diagnosis.

Although Canadian Indian and Native American people have lower rates of cancer than other populations in their respective countries they experience higher risks for developing certain types of cancers. Influenced by differing linguistic, cultural, and historical backgrounds aboriginal groups are not homogenous in their experiences with cancer. Also, epidemiological studies indicate that cancer sites among aboriginal groups are changing over time. Aboriginal people are developing cancers of the breast, cervix, colon and rectum, and prostate as result of industrial affluence, underestimation in earlier periods of studies, exposure to elements of the environment, socio-economic status, and access to, and utilization of cancer screening. The incidence of these types of cancer among some aboriginal groups were comparable to, or exceeded, the rates of the general population. The change in cancer sites and increased incidence of these tumour sites are affecting the incidence for all cancer sites among aboriginal groups.

#### Beyond Statistics: The Experience of Cancer Among First Nations

Statistical studies provide one aspect of the cancer experience within the First Nations community. Socioeconomic, cultural and political factors require consideration (Antle, 1987, p. 72; Olsen, 1993, p. 45). The unique views aboriginal people have about cancer will broaden the picture considerably. To date, few nursing studies have explored the understanding, beliefs and experiences of First Nations' People with cancer.

The beliefs First Nations' People have about cancer can influence their participation in prevention and early detection activities, decisions about treatment, emotional responses, and sexual and family relationships (Nielsen, McMillan & Diaz, 1992, p. 110). Beliefs about the diagnosis and treatment of cancer include the cause, onset, pathophysiology of cancer; the severity and length of illness; the kind of self-care methods; the kinds of treatment that should be received (p. 112); and beliefs about healing practices (Songishe & Levy, 1990; Varricchio, 1987). The role of the family, community, and health care provider are important to understanding the experiences of First Nations People and cancer (Spreitzer, 1991).

Serious limitations in research design hindered a greater understanding about Alaskan aboriginal perspectives about cancer etiology (Sprott, 1988). Knowing the meaning and cultural interpretation of health beliefs is essential to providing health and cancer care and promoting quality of life (Varricchio, 1987, p. 58).

The Cancer 2000 Manitoba Provincial Working Group identified the absence of culturally sensitive educational resources as one of the reasons why programs are lacking in their effectiveness to educate the public about the prevention of cancer (Cancer 2000 - Manitoba, 1992, p.18). In a study identifying the needs of people living with cancer in Manitoba, patients did not receive necessary information about the importance of early diagnosis, the impact of treatment, pain management strategies, support and palliative care, and the community resources available to them (Vachon, Lancee, Conway, & Adair, 1990). The needs of Native Canadians and Métis people living with cancer were not identified in this study because the sample

size was too low. The sample may have been low because aboriginal people identified themselves as Canadian rather than Native Canadian or Métis. Moreover, only 3 of the 11 Native Canadian people in the sample from the cancer registry agreed to be interviewed (p. 31). A goal of the National Cancer 2000 Task Force (1992) is to design culturally specific prevention and health education programs, and to deliver cancer care programs that are sensitive to the needs of minority cancer patients.

A lack of educational resources reduces the amount of time health professionals spend teaching cancer patients and their families about the disease process and the support services available to them (Cancer 2000 - Manitoba, 1992). The absence of culturally appropriate resources and the lack of knowledge health professionals have about diverse cultural groups' cancer experiences result in decreased teaching time. Specifically, the lack of culturally sensitive educational resources limits First Nations Peoples' access to knowledge of cancer prevention and cancer care services (Cancer 2000 - Manitoba, 1992).

Manitoba's Cancer Working Group has recommended that all public educational programs target specific groups including First Nations communities to decrease the incidence of cancer. The National Cancer Task Force recommended the development of appropriate care strategies and responses to support health professionals' quest for knowledge about the experiences of First Nations cancer patients and their families.

In summary, First Nations Peoples' experiences with cancer is understood statistically. This knowledge, however, is fragmented and limited in scope. Canadian

Indian and Native American people have lower rates of cancer than other populations in their respective countries. However, they are at higher risk for developing certain types of cancer. Further, a homogenous cancer pattern does not exist among aboriginal people. Their experiences with cancer are influenced by differing linguistic, cultural, and historical backgrounds. Trends indicate that prevalent cancer sites among aboriginal groups are changing. Industrial influence, underestimation in earlier periods of studies, environmental factors, socio-economic status, and access to, and utilization of cancer screening are thought to have impacted upon the development of breast, cervical, colon and rectum, and prostate cancer in aboriginal people. Indicators from the biomedical model serves to provide a limited perspective in understanding the cancer experience among aboriginal people.

First Nations People have expressed concern about the increasing incidence of cancer in their communities. Finding a cure for cancer has emphasized the physical aspect of understanding cancer. Largely ignored is research that examines the emotional, social, cultural, and spiritual ramifications of cancer among First Nations People. The contemporary aboriginal explanation of cancer is absent.

#### Research Questions

This study was exploratory in nature and describes the following: The experiences of First Nations People diagnosed with cancer and Elders' perceptions of cancer. The research questions are as follows:

1. What beliefs do First Nations People have about the origins and pathophysiology of cancer?

2. What perceptions do First Nations People have about the cancer treatment they have received/are receiving?
3. What have First Nations People experienced regarding the cancer treatment process?
4. What is the concept of healing from the native perspective? What strategies are used to foster the healing process?
5. What experiences have First Nations People had around accessing and incorporating traditional healing practices?
6. What role does the traditional healer have in relation to the cancer patient?
7. What is the experience of cancer for family members?
8. What perceptions and beliefs do community members hold about cancer?

#### Purpose

The purpose of this study was to identify the experiences and beliefs of First Nations People diagnosed with cancer. The findings of this study contribute to the knowledge base and understanding of the cancer experience among First Nations People. Finally, the study identifies where changes can be made to teach about the prevention of cancer and improve cancer care provided to First Nations People.

#### Assumptions

Assumptions underlying the study are:

1. All people have beliefs.
2. All peoples' perceptions are guided by their beliefs.



3. People sharing similar beliefs have similar language symbols that allow for understanding.
4. People living with cancer enact their beliefs about healing, curing, death and dying.
5. Beliefs about healing, curing, death and dying, guide people on their healing pathways, curing pathways, healing/curing pathways, and dying paths.

### Conceptual Framework

The Medicine Wheel provided the conceptual framework for this study. An ancient and powerful tool used by indigenous nations to guide their learning and healing pathways to attain and maintain health, the Medicine Wheel reflects the philosophy of traditional aboriginal health and sickness. As a First Nations person and nurse I believed the Medicine Wheel would guide my exploration and understanding of First Nations Peoples' experiences, perspectives and beliefs about cancer. Using the Medicine Wheel as a guide to understanding First Nation Peoples' views and beliefs of health and disease is a new practice in nursing research (Clarke, 1990). No nursing researchers have used the Medicine Wheel to understand First Nations Peoples' perspectives on chronic diseases. The traditional aboriginal view of health and sickness as well as the "traditional healer" are defined. Then, the Medicine Wheel as a conceptual guide for this research project is presented.

### Health and Sickness

Traditional aboriginal people view the attaining and maintaining of health and the occurrence of sickness as a dynamic, inter-relational, inter-dependent,

multidimensional and holistic process (Bopp, Bopp, Brown & Lane, 1989; Garrett, 1991; Malloch, 1989). Health, also known as Indian medicine, is the interaction between the physical, mental, emotional and spiritual realms which constitute a person, a family and a community (Bopp et al., 1989; Garrett, 1991). When the inter-dependent relationship of these realms is disrupted, a person will develop sickness. Sickness is not only manifested in the body. When one realm is affected, the other realms will also be affected. Indeed, a physical sickness may be preceded by emotional or spiritual signs (Hamilton & Sinclair, 1991, p. 20). Indian medicine goes beyond the confinement of a human body and includes an inter-dependent relationship with all that is within the universe (Bopp et al., 1989).

Indian medicine is the inter-dependent relationship people have with the natural world and keeping one's spirit strong (Hamilton & Sinclair, 1991; Malloch, 1989). It is a holistic concept. Human beings are part of the universe. They are a part of a single whole. This inter-connectedness occurs in two worlds, the physical and spiritual. Both of these worlds are aspects of one reality.

The physical world is real. The spiritual world is real. These two are aspects of one reality. Yet, there are separate laws which govern each one of them. Violation of spiritual laws can affect the physical world. Violation of physical laws can affect the spiritual world. A balanced life is one that honours the laws of both of these dimensions of reality. (Bopp et al., 1989, p. 26)

When the laws of the physical and spiritual worlds are disrupted, people become sick.

At the core of Indian medicine is the Creator. Health is a gift from the Creator and is the responsibility of each person to maintain (Malloch, 1989). By taking care of our health we are showing respect for ourselves, our health, and to the gifts from

the Creator. Health is following the traditional way; it is "good" Indian medicine (Garrett, 1991, p. 172).

The principles that guide the practice of Indian medicine may not be the values of all aboriginal people, but are essential to people living according to the traditional Native teachings (Malloch, 1989). The attitudes and beliefs of First Nations People are diverse. Black Feather (1992) broadly describes five categories of aboriginal perspectives: traditional, transitional, assimilated, dualistic and "returning". The traditional Native people follow their traditional beliefs; the transitional people are in the process of accepting the way of the mainstream culture in which they have relocated; the assimilated people have become alike or similar to the culture they have adopted as their own; and, "returning" are those who are turning to their traditional roots (p. 140).

#### Traditional Healer

A traditional healer or medicine person possesses knowledge and abilities to heal through spiritual ceremonies and herbal medicines. The gift of healing is the power of the Creator. The healer is concerned with the person's body, mind and spirit and the connectedness this person has with the natural and spirit worlds. The traditional healer is a channel through which healing powers flow from the Creator to the one who is sick. The healer is accountable to the Creator and to the people, and is governed by the natural laws of the Universe (Malloch, 1989).

#### The Medicine Wheel

According to traditional aboriginal beliefs, the Medicine Wheel symbolizes all

that provides meaning to the human experience (Bopp et al., 1989, p. 20). The Medicine Wheel symbolically reflects the philosophy of traditional aboriginal health and sickness. It is a multi-dimensional framework where all creation is symbolically articulated as interdependent and dynamic. Exploring cancer experiences, perspectives and beliefs of First Nations People required a holistic framework to accommodate the diverse views I had anticipated among the informants who participated in this study. Comprised of concentric circles and the four directions ie: east, south, west, and north, the Medicine Wheel is a relevant framework to guide the exploration about First Nations Peoples' experiences and views about cancer.

The inter-relationship of concentric circles and the directions offer endless possibilities in understanding the cancer experience of First Nations People. The four directions of the Medicine Wheel traditionally are thought to offer gifts for learning how to live full, healthy lives. While each circle or group of concentric circles in the Medicine Wheel convey a theme, the four directions serve as reference points for each theme. A brief explanation of the themes in the circles and directions and how they are relevant to understanding First Nations Peoples' experiences and views of cancer are discussed. The interconnection between the layers of circular and directional themes then become evident.

The lifegiving forces ie: earth, air, water, and fire, shown in Figure 1, must be considered to understand cancer in First Nations communities (Bopp et al., 1989). Without these elements human beings could not exist on this planet, Mother Earth. Air symbolizes oxygen and quality air. And fire symbolizes the energy provided by

the sun. Pollution is a carcinogenic threat to most of these elements and to the existence of human beings.

The colours red, yellow, blue/black and white, in various directions of the Medicine Wheel, symbolize different societies (see Figure 1). White symbolizes industrial progress and the medical model of health care service delivery. The colours blue or black symbolize Indian medicine and spirituality. The remaining colours represent other societies' ways of living and healing. All potentially influence the diagnosis and treatment of cancer in First Nations People. The exploration of how the informants in this study manage their cancers will be accommodated by this framework. The range of beliefs First Nations People may have about the diagnosis and treatment of cancer will be accommodated by this level of the Medicine Wheel.

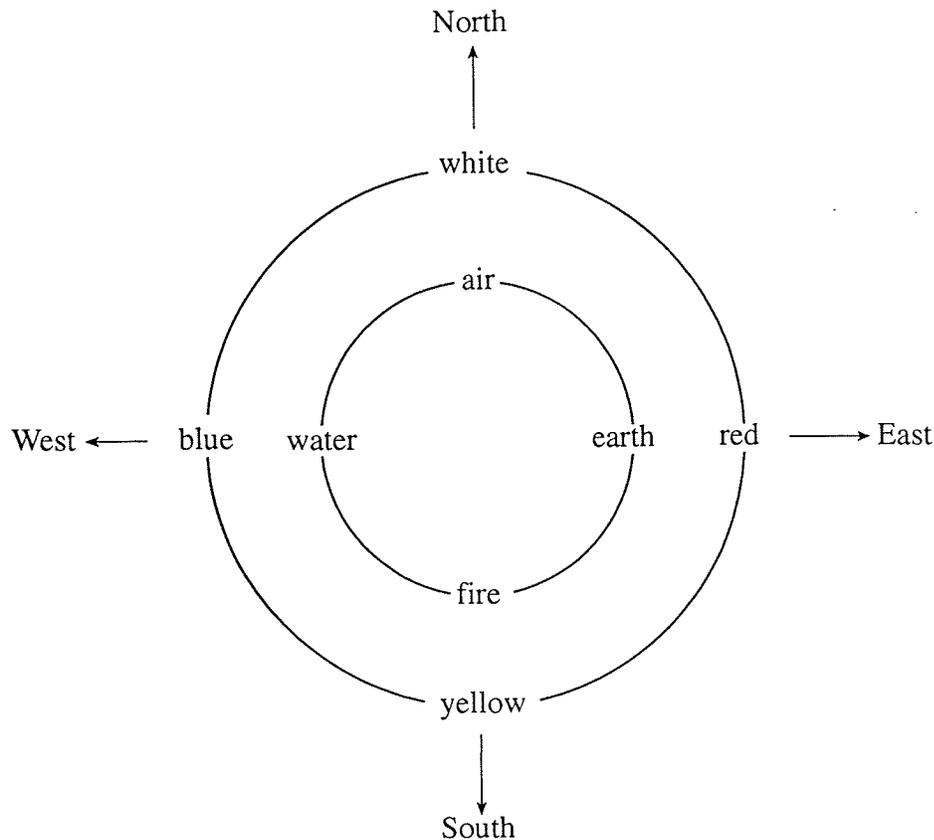


Figure 1. Elements of the Medicine Wheel

The life cycle of people is another dimension of the Medicine Wheel. "Human beings are born, live their lives, die and enter the spirit world" (Bopp et al., 1989, p. 27). The life cycle symbolically correlates with the seasonal cycle on the Medicine Wheel. As the seasons are delineated by the directions on the Medicine Wheel, so are some stages of the life cycle (see Figure 2). These cycles begin in the east marking birth and spring. The life cycle also accommodates the role of each informant within the family and community. Of particular significance to this study is the relationship between Elders and people diagnosed with cancer in the community. Because of the

way they have travelled through their life cycles, the elderly have knowledge and experience about the origins and pathophysiology of cancer. The experience the Elders have with cancer will influence the relationship they have with the people diagnosed with cancer.

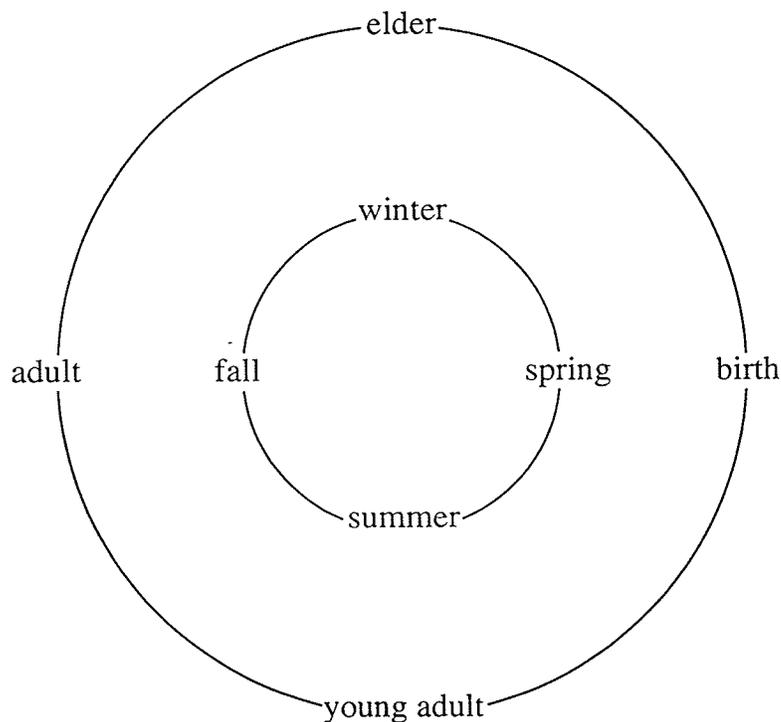


Figure 2. Life Cycle of the Medicine Wheel

The individual, family and community are represented in a set of concentric circles as shown in Figure 3. The spiritual, emotional, physical and mental aspects of the person, family, and community, shown in Figure 4, are integral to the Medicine Wheel (Bopp et al., 1989). A person's experiences with cancer affects her/him spiritually, emotionally, physically and mentally. Similarly, when a family member

has cancer, the entire family is also affected spiritually, emotionally, physically and mentally. This is also a consideration for a community when its members have cancer. The Medicine Wheel accommodates the cancer experience between the individual diagnosed with cancer and her/his family and community.

The knowledge obtained about cancer from each direction is the interplay (analysis) of the data that the informants provide at each concentric circle and direction. For example, family members' thoughts and feelings about having one of its relatives seek the counsel of a traditional healer rather than seek the help of a physician in treating her/his cancer. And, what does the community say about the roles of Indian medicine and western medicine in treating cancer?



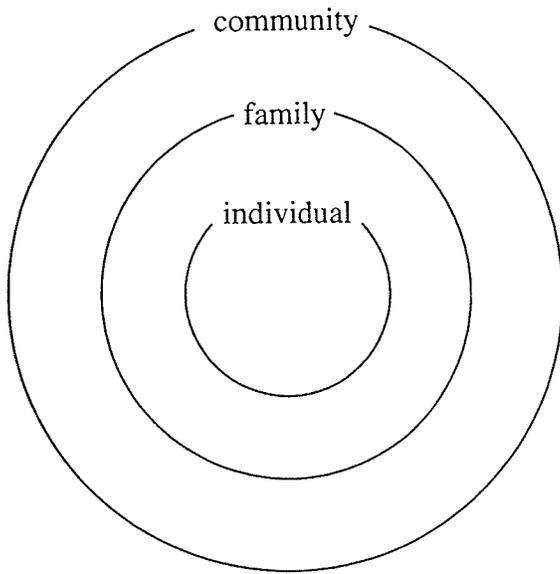


Figure 3. Individual, Family and Community in the Medicine Wheel

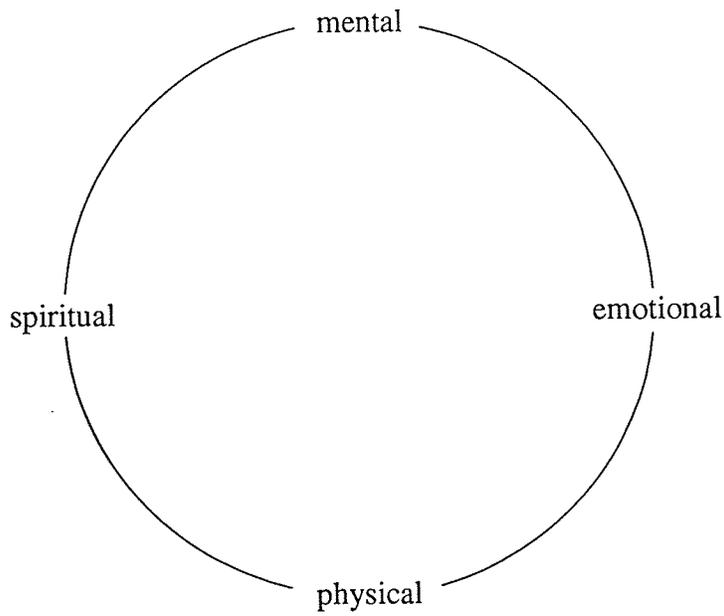


Figure 4. Aspects of the Individual, Family and Community

### Summary

This chapter presented an overview of existing cancer research among First Nations Peoples. With the emphasis on epidemiological research, few studies address First Nations Peoples' beliefs and experiences with cancer. The purpose of this study is to explore the experiences and beliefs First Nations have about cancer. The Medicine Wheel provides the conceptual framework for this exploration. The second chapter is a review of the literature.

## CHAPTER 2

## LITERATURE REVIEW

## Cancer and First Nations People: Epidemiology and Social Science Research

1. Native People of the Northwest Territories, Alaska and Greenland
  - A. Modern Cancer Sites for Arctic Inuit and Eskimo
  - B. Summary: The Native People of the Northwest Territories
2. Native People of Western Washington, Saskatchewan, Manitoba, Ontario, Dakotas, New York State and New Mexico State:
  - A. American Native People in Western Washington State
  - B. Aboriginal People in Saskatchewan
  - C. First Nations People of Manitoba
  - D. First Nations People of Ontario
  - E. Indian People of the Dakotas
  - F. Indian People in New York State
  - G. Indian People of New Mexico State
  - H. Discussion: Native People of Manitoba, Ontario, Saskatchewan, Western Washington, Dakotas, New York State, and New Mexico
3. Specific Cancer Sites: The Aboriginal Population
  - A. Nasopharynx
  - B. Salivary Gland
  - C. Esophagus
  - D. Kidney
  - E. Choriocarcinoma
  - F. Gallbladder
  - G. Lung
  - H. Cervix
  - I. Breast
  - J. Colon and rectum
  - K. Stomach
  - L. Liver
  - M. Urinary & Prostrate
  - N. Melanoma
  - O. Summary: Specific Cancer Sites
  - P. Survival
  - Q. Mortality
  - R. Cancer Prevention
  - S. Early Detection and Screening
4. Conclusion

**Figure 5.** Topics of Cancer and First Nations People: Epidemiology and Social Science Research

The literature reveals that our knowledge and understanding about cancer in First Nations Peoples is incomplete and limited in both depth and breadth. Although

epidemiological studies dominate, there is no evidence of systematic and sustained epidemiological studies. Consequently, the depth of knowledge and understanding of aboriginal peoples' experience with cancer is lacking. There is a real absence of psycho-social studies. The cancer experience among the First Nations' People is primarily understood statistically. Establishing prevalence and incidence rates has received the majority of research attention.

Identifying comprehensive cancer patterns and experiences among Native people has lagged behind other diseases such as diabetes and hypertension. This may be due to the persistent belief that cancer is rare among aboriginal people. And if it is not so rare, it is believed that there are other more serious health issues that warrant careful consideration. Research has focused on health issues such as accidental injuries, alcoholism, diabetes, mental health and infectious diseases (Joe & Justice, 1992, p. 10).

There is no national aboriginal cancer registry in Canada nor the United States. With the exception of the identification of the Inuit population in the National Cancer Incidence Reporting System (NCIRS), "ethnicity" is not a demographic category in Canada's national cancer registry. The Northwest Territories and the Province of Quebec also have cancer registries which identify the Canadian Inuit (Gaudette & Barreto, 1988). The Saskatchewan Cancer Registry of the Saskatchewan Cancer Foundation establishes the identities of registered Indian people with the symbol "R" and their Indian band registration number. However, it cannot be determined from the registry whether Indian people with cancer live on or off the

reserve. To obtain this information their Saskatchewan Health Insurance registration numbers must be accessed to identify the usual location of residence (Irvine et al., 1991, p. 447).

There are implications for not having a national Native cancer registry in Canada. If the specific ethnic group is not recorded then the national and provincial cancer rates among First Nations People is not known. Without a comprehensive aboriginal cancer data base, the cancer patterns among remote, rural and urban Indian people, regionally or provincially, cannot be studied to obtain the impact and timing of acculturation; nor can clusters of specific cancer sites be identified by band or by tribe.

Research studies requiring an aboriginal data base generally reflect the populations that are easier to locate within existing cancer registry systems: the Inuit and registered Indian people. Presently, in Manitoba, residents of Indian reserves can be identified from residence codes which refer to the usual address of patients at the time of diagnosis. Unfortunately, this method is ineffective for identifying cases of cancer among Indians who are not residents on reserves. It is also an ineffective resource for distinguishing between non-Indian people and Indian people living on reserves (Young & Choi, 1985, p. 1269). The cancer incidence rates for Manitoba's total Indian population cannot be calculated because not all registered Indian people with cancer can be determined in this manner. The Métis and aboriginal people who are not registered Indian people are impossible to locate without being identified by ethnic origin.

Similarly, there is no national Native American cancer registry in the United States. As in Canada, the published cancer incidence data for American Indians is from accessible sources. The New Mexico Tumour Registry (NMTR), located at the University of New Mexico Cancer Centre, collaborates with the Indian Health Service (IHS), the Arizona Central Cancer Registry and the National Cancer Institute to maintain databases of cancer cases occurring in the American Indian populations of New Mexico and Arizona. The NMTR is one of nine population-based cancer registries that constitute the Surveillance, Epidemiology and End Results (SEER) program. This program monitors changes in cancer incidence, stage of disease at diagnosis, treatment, and survival in the states of Connecticut, Hawaii, Iowa, New Mexico and Utah, and in the metropolitan areas of Atlanta, Detroit, San Francisco and Seattle. NMTR is the primary source of cancer data for the SEER program regarding American Indians (Key & Becker, 1992, p.53).

Of the SEER project areas, it is only through the New Mexico Tumour registry that data can be retrieved by specific groups such as Apache and Navajo. However, tribes are not identified. For example, the Apache consists of four tribes: The Mescalero, Jicarilla, San Carlos, and White Mountain (Joe & Justice, 1992, p. 13). Hence, studies tend to focus on the Native American people of Alaska and the southwestern part of the United States.

To locate information about the topic of cancer and the Native people of Canada, United States, and other countries, a computer search using ERIC, MEDLINE, CINHAHL and psychological abstracts was conducted. This review is

presented in two sections. The first part is an examination of studies which describe the epidemiology of cancer and Native people on a regional basis and includes gross patterns and trends. The second section consists of literature which focuses on relevant specific cancer sites in the First Nations population.

The major features of each study are highlighted and include: geographical study area, duration, sample size, comparison group, cancer risk for overall cancer sites, trends, and cancer sites with significant standard incidence ratios. The studies are primarily descriptive, retrospective and cohort in design, and were published in 1983 or later. Each study covered various time periods from 1950 to 1988 and collectively these time periods overlap. With the exception of two studies, each reported standardized incidence ratios (SIR) which are ratios of an observed number of cancer cases relative to the number of expected cancer cases based on cancer incidence in a comparison population. SIRs were adjusted for difference in sex and age between the study cohort and the comparison population.

To better understand the incidence of native cancer, studies will be grouped in geographical regions: Native People of Northwest Territories and Alaska; Washington State; Saskatchewan, Ontario and Manitoba; New York State and, the Native People of New Mexico and Arizona.

Native People of the Northwest Territories, Alaska and Greenland

Historically, cancer research in the Arctic was anecdotal in nature and was based on case studies. The initial findings of cancer in the Arctic Eskimo and Inuit ensued from personal medical encounters. In 1923, Fibiger reported that 3 of the 14

cancers found in Greenlandic Eskimos from 1911 to 1922 were parotid tumours (cited in Nielsen, 1986). Because cancer was considered rare among Canadian Inuit and Alaskan Eskimos, a single cancer case involving a Canadian Inuit was reported (Brown, Cronk, & Boag, 1952). The prevalence of salivary gland tumours among the Canadian Inuit was reported (Schaefer, 1959). Malignant tumours in Eskimos and Indians in Alaska were identified through autopsies from 1956 to 1958 (Gottmann, 1960). Hildes (1960) compiled evidence to dispel the commonly held belief that there was no carcinoma among the Inuit of Canada and Eskimo of Alaska.

Research efforts were directed at identifying the extent of cancer in the aboriginal population of the Arctic. In Alaska, Hurst (1964) and Fortuine (1969) reviewed hospital records and identified a high prevalence of esophageal cancer among Eskimos in comparison to Caucasian rates in the United States. Canadian Inuit patients, who were diagnosed with cancer, were tabulated through a retrospective review of Arctic patients' medical records during the time periods from 1949 to 1974 (Schaefer et al., 1975) and from 1950 to 1980 (Hildes & Schaefer, 1984) to identify patterns and trends of cancer. However, without a central aboriginal cancer registry, published information about the Canadian Inuit focused on the Western Northwest Territories. Data collected on Inuit residents of Central Northwestern Territories were incomplete because of the difficulty in assuring the identification of Inuit cancer cases. Data from the northern Quebec and Labrador regions were absent from these initial publications.

During 1949-64 (Schaefer et al., 1975) and 1950-66 (Hildes & Schaefer, 1984)



salivary gland, kidney and nasopharyngeal or "traditional" tumours occurred most frequently in the Inuit in comparison to other Canadians. Fifteen of the 61 malignant neoplasms (24.6%) diagnosed in the Inuit from 1950 to 1966 originated in the salivary glands. In comparison, these tumours in other Canadians were rare. They were counted as "other" head and neck sites and accounted for less than five per cent of all cancers. Factors thought to contribute to the development of this type of cancer included: genetics; the chewing and salivation required to work leather; the consumption of raw frozen meat and fish; and, exposure to infectious agents particular to the Arctic environment.

Cancer mortality from 1967-73 for Inuit women who were 45 to 64 years of age and residents of the central Arctic was five times that of all Canadians. To explain the elevated morbidity and mortality in the Inuit, an age shift of the population to a more cancer prone older age was ruled out for this time period because the percentage of females and males greater than 40 years of age was 7.13 and 8.59 respectively in 1961; and, 6.26 and 7.48 respectively in 1971 (Schaefer et al., 1975).

Nielsen (1986) in a retrospective study of cancer morbidity from 1950 to 1974, established that for Greenlandic Inuit men and women, cancer of the nasopharynx was 20 times that of the Danish population. Salivary gland cancer was ten times that of the Danish population. Esophageal cancer occurred eight times as frequent in Inuit women, and five times the frequency of the Danish population for Inuit men. The prevalence of lung cancer for Inuit men and women equalled that of the Danish

population. For Inuit women during the 1970 to 1974 time period, cancer of the cervix increased to twice the Danish incidence while breast cancer remained significantly low (Nielsen, 1986).

Head and neck cancer tumours were markedly prevalent in the Inuit and Eskimo of the Arctic. Although the Greenlandic Inuit Fibiger studied were partially European (cited in Schaefer et al., 1975), they were found to have parotid gland tumours while the Canadian Inuit who were noted to be "pure blooded" had salivary gland tumours (Schaefer et al., 1975). The incidence of the traditional head and neck tumours prevailed in the Greenlandic Inuit as in the Canadian Inuit when compared to the Danish and Canadian populations, respectively. High incidence of esophageal cancer and low incidence of breast cancer were observed in the Eskimo and the Inuit of the Arctic.

Tumours which reflect acculturation were becoming evident in the Eskimo and Inuit of the Arctic. Cervical cancer in the Greenlandic Inuit was twice the Danish incidence; it was evident in the Alaskan Eskimo and was markedly increasing in incidence in the Canadian Inuit (Schaefer et al., 1975). Lung cancer in the Greenlandic Inuit equalled the Danish population while in the Canadian Inuit the incidence of lung cancer increased from the 1950-66 study period to the 1967-74 study period (Schaefer et al., 1975).

#### Modern Cancer Sites for Arctic Inuit and Eskimo

Changes in the prevalence of the type of tumours among the Inuit of the Northwest Territories was evidenced in a study from 1974 to 1980 when "traditional"

tumours were gradually replaced by those of the cervix, colon-rectum, and lung. The influx of traders and whalers, changing economy, and urbanization influenced changes in the Inuit lifestyle and subsequent change in the prevalence of cervical, colorectal, and lung cancer. From 1974 to 1980, the "traditional" tumours declined: salivary gland cancer decreased from 25 to 5 per cent; nasopharynx from 10 to 5 per cent; kidney from 11 to less than 5 per cent and esophagus from 5 to less than 5 per cent (Hildes & Schaefer, 1984). The impact of acculturation could be seen by the gradual replacement of "traditional" tumours by those of the lung, cervix and colon-rectum.

The changing cancer trend, where Inuit women with cancer are increasingly outnumbering the Inuit men with cancer, is another reflection of acculturation. This variation in trend could be due to increased incidence of invasive cervical cancer and epidemic prevalence of lung cancer among the Inuit women. However, breast cancer among Inuit women continued to remain low (Hildes & Schaefer, 1984).

The modern cancer pattern among Canadian Inuit included tumours which reflected acculturation and the "traditional" types of cancer (Gaudette et al., 1991; Gaudette et al., 1993). Two studies presented the most frequently occurring types of cancer among the Inuit. One study involved the Inuit residing in the Northwest Territories from 1969 to 1988. The other, Inuit in northern Canada, included Inuit residing in the Northwest Territories, Nouveau-Quebec, and Labrador from 1970 to 1984. These two studies depicting the predominant types of cancer in Canadian Inuit are presented in Table 1.

The most frequently occurring types of cancer in Inuit men living in the

Northwest Territories during the period from 1969 to 1988 were as follows: lung (43%); nasopharynx (9%); leukemia (6%); stomach (5%); salivary gland (4%); and, kidney (4%) (Gaudette et al., 1993). The most common types of tumours occurring in Inuit women were: lung (37%); cervix (12%); salivary gland (6%); rectum (4%); esophagus (4%); and, nasopharynx (3%). Similarly, lung cancer was the most common occurring cancer site among the Inuit in northern Canada (Gaudette et al., 1991).

The Inuit in northern Canada include Inuit with cancer from the Northwest Territories, Nouveau-Quebec and Labrador during the time period from 1970 to 1984. Cancer of the nasopharynx and stomach are the second and fourth leading cancer sites among Inuit men in northern Canada. Cancer of the cervix and salivary gland are the second and third most common cancer sites occurring in Inuit women living in northern Canada. However, leukemia is the third leading cancer site among the people in the Northwest Territories and in northern Canada, it is the fifth leading cancer site. This variation in leading cancer sites is probably due to a combination of incomplete registration and regional occurrence.

The data base for all the Inuit in northern Canada is a compilation of the National Cancer Incidence Reporting System (NCIRS) in Canada which includes reports from each provincial and territorial registry in Canada; the cancer registry for the Northwest Territories; the cancer registry for the Quebec Inuit; patient lists supplied by Schaefer and Hildes; and the Mortality Data Base maintained at Statistics Canada.

TABLE 1  
Predominant Cancer Types in Inuit  
(% Distribution)

Northwest Territories 1969 - 1988		Northern Canada 1970 - 1984	
Men	Women	Men	Women
Lung 43	Lung 37	Lung 40	Lung 30
Nasopharynx 9	Cervix 12	Nasopharynx 6	Cervix 15
Leukemia 6	Salivary Gland 6	Colon 6	Salivary Gland 6
Stomach 5	Rectum 4	Stomach 6	Colon 6
Salivary Gland 4	Esophagus 4	Leukemia 5	
Kidney 4	Nasopharynx 3		

Cancer incidence rates observed in the Inuit population of northern Canada were compared to those expected from the general Canadian population during the period from 1970 to 1984 (Gaudette et al., 1991). As Table 2 indicates the Inuit are at greater risk for developing tumours of the nasopharynx and salivary gland when compared to the general Canadian population. Cancer of the nasopharynx occurred 21.5 times and salivary gland occurred 9.2 times more often in Inuit men as the Canadian population. In Inuit women, tumours of the nasopharynx occurred 26.9 times and salivary gland occurred 20.7 times more often than the Canadian population. Also, the incidence of choriocarcinoma is significant among Inuit women of northern Canada. It occurs 17 times more often among Inuit women than the general Canadian population.

Certain types of cancer are lower than expected among Inuit living in northern Canada when compared to the general Canadian population. Among Inuit men, both

cancer of the prostate and bladder occurred one-tenth the expected rate. Among Inuit women, cancer of breast (0.2x) and endometrium (0.1x) occurred less frequently than expected.

The incidence of tumours occurred at the expected rates for Canadian population. For Inuit men, cancer of the stomach, colon and rectum, kidney, and leukemia occurred at similar rates as the general Canadian population. Colorectal cancer in Inuit women occurred at the expected rate.

TABLE 2  
Higher Than Expected Rates of Cancer in the Inuit  
(Compared with Canadian Population)

Northern Canada 1970 - 1984			
Men		Women	
Nasopharynx	21.5x	Nasopharynx	26.9x
Salivary Glands	9.2x	Salivary Glands	20.7x
Lung	2.4x	Lung	6.4x
		Choriocarcinoma	16.7x
Esophagus	3.1x	Esophagus	5.6x
Nasal Cavities	7.4x		
		Gallbladder	4.8x

The cancer pattern in the Alaskan Eskimo during the period from 1969 to 1983 varied from that of the Inuit of northern Canada (Lanier et al., 1989). Data for this study were collected from the Centres for Disease Control and Indian Health Service collaborative cancer surveillance project where all Alaskan Native patients who have been diagnosed with invasive cancer from 1969 to 1983 have been registered. The

registry identifies ethnicity and with the use of the Indian Health Service medical record, the patients were further classified as Indian, Eskimo or Aleut.

Among Alaskan Eskimo men with tumours, 23% were lung; 12% colon; 9% stomach; 7% liver; and, 5% nasopharynx. Of all the Alaskan Eskimo women with cancer, 16% had cancer of the colon; 14% had cancer of the breast; 10% had cancer of the cervix; and, 6% had cancer of the lung.

The Alaskan Eskimo cancer rate for certain types of cancers was higher than expected when compared to the Caucasian population of the United States. In Eskimo men and women, nasopharyngeal cancer occurred 20.2 times and 22.7 times the rate of the Caucasian population in the United States, respectively. Compared to the Caucasian population in the United States, salivary gland cancer occurred twice the rate among Eskimo men and 4.4 times the rate among Eskimo women. And, compared to the Caucasian population in the United States, esophageal cancer occurred 2.0 times the rate among Eskimo men and 3.5 times the rate among Eskimo women. Other cancer sites which are higher than expected (O:E) in Alaskan Eskimo men and women are shown in Table 3.

During this same time period the Eskimo men of Alaska experienced lower than expected rates (O:E) for melanoma (0.2), tumours of the prostate (0.3) and bladder (0.3) in the caucasian population of the United States. The Alaskan Eskimo women had lower than expected levels of American women for melanoma (0.4), and cancer of the breast (0.4), ovary (0.4) and uterus (0.1).

During 1969 to 1983, Alaskan Eskimo men had similar rates for cancer of the

rectum, lung, colon and pancreas as did the Caucasian population in the United States (Lanier et al., 1989). Alaskan Eskimo women had similar rates for cancer of the rectum, lung, thyroid, pancreas and stomach as Caucasian women.

TABLE 3  
Higher Than Expected Rates of Cancer in the Eskimo  
(Compared with the White Population in United States)

Alaska 1969 - 1983			
Men		Women	
Nasopharynx	20.2x	Nasopharynx	22.7x
Liver	8.5x	Gallbladder & Ducts	6.6x
Stomach	2.6x	Salivary Gland	4.4x
Gallbladder	2.6x	Esophagus	3.5x
Salivary Gland	2.2x	Liver	2.9x
Esophagus	2.0x	Kidney	2.4x
		Cervix	2.1x

Two studies were done to survey the incidence of cancer in Arctic Indian people: Gaudette et al. (1993) examined the Indian people of the Northwest Territories from 1969 to 1988 and Lanier et al. (1989) reviewed the Indian people of Alaska from 1969 to 1983. As shown in Table 4 similar distribution of predominant types of cancer exist among the Indian People in the Northwest Territories and Alaska. Among Indian men, the leading cancer sites are lung, colorectum and prostate. And, among Indian women, breast, cervix, colon and lung are the leading cancer sites. Cancer of the breast, prostate and colorectum are considered diseases of Western civilization and are thought to be associated with dietary fat.



TABLE 4  
 Predominant Cancer Types in Indian People  
 (% Distribution)

Northwest Territories 1969 - 1988		Alaska 1969 - 1983	
Men	Women	Men	Women
Lung 23	Breast 26	Lung 17	Breast 20
Rectum 15	Colon 12	Prostate 15	Cervix 12
Prostate 8	Lung 11	Colon 11	Colon 10
Kidney 8	Cervix 10	Rectum 7	Lung 6
Colon 5	Kidney 7		Rectum 5

The Indian People in the Northwest Territories and Alaska evidenced a trend of low risk for overall cancer sites (Gaudette et al., 1993; Lanier et al., 1989). Throughout the 20 year study, the standard incidence ratios for Status Indian men living in the Northwest Territories were significantly low at 0.6. The standard incidence ratios for Status Indian women were slightly higher at 0.8. However, as shown in Table 5, Indian People in the Northwest Territories and Alaska are unique in their risk for certain cancer types (Gaudette et al., 1993; Lanier et al., 1989).

Indian men and women had higher than expected rates for the total Canadian population for cancer of the nasopharynx. As with the Eskimo, the Indian people showed significant increases in incidence for nasopharyngeal cancer when compared with the Caucasian population in the United States. Indian men had observed-to-expected ratios of ten while the Indian women had ratios of 14.

TABLE 5  
Higher Than Expected Ratios of Cancer in Indian People

ALASKA 1969 - 1983		NORTHWEST TERRITORIES 1969 - 1988	
Men	Women	Men	Women
Nasopharynx 10.0	Nasopharynx 14.0	Nasopharynx	Nasopharynx
Multiple Myeloma 3.0	Salivary Glands 5.0		Salivary Glands
Gallbladder 2.0	Gallbladder 4.0		Cervix
Liver 2.0	Cervical 2.5		Lung
Testes 1.6	Stomach 2.0		
Other Male Genital 2.4	Kidney 1.7		

Incidences of colon, bladder and rectal cancer were low in Indian men residing in the Northwest Territories when compared to those expected from the Canadian population. The pattern of lower levels for these cancer types reflect similar trends found in developing countries. The low standard incidence ratios may be attributed to socio-economic factors; differences in accessibility or use of diagnostic procedures; and, since these types of tumours have good survival rates, undiagnosed cancers might have never been reported.

Indian women in the Northwest Territories experienced cancer of the uterus less frequently than expected in the Canadian population. However, the incidence of cancer of the lung and cervix among Indian women was comparable to the total Canadian population.

Lower than expected incidence (O:E) of cancer for Alaskan Indian men were:

melanoma 0.1 and bladder 0.2 and for Indian women the ratios were: melanoma 0; uterus 0.2; and bladder 0.2. Lung, stomach, breast and colon cancer incidence for Alaskan Indian men and women were as high as those of the Caucasian people in the United States.

Summary: The Native People of the Northwest Territories, Alaska and Greenland

Until anecdotal accounts revealed that head and neck tumours were markedly increased in the Inuit and Eskimo of the Arctic, it was believed that they did not get cancer. Cancer of the salivary gland, kidney and nasopharynx which became known as the "traditional" tumours, occurred frequently in Canadian Inuit and rarely in other Canadians. Similarly, cancer of the esophagus prevailed among the Alaskan Eskimos when compared with the Caucasian population in the United States. When compared to the Danish population, the Greenlandic Inuit had a high prevalence of parotid and salivary gland, nasopharyngeal, and esophageal tumours. It was postulated that genetics, and the traditional Inuit lifestyle such as the chewing and salivation required to work leather; the consumption of raw frozen meat and fish; and exposure to infectious agents specific to the Arctic environment contributed to the development of these types of cancer. Lactation practices were believed to contribute to the rarity of breast cancer in the Eskimo and Inuit of the Arctic.

Lung, cervical and colorectal tumours, which reflect acculturation patterns of the Inuit of the Northwest Territories, gradually replaced the "traditional" tumours. This trend of increasing tumours reflecting western lifestyle was also seen nationally, in the Inuit of northern Canada and in the Alaskan Eskimo. However, in the Alaskan

Eskimo the traditional tumours showed no signs of decreasing incidence (Lanier, 1993).

The primary type of cancer in the Inuit of northern Canada, Alaskan Eskimo men, and Indian men of the Northwest Territories and Alaska is lung cancer. The Native People of northern Canada and Alaska share other similarities. Cancer of the colon and stomach prevail in the Inuit of northern Canada and Alaskan Eskimo men. The predominant types of cancer in Indian men of the Northwest Territories and Alaska are rectum, prostate, kidney and colon. Cancers of the lung, cervix, colon, and breast are the predominant types in northern Canadian Inuit and Alaskan Eskimo women, and Indian women of the Northwest Territories and Alaska.

The Inuit and Indian people of the Northwest Territories, and Eskimo and Indian people of Alaska have unique cancer patterns which differ from the comparison populations (general Canadian and United States White). Nasopharyngeal cancer is the primary type of cancer which is at higher than expected levels in the northern Canadian Inuit and Alaskan Eskimo, as well as in the Indian people of the Northwest Territories and Alaska. Higher than expected levels for cancer of the salivary glands are in all of these groups with the exception of the Indian people of Alaska. Cervical cancer is at higher than expected levels in all Arctic Native women except the Indian women of the Northwest Territories. The Indian women have similar rates of cervical cancer as Canadian women.

Canadian Inuit men and women have higher than expected lung cancer rates than in other Canadian people. In the Alaskan Eskimo and Indian men and women,

lung cancer occurs at similar rates as in the Caucasian population of the United States. Lung cancer also occurs at similar rates in Canadian Indian people as in the rest of Canadian population.

Canadian Inuit, Alaskan Eskimo, and Indian men of the Northwest Territories and Alaska have lower than expected rates for bladder cancer. The Inuit women of Canada and the Eskimo women of Alaska have lower than expected levels of breast cancer. The Eskimo and Indian men, and the Eskimo and Indian women of Alaska have lower than expected rates of melanoma. Canadian Inuit men and women; Alaskan Eskimo men; and, Alaskan Indian men and women have similar rates of colon cancer as their countries' respective counterparts.

The overall level of cancer incidence among the Inuit of the Northwest Territories shows a standard incidence ratio of less than 1.0 during the 1969 to 1978 period of study and a level greater than 1.0 during the 1979 to 1988 period (Gaudette et al., 1993). Similarly, the risk for overall cancer sites in Alaskan Native people approaches that of the United States White population. Although statistically nonsignificant, there has been an increase over time of all types of cancer in Alaskan Eskimo women. The risk of overall cancer sites for these women was initially low but shows an increase during the time period from 1979 to 1983. None of the frequently occurring cancers in Alaskan Native people are showing a downward trend (Lanier et al., 1989).

Native People of Western Washington, Saskatchewan, Manitoba, Ontario, Dakotas,  
New York State, and New Mexico

Native American People in Western Washington State

Native American people in Western Washington State experienced approximately half the incidence of cancer as the Caucasian residents of this area of the State during the period from 1974 to 1983 (Norsted & White, 1989). Data for this study were collected from the Seattle-Puget Sound cancer registry which is one of the 11 registries in the Surveillance, Epidemiology and End Results (SEER) Program of the National Cancer Institute. Overall, Native American men experienced 42 per cent of the Caucasian cancer rate (age-adjusted incidence rate) while Native American women experienced 56 per cent of the Caucasian cancer rate. Of the cancer cases reported during the ten year study period, 289 were Native American people and 85,830 were Caucasian.

With the exception of gallbladder and cervical cancer, no cancer sites were significantly increased in incidence among Native American people when compared to the Caucasian population. The actual number of gallbladder cancer cases was small (six cases). When compared to the standard incidence ratio experienced by the Caucasian people (SIR=1.8) and 1.8 the expected proportional incidence among Caucasians (PIR=3.3,  $p < 0.05$ ), only 3 cases of gallbladder cancer in the Native American population would be expected.

The incidence of cervical cancer is greater than 1.5 times the rate of incidence for the Caucasian women in this region. The increased rate of invasive cervical cancer

may be due in part to ineffective pap smear screening programs for Native American women. They were 1.5 times more likely than Caucasian women to have cervical cancer diagnosed at an invasive stage (Norsted & White, 1989).

No cases of nasopharyngeal carcinoma were reported among the Native American people. Significant deficits were found for cancer of the colon, lung, bladder and breast (Norsted & White, 1989).

Incorrect reporting of ethnicity or race on medical records, differences in medical care, utilization, access to medical care and genetic predisposition may contribute to the low incidence of cancer among Native American people of Western Washington (Norsted & White, 1989). Health care personnel may be completing racial information based largely on appearance rather than asking the patient for racial information (Frost, Taylor & Fries, 1992). Accurately identifying Native American people in this manner is more likely to occur in areas where the Native American population is higher or the hospital services are delivered by Indian Health Services.

Differences in medical care utilization between Native American and Caucasian people may explain the lower incidence of cancer in the Native American population (Norsted & White, 1989). American Native people who are economically poor and not enrolled in a federally recognized tribe may have less access to medical care services (Norsted & White, 1989). Many American Native people in this region experience poverty and, without the provision of health care services provided by Indian Health Service, they must find alternate ways to obtain health care.

Genetic predisposition, diet, and lifestyle may also contribute to the low

incidence of cancer in Native American People in Western Washington State.

Although Native American people in this region have become more assimilated and urbanized, their Asian origin and existence before European contact may influence the low incidence of cancer. Northwest Coast Native American people may be genetically linked to Asians and in Asian countries the incidence of cancer is markedly less than in the United States. Lifestyle and diet (ie: berries, whole grains, and seafood) may also contribute to a low risk for developing cancer (Norsted & White, 1989).

#### First Nations People of Saskatchewan

The overall incidence of cancer among registered Indian people and other people living in the northern half of Saskatchewan is significantly lower than the general population in Saskatchewan (Irvine et al., 1991). Approximately one-third of registered Indian people living in Saskatchewan reside in the northern half of the province and represent about five percent of the total provincial population. Fifty per cent of the Saskatchewan northerners are registered Indians, 30% are Métis, and 20% are from other ethnic groups. The northerners of Saskatchewan live in small remote communities located in the Subarctic between 54 and 60 degrees latitude. They are served by the Northern Health Services Branch of Saskatchewan Health.

All cancer cases in these studies were identified from the Saskatchewan Cancer Registry of the Saskatchewan Cancer Foundation. Since 1962, all registered Indians living in Saskatchewan have been assigned the prefix "R" as well as a number which identifies the Indian Band to which each person is registered. However, it cannot be determined from this registry whether First Nations People live "on" or "off" reserve.



Northerners are identified by residence codes in the Saskatchewan Cancer Registry which refer to the patient's usual location of residence (Gillis et al., 1991; Irvine et al., 1991; Irvine et al. 1993).

For all cancer sites, registered Indian people experienced a four-fold increase in cancer (age-standardized) incidence per 100,000 through the 20 year study period while northerners showed a two-fold increase. Cancer cases were first analyzed for a 20 year period and then separately for each of the following five year periods: 1967-71; 1972-76; 1977-81; and 1982-86. The greatest increase in incidence occurred during the last decade of study in the First Nations population and during the first five years among other northerners. However, the provincial rate also increased by 19 per cent over this 20 year period. This rise in cancer incidence was significant among all groups (Gillis et al., 1991).

Among Registered Indian people, 15.5% of all cases were cancer of the cervix while 11.8% lung, 10.3% breast, 10.1% rectum and colon, 8.4% prostate, 4.9% leukemia, 2.2% each for uterus and stomach, and 0.6% bladder. The distribution of cancer cases diagnosed by cancer sites for northerners were as follows: lung 17.8%; breast 12.6%; prostate 9.5%; rectum and colon 9.1%; cervix 6.6%; leukemia 3.5%; bladder 2.7%; uterus 2.3%; and, stomach 1.9%. Fourteen percent of all cancer cases in the Saskatchewan general population was rectum and colon, breast 12.9%; prostate 12.2%; lung 11.3%; bladder 4.9%; stomach 4.1%; leukemia 3.5%; uterus 3.3%; and, cervix 1.6%.

For all registered Indian people living in Saskatchewan, the male to female

ratios showed that the rates of cancer for women were consistently higher than for men in each of the four study periods (Gillis et al., 1991). However, this ratio differential between First Nations men and women has decreased consistently over time.

Cancer rates among Indian women are approaching those of Indian men (Irvine et al., 1991). Indian people, residents of northern Saskatchewan, and the general population of the province, showed increases in age standardized incidence rates of lung cancer during each of the four study periods: 1967-71, 1972-76, 1977-81 and 1982-88 (Irvine et al., 1991). During the earlier years of study, 1972-76 and 1977-81, there was a deficit in the incidence of lung cancer for Indian women when compared with the rest of the people in the province. However, these deficits have become smaller from one time period to another. Then, during the 1982-88 time period the rates for Indian women with lung cancer exceeded, although not statistically significant, the provincial incidence rates.

Another reason registered Indian women cancer incidence rates are approaching those of Indian men in Saskatchewan is the dramatic increase in the age-standardized breast cancer incidence rates over the 20 year period (Irvine et al., 1991). Breast cancer incidence rates have increased almost four and one-half times (4.4) for Indian women in Northern Saskatchewan while remaining relatively stable (5.4% increase) for Saskatchewan women as a whole during the 20 year study period.

The age-standardized incidence rate for cervical cancer among Indian women of northern Saskatchewan was not only greater than the rate of Saskatchewan women

as a whole, but it was also greater than the rate for women in northern Saskatchewan throughout the 20 year period (Irvine et al., 1991). While the cervical cancer rate for Saskatchewan women declined by 45 per cent during the 20 year period, the rate of cervical cancer for Indian women in Northern Saskatchewan increased by 52 per cent. The incidence rate for Northern women increased by 10 per cent.

Incidence rates for all types of cancer among northerners were significantly below those of the provincial rates for men and women combined, and for men for each of the four 5-year periods (Irvine et al., 1993). However, over the 20 year period (1967 to 1986), northerners experienced a 100% increase (126.3 to 258.7 per 100,000) in total cancer incidence while the provincial incidence rate increased by 19% (258.8 to 308.5 per 100,000).

When compared with the total female population in the Province, northern women had lower cancer incidence during the first 10 years of the study. However, this gap closed as the incidence in cancer increased in northern Saskatchewan women during the 1977-81 and 1982-88 time periods. The percentage distribution by major cancer sites have been discussed in the aforementioned studies.

#### First Nations People of Manitoba

The overall risk of cancer for Manitoba Indian people living on reserves was significantly lower when compared to the general Manitoba population during the time period from 1970 to 1979 (Young & Choi, 1985). Cancer cases for this study were identified from the cancer registry of the Manitoba Cancer Treatment and Research Foundation. The registry does not include codes for ethnic origin. Residents of Indian

reserves were identified from the resident codes which refer to the usual address of patients at the time of diagnosis.

With this method, it is impossible to identify Indian people who are not residents of reserves. By using only residents living on reserves as the study population, there results an underestimation of the number of cancer cases among Manitoba Indian people. Therefore, the incidence rates discussed in this study reflect the relative risk of cancer among residents of Indian reserves.

Twenty three percent (23.4) of cancer cases in Indian men residing on reserves in Manitoba were prostatic and 13.5% were lung. Among Indian women almost 20% of cancer cases were breast. Table 6 shows the predominant types of cancer among Indian People residing in Manitoba reserves.

TABLE 6  
Predominant Cancer Types in Indian People  
(% DISTRIBUTION)

Manitoba Reserves 1970 - 1979			
Men		Women	
Prostate	23.0	Breast	19.1
Lung	13.5	Cervix	13.9
Melanoma	9.9	Melanoma	7.8
Kidney	8.1	Kidney	7.0

Significant age-standardized incidence ratios were as follows: (i) Indian women had three times the risk of developing gallbladder cancer, while Indian men were at less risk (0.74) when compared to the provincial population, (ii) Indian women were

at three times the risk for developing cancer of the kidney when compared to the general population of Manitoba, while Indian men were only at a slightly greater risk than the general Manitoba population; and, (iii) Indian women had almost one and one half times the risk of developing cervical cancer compared to all women in Manitoba.

Information about exposure to risk factors among Canadian Indian People is limited. The relationship between cancer of the gallbladder and cigarette smoking, dietary changes, obesity, and gallstones is speculative. The relationship between cervical cancer and practices and behaviours surrounding sexual intercourse, pregnancy, childbirth and lactation is also speculative. However, the level of screening for cervical cancer likely has contributed to the prevalence of cervical cancer in Manitoba Indian women. Forty five per cent of Indian women who participated in Medd, Wotton, MacDonald et al.'s study never had a Papanicolaou smear (as cited in Young & Choi, 1985).

#### First Nations People of Ontario

In a study of 88 Cree and Ojibwa Treaty Indian people residing in a northwestern area of Ontario from 1972 to 1981, the overall age-adjusted risk for all cancer sites in Sioux Lookout Zone for Indian men was half as great as the Canadian population, while for the Indian women it was comparable (Young & Frank, 1983). Age-adjusted comparisons were made with the Canadian national population to examine the incidence of cancer among the First Nations People in this region. Medical Services Branch of the Department of Health and Welfare Canada provides

health services to this geographically isolated and socially homogeneous population in the Zone designated as Sioux Lookout. The authors did not ascertain that the study participants were "full-blooded" Indians but indicated that in 1970, a serological study that used several genetic markers, identified very little evidence of Caucasian admixture in one community in the Zone.

The small numbers of cancer cases over this nine year period presented a challenge to "statistical significance". Kidney cancer was of primary concern with this group where men were affected twice as often as women. Other predominant types of cancer among Indian People in Sioux Lookout Zone are listed in Table 7.

TABLE 7  
Predominant Cancer Types in Indian People  
(% DISTRIBUTION)

Sioux Lookout Zone 1972 - 1981			
Men		Women	
Kidney	25.0	Kidney	10.0
Prostate	15.0	Colon	8.0
Colon	7.5	Gallbladder/Bile Ducts	8.0
Lung	7.5	Breast	8.0
Myeloid Leukemia	7.5	Pancreas	6.0

The risk for developing lung cancer is much lower for the native people of Ontario (SIR 0.25) in comparison to the general population of Canada. Although women's risk of developing breast cancer was lower in comparison to the Canadian population, (SIR 0.27) there was a nine fold greater risk for the development of

gallbladder cancer and eight fold greater risk for the development of kidney cancer. As shown in Table 8, skin cancer is rare among Ontario Indians and there were no urinary bladder or stomach cancer cases reported. This cancer profile is 15 years old. An updated profile for Indian People in Sioux Lookout Zone might present different types of cancers which are higher than expected in the Canadian population.

TABLE 8  
Higher Than Expected Rates of Cancer in Indian People  
(Compared with Canadian Population)

Sioux Lookout Zone 1972 - 1981			
Men		Women	
Kidney	7.1	Gallbladder	9.0
Gallbladder	5.4	Kidney	7.7
Leukemia	3.7	Pancreas	3.0

#### Indian People of the Dakotas

Justice (1992) examined the primary cancer distribution of the Oglala Lakota Sioux of the northern plains in the United States during the period from 1970 to 1979. The records of people diagnosed with cancer were located through the Indian Health Service (IHS). Other resources included death certificates, tribal registries, and the tumour registries at Rapid City in South Dakota. Records were retrieved and reviewed from 18 hospitals from Portland, Oregon to the Mayo Clinic in Minnesota including the IHS hospitals in Pine Ridge, Rosebud and Rapid City.

Of all neoplasms, Dakota men were diagnosed with cancer of the lung most

often (15.3%) while among Dakota women breast cancer was diagnosed most often (28.6%). Predominant cancer types among Dakotas are listed according to percentage distribution in Table 9.

TABLE 9  
Predominant Cancer Types in Indian People  
% DISTRIBUTION

Dakotas 1970 - 1979			
Men		Women	
Lung	15	Breast	29
Prostate	11	Cervix	16
Stomach	10	Lung	11
Gallbladder	4	Leukemia	7
Pancreas	4	Stomach	6

When compared to the total United States population, the mean annual incidence rates per 100,000 from 1970 to 1979 were increased for specific tumours in the Indian People of the Dakotas. Notably, Dakota men have a higher annual incidence rate of cancer for penis 10.7 (U.S. 0.9) and Dakota women have a higher rate of cervical cancer 46.9 (12.6). Table 10 lists the cancer types which have higher than expected rates of cancer among the Indian People in the Dakotas.

When compared to the United States population, the Dakota men have less cancer of the lung 46.9 (US 76.1), prostate 19.4 (US 65.4), colon 10.8 (US 35.6) and bladder 7.8 (US 25.4). However, Dakota women have lower cancer rates for breast



47.5; uterus 9.8; bladder 0; kidney 0; and, melanoma 0. In comparison, the rates for the United States were: breast 84.9; uterus 30.0; bladder 6.9; kidney 4.3; and melanoma 5.3.

TABLE 10  
Higher Than Expected Rates of Cancer in Indian People  
(Compared with Total United States Population)

The Dakotas 1970 - 1979			
Men		Women	
Penis	12.0x	Cervix	3.7x
Gallbladder	4.5x	Gallbladder	3.7x <sup>1</sup>
Kidney	2.0x	Stomach	3.0x
		Lung	1.5x
		Leukemia	1.5x

Although cancer of the lung is a common type of cancer among the Dakota people, the annual incidence rate is lower than the population in the United States. When compared to the population in the United States, cancer of the kidney is higher among Dakota men, and cancer of the cervix is higher among Dakota women.

Cigarette smoking may contribute to the increased incidence of lung and bladder cancer. Tobacco has cultural and religious significance among the Oglala Dakota Sioux. Eighteen of the twenty one lung cancer cases had histories of consuming more than one pack of cigarettes per day.

---

<sup>1</sup>Rate based on less than three cases.

### Indian People of New York State

When compared to the cancer incidence patterns exhibited by the general population of New York State, excluding New York City, no cancer sites were significantly increased among the people of the Seneca Nation between 1955 and 1984 (Mahoney, Michalek, Cummings, Nasca, & Emrich, 1989).

Among the men of the Seneca Nation, 16.3% of all tumours from 1955 to 1984 were lung, while prostate were 12.8%; colon 10.5%; rectum 9.3%; pancreas 7.0%; and kidney 5.8%. Among Seneca women, cancer of the breast was most prevalent 16.3%. Cancer of the lung was 13.8%, cervix 11.3%, uterus 8.8%, colon, 8.8%, cervix 11.3% and rectum 5.0%.

For all sites combined, a significant deficit of cancer incidence was observed for both men (0.64) and women (0.53) of the Seneca Nation. Compared to the people of New York State, the Seneca men had half (0.49) the incidence of lung, and one tenth the incidence of bladder cancer. Seneca women had less than one half (0.43) the incidence of colon cancer, one third the incidence of breast cancer, and no bladder or pancreatic cancer.

### Indian People of New Mexico State

The incidence of cancer among the Zuni Indian people of New Mexico was compared to the Caucasian population and American Indian non-Zuni population of New Mexico during the period from 1969 to 1982 (Sorem, 1985). A variety of sources was used to identify Zuni Indian People for this study. The Zuni Public Health Services Hospital was used to identify Zuni Indian people with cancer from

1969 to 1982. The hospital is registered with the New Mexico Tumour Registry which is part of the National Cancer Institute Surveillance, Epidemiology and End-Results (SEER) program. The Zuni Service Unit 1982 annual report from the New Mexico Tumour Registry includes a cumulative list of all the cancer patients reported through the Zuni Public Health Services Hospital from 1969 to 1982. Zuni cancer patients who were reported through other hospitals such as the Gallup Indian Medical Centre and Albuquerque Indian Hospital were also included in the study.

The Zuni are one of the tribes of the Pueblo Indian people and are genetically distinct from the Caucasian people (Jordan & Key, 1981). They are less assimilated into the Anglosaxon and Hispanic cultures than other Indian people who live in the larger urban centres of New Mexico.

In overall age-adjusted incidence of cancer, malignant neoplasms occurred half as frequently (0.52) in Zuni Indian men as in the Caucasian men of New Mexico (Sorem, 1985), and half the incidence of the United States male population. For Zuni women, for all sites combined, the number of cancer cases observed was significantly lower than the expected rate of Caucasian women: 62% for malignant and carcinoma in situ (CIS) and 45% for malignant only.

For the period of study the predominant cancer types were identified among Zuni and other Indian people living in New Mexico (Sorem, 1985). Prostate cancer occurred in 35% of all cancer cases among Zuni Indian men and 25% of all cancer cases among American Indian non-Zuni men. Almost half of all cancer cases (45%) among Zuni women were cervical. Similarly, among American Indian non-Zuni

women, 40% of all cancer was cervical. Table 11 shows the distribution of predominant types of cancer in Indian People living in New Mexico.

TABLE 11  
Predominant Cancer Types in Indian People  
(% Distribution)

New Mexico State 1969 - 1982							
Zuni			Non-Zuni				
Men	Women		Men	Women			
Prostate	35	Cervix	45	Prostate	25	Cervix	40
Stomach	21	Gallbladder	15	Stomach	15	Breast	7
Liver	6	Breast	5	Lung	6	Gallbladder	6
Gallbladder	6	Ovaries	5	Colon	5	Ovarian	4
Kidney	6						

Among Zuni people, cancer sites that exceeded the expected rate for Caucasian people in New Mexico included gallbladder, stomach and liver. In Zuni Indian, men gallbladder cancer occurred 14.3 times more often than expected in Caucasian men, and twice (O:E 2.2) the expected rate in American Indian men. Stomach cancer occurred almost four times (O:E 3.6) the expected rate in Caucasian men and one and one half times the expected rate of American Indian men. Cancer of the liver occurred almost four times (O:E 3.7) the expected rates in both the Caucasian and American Indian men. (see Table 12)

Kidney and prostatic cancer occurred among Zuni men at the expected rate of

Caucasian men, but 1.5 times the expected rate of American Indian men. The expected rate of lung cancer among Zuni men was 10% that of Caucasian men.

Gallbladder neoplasms in Zuni women, occurred 19.4 times more often than the expected rate in Caucasian women, and twice the expected rate in American Indian non-Zuni women. (see Table 12) Ovarian and cervical neoplasms were diagnosed at almost the expected rates of the Caucasian women, observed-to-expected ratios of 0.9 and 0.8 respectively. Breast cancer was observed at 20 percent and 60 percent the expected rates of the Caucasian and American Indian women. The observed-to-expected ratio for lung and colon cancer among Zuni Indian women was zero when compared to the Caucasian and American Indian women.

TABLE 12  
Higher Than Expected Rates of Cancer in Indian People  
(Compared with New Mexico Caucasian)

New Mexico			
Men		Women	
Gallbladder	14.3x	Gallbladder	19.0x
Stomach	4.0x		
Liver	4.0x		

Cancer of the gallbladder was significantly higher in the Zuni Indian people, particularly Zuni women, when compared to the rates among Caucasian and American Indian people. The incidence of lung and colon cancers were significantly lower among the Zuni Indian people when compared to the Caucasian and American Indian population in New Mexico. Staff members at the Zuni Public Health Services

Hospital indicated that among the Zuni, habitual smoking of more than 5 to 10 cigarettes per day is unusual. The differences in lung cancer incidence between the Zuni people and American Indian people may be due to uranium mining. Zuni people do not mine uranium, however Navajo Indian men do. Therefore, the number of affected Navajo miners may contribute to the differences in lung cancer in American Indian men in New Mexico.

Discussion: Native People of Manitoba, Ontario, Saskatchewan, Western Washington, Dakotas, New York State and New Mexico

The overall incidence of cancer among Indian people of Manitoba, Ontario and Saskatchewan is significantly lower than their comparison populations. This has also been noted in the American Native populations in Western Washington, The Dakotas, New York State, and New Mexico.

The Indian People of Manitoba share similarities with other native populations in Canada and the United States. Among Indian men, prostate and lung cancer are the most prevalent types of cancers in Manitoba. This is similar to Indian men in Ontario, Saskatchewan, The Dakotas, and among the non-Zuni Indian men of New Mexico. Among Indian women, breast and cervical cancer are the leading types of cancer in Manitoba. With the exception of Indian women in northwestern Ontario, both the breast and cervix are the most prevalent sites for cancer. In northwestern Ontario breast cancer is the fourth leading type of cancer.

The First Nations People of Manitoba, like other aboriginal groups in Canada and the United States, have unique cancer patterns. For example, melanoma is the

third leading cause of cancer among Indian people in Manitoba. However, it is not prevalent among Indian people in northwestern Ontario, Saskatchewan or United States.

The First Nations People of Manitoba are similar to other Native groups in that the incidence of certain cancer sites exceed those of the general provincial and national populations. Indian men and women of Ontario experience higher than expected rates of kidney cancer than the Canadian population. Similarly, Indian women of this region experience higher than expected rates of gallbladder cancer. However, the Indian people of Saskatchewan experience higher than expected levels of cervical cancer, but kidney and gallbladder cancer are not higher than expected when compared to the general Saskatchewan population. Kidney, cervix, and gallbladder are cancer sites among Dakota men exceeding the general population in the United States. Incidence rates among Zuni people for gallbladder cancer also exceeds rates among the non-Hispanic White population of New Mexico. Among non-Zuni women, the incidence for cervical and gallbladder cancer exceed the expected rates of cancer in the non-Hispanic White population of New Mexico.

Examination of trends in Saskatchewan status Indian people show an increase in the overall incidence of cancer (Gillis et al., 1991). For all types of cancer, the risk for developing cancer among registered Indian people in Saskatchewan is lower than the Northerners and the total population. During the time period from 1967 to 1986, the registered Indian People of Saskatchewan evidenced a four-fold increase, from 59 to 249 per 100,000 in cancer age-standardized incidence. Northerners who

are primarily of Indian and Métis ethnic origin showed a two-fold increase (from 126 to 259 per 100,000) and the Saskatchewan population incidence rate increased by only 19% (from 259 to 309 per 100,000). During this 20 year time period the greatest increase in incidence occurred during the last decade of the study in the Indian population and during the first five years among the Northerners. The incidence of cancer is increasing and does not indicate a downward trend among First Nations People in Saskatchewan.

#### Specific Cancer Sites: The Aboriginal Population

Specific cancer sites are discussed in this section of the literature review. The predominant sites of cancer are included. These are cancers of the nasopharynx, salivary gland, esophagus, kidney, choriocarcinoma and gallbladder. Cancer types influenced by Western lifestyle or "acculturation" are discussed. These are cancers of the lung, cervix, breast and colorectum. After an overview of stomach and liver cancer, which are prevalent among the American native population, information about urinary, prostate and melanoma cancers which are significantly lower in incidence among Indian people in the Canada and the United States are presented. Finally, this chapter ends with a discussion about the review of the literature.

#### Nasopharynx

Higher than expected ratios for developing nasopharyngeal cancer were identified in the Inuit/Eskimo of Canada, Alaska and Greenland; and the Indian and Aleut of Alaska. In Canadian Inuit males and females, nasopharyngeal cancer is 21.5 and 26.9 times higher than the general Canadian population (Gaudette et al., 1991).



For the Alaskan Eskimo male and female the observed/expected ratio was 20 and almost 23 respectively (Lanier et al., 1989). Greenlandic Inuit develop nasopharyngeal cancer 20 times more frequently than the Danish population. With the exception of the Indians and Aleuts in Alaska, nasopharyngeal cancer is not significant in other native populations.

Genetics, dietary and environmental factors, and viral infection are hypothesized as contributing to elevated nasopharyngeal carcinoma rates among these native groups. The Inuit/Eskimo of Canada and Alaska share genetic partiality with the Chinese; the Inuit migrated to Canada and Alaska from northeast Asia. The excess risk for nasopharyngeal cancer is also seen in parts of China and among people of Chinese descent in various parts of the world (National Cancer Institute of Canada, 1991). The risk of cancer was significantly increased in siblings of Eskimo, but not Aleut or Indian nasopharyngeal carcinoma patients (Ireland, Lanier, Knutson, Clift & Harpster, 1988). In response to a questionnaire survey, it was found that nasopharyngeal carcinoma patients ate salted fish more frequently in childhood, smoked cigarettes, and were exposed to noxious fumes more frequently than the control groups (Lanier et al., 1980). The analysis of various case control studies in high risk populations have revealed that the ingestion of preserved foods such as salted fish by the Chinese may contribute to the development of nasopharyngeal cancer (Yu, 1990). Collection and analysis of the most common preserved foods (dried, salted and fermented) from China and Greenland found that nitrosamine-containing food items are among those consumed most frequently in high risk areas.

However, since other low risk groups have similar food consumption, the age when nitrosamine-containing foods are introduced to children requires investigation (Poirier et al., 1987).

In comparing high risk Greenlandic Eskimo children with low risk Danes, it was found that the high risk group were infected with the Epstein-Barr virus at a very early age and have higher viral capsid antibody (IgG) and soluble antibody titers than the low risk group (Melbye, Ebbesen, Levine, & Bennike, 1984). More case controlled research is required to identify causative agents and contributing factors for the development of nasopharyngeal carcinoma.

#### Salivary Gland

The Inuit women and men of the Northwest Territories, Canada and Greenland and the Eskimo women of Alaska are at significantly greater risk for developing cancer of the salivary glands (Gaudette et al., 1993; Nielsen, 1986). Inuit/Eskimo women are particularly at high risk. Canadian Inuit women exceed the general Canadian population by 20.7 (Gaudette et al., 1991) and Alaskan Eskimo women exceed the United States caucasian population by 4.4 (Lanier et al., 1989).

Salivary gland carcinoma, also known as malignant lymphoepithelial lesion and salivary gland lymphoepithelioma, rarely occurs outside the Arctic regions and is histopathologically indistinguishable from undifferentiated nasopharyngeal carcinoma. In a study of 11 Greenlandic salivary gland carcinoma cases, Epstein-Barr virus genomes were detected in each case (Hamilton-Dutoit et al., 1991). In another morphological study of 16 Alaskan salivary gland cancer cases, however, no

relationship was found between this cancer and the Epstein-Barr virus (Krishnamurthy, Lanier, Dohan, Lanier, & Henle, 1987). More Arctic based studies with larger sample sizes are required to determine the link between the Epstein-Barr virus and salivary gland carcinoma.

### Esophagus

The risk for developing esophageal cancer is high among Inuit and Eskimo people in the Arctic, however, this risk is especially high for Inuit and Eskimo women. Esophageal cancer occurs six times as frequently in Inuit women and three times as frequently in Inuit men than in the Canadian population (Gaudette et al., 1991). Similarly, Eskimo women in Alaska were three and one half times more likely to develop esophageal cancer (O:E 3.5) than "U. S. Whites" while Eskimo men are twice as likely as "U. S. Whites" to develop the same cancer (O:E 2) during the period from 1969 to 1983 (Lanier et al., 1989). Similar patterns were evident in Greenlandic people which Nielsen studied during the period from 1975-1983. When compared to the Danish population, esophageal cancer was eight times higher in Inuit women and six times higher in Inuit men (Nielsen, 1986).

The prevalence of esophageal cancer among Eskimo and Aleut people in Alaska may be related to factors surrounding life-long geographical residence (Lanier, Kilkenny, & Wilson, 1985). An epidemiological review of 42 Alaskan natives with esophageal cancer diagnosed during the period from 1955 to 1981 revealed that 40 of the patients were Eskimos and Aleuts who resided in similar geographical areas on the Alaskan coast. The patients lived in the same or nearby village at the time of their

diagnosis as that in which they had been born; lived in areas occupied by Eskimo-speaking people (Inupiagn, Yupik and Sugpiag); and, none were known to be closely related. Further research is required to monitor for cancer clustering phenomenon that may be present in Inuit/Eskimo communities.

### Kidney

The risk of developing kidney cancer is high among certain aboriginal groups. For example, the Alaskan Eskimo women and status Indian people in Manitoba reserves and isolated areas of northwestern Ontario are at greater relative risk. While Alaskan Eskimo women have more than twice the risk of developing kidney cancer when compared to United States Whites (Lanier et al., 1989), Canadian Inuit women experience kidney cancer at less than expected levels when compared to the Canadian population (Gaudette et al., 1991). Kidney cancer among Canadian Inuit men does not occur at a rate significantly different from the rest of the Canadian population.

The status Indian people in the Northwest Territories are comparable to the Canadian population with regard to developing kidney cancer (Gaudette et al., 1993). However, kidney cancer is the fourth leading cancer among these Indian men (8% of all new cancer cases) and in the Indian women, it is fifth (7% of all cancer cases). Similarly, the Indian people in Alaska are comparable to the White population in the United States for developing kidney cancer (Lanier et al., 1989).

Indian people living in Manitoba reserves from 1970 to 1979 developed kidney cancer twice as often as the general Canadian population (Young & Choi, 1985). However, the risk of developing kidney cancer among isolated Indian people in

northwestern Ontario during the period between 1972 and 1981 was seven times higher than the Canadian population (Young & Frank, 1983). Kidney cancer deaths accounted for 15% of all cancer deaths in northwestern Ontario natives during this time period while in the general Canadian population, 2% of all cancer deaths were attributed to kidney cancer.

Smoking cigarettes may be a contributing factor toward the development of kidney cancer in aboriginal people in this region. Almost half of respondents (48%) of a community health survey over fifteen years of age were cigarette smokers and, in comparison, 38% of the Canadian population in the same age category were cigarette smokers (cited in Young & Frank, 1983). However, other factors including diet and environment may be influencing the development of cancer (Mahoney & Michalek, 1991). The prevalence of kidney cancer among Indian people in Manitoba and Ontario requires monitoring and further research.

#### Choriocarcinoma

Canadian Inuit women are at a significantly high risk (SIR 17) for developing choriocarcinoma, cancer in the uterine lining, than their Canadian counterparts. No evidence of this cancer site has been presented for Alaskan Eskimos, Greenland Inuit nor the Indians of Canada and United States. Reasons for the prevalence of this cancer has not been discussed in the literature.

#### Gallbladder

Indian women of northwestern Ontario and Manitoba are at nine and three times greater risk, respectively, of developing cancer of the gallbladder (Young &

Choi, 1985; Young & Frank, 1983). There is also a significant increase for this type of cancer among Indian women in Washington and New Mexico States (Norsted & White, 1989; Sorem, 1985). No Inuit women, except those in Canada, show elevated SIRs (Gaudette et al., 1991; Lanier et al., 1989; Nielsen, 1986). While New Mexico Indians with gallbladder cancer were more advanced in disease at the time of diagnosis, 30 per cent did not receive treatment (Samet, Key, Hunt, & Goodwin, 1987).

Since obesity is a risk factor for gallstones and could be indirectly associated with gallbladder cancer, the prevention of obesity could possibly reduce rates of gallbladder cancer (Welty, 1991). For women with gallstones greater than 3 centimetres in size, the risk for developing gallbladder cancer was 9 per cent greater than for women with small gallstones. Native women tend to have larger gallstone size (Lowenfels, Walker, Althaus, Townsend, & Domellof, 1989). Mean gallstone size in female gallbladder cancer was 2.5 plus or minus 1.4 SD centimetres compared to gallstone size in benign gallbladder disease which was 1.5 centimetres (Lowenfels, 1992).

### Lung

Status Indian people in a remote northwestern area in Ontario were at a lower risk than Canadian people for developing lung cancer for the period 1972-1981. That the effects of cigarette smoking had not been evidenced in the population at the time of the study is one possible reason for the lung cancer deficit in Ontario. People residing in Manitoba Indian reserves between 1970 to 1979 were a lower risk than the

general Manitoba population for developing lung cancer (Young & Choi, 1985). The Native American people in Western Washington during the time period 1974 to 1983 developed lung cancer less than half the rate the caucasian people did in the same region (Norsted & White, 1989). The Indian people in Alaska from 1969 to 1983 developed lung cancer at a rate slightly less than the White population in the United States.

Lung cancer rates for both Saskatchewan Indian men and women and Northern men and women exceeded the provincial rates from 1967 to 1986. The Oglala Lakota Sioux women have higher annual incidence rates of lung cancer per 100,000 (35) than the population in the United States (21). However, Oglala Lakota Sioux men experience half the risk of developing lung cancer (47 per 100,000) than the rest of the American population (77 per 100,000). Cigarette smoking likely contributes to the increased incidence of lung cancer. Eighteen of the twenty one cancer cases had histories of smoking more than one pack of cigarettes per day (Justice, 1992). Among the Oglala Dakota Sioux, tobacco use has cultural and religious significance. However, smoking tobacco beyond religious ceremonies is a consideration.

Lung cancer rates among the American Indian people in New Mexico is similar to those experienced by the Anglo population in the same state. Lung cancer is rare among Zuni people in New Mexico and may be attributed to lack of cigarette smoking. Also, in New Mexico, six per cent of all cancer cases in American Indian men are lung. The increased incidence of lung cancer may reflect the effects of uranium mining on Navajo miners. The association between uranium mining and lung

cancer in a predominantly nonsmoking population was made with two studies: (i) seventy two per cent of 32 Navajo men with primary lung cancer had been employed as uranium miners (Samet, Kutvirt, Waxweiller, & Key, 1984) and, (ii) 16 of 17 Navajo lung cancer patients were uranium miners (Gottlieb & Husen, 1982).

Lung cancer is at expected levels for Alaskan native people, however, it is the second most frequently diagnosed invasive cancer when compared to the White population in the United States. Increases in lung cancer rates suggest that the incidence of lung cancer among Alaskan native people will eventually exceed those of the White population in the United States. Smoking prevalence among Alaskan adult natives has been as high as 60 per cent (Lanier et al., 1989). Lung cancer is considered to be one of the diseases of acculturation.

The impact of acculturation is seen by the gradual replacement of "traditional" tumours ie: salivary gland, esophagus, and nasopharynx by those of lung. From 1980 to 1984, Canadian Inuit woman developed lung cancer six times more frequently than the general Canadian population, while Canadian Inuit men experienced twice the risk of developing lung cancer (Gaudette et al., 1993). The incidence of lung cancer among Canadian Inuit rose dramatically between 1970 to 1974 and 1980 to 1984. When standardized to the world population, the rates of lung cancer among Canadian Inuit is alarmingly high with males at 189.3 and females at 164.8 per 100,000 (Gaudette et al., 1991). These lung cancer rates for Canadian Inuit people are more than twice those for Greenlandic Inuit where the rate for Inuit men is 81 per 100,000 and the rate for Inuit women is 50 per 100,000. As with the Inuit women in Canada,



Greenlandic women experienced a dramatic increase in the incidence of lung cancer from 1950 to 1984 (Nielsen, Prener, Hart Hanson, & Jensen, 1988). Canadian Inuit females have the highest recorded rate for lung cancer of any population in the world (Gaudette et al., 1993).

The high rates of lung cancer in Canadian Inuit women may be related to cigarette smoking, use of seal oil lamps and extreme cold (Hildes & Schaefer, 1984; Schaefer et al., 1975). Between 1950 and 1966, the "traditional" tumours (head and neck tumours such as salivary glands and nasopharynx among the Eskimo and Inuit in the Arctic) were the predominant cancer sites. Lung cancer during this period was restricted to elderly Inuit women because they tended open-flame seal or fish oil lamps and inhaled lamp fumes and smudge. After 1966, the cancer pattern among Inuit men and women changed when Inuit women outnumbered Inuit men in developing lung cancer. The increasing number of Inuit women developing lung cancer may be due to a combination of biological interaction with cigarette smoking and smoke inhalation from oil lamps (Hildes & Schaefer, 1984). More research is required to update smoking trends and lung cancer incidence among aboriginal people in various regions in Canada and the United States.

#### Cervix

Cervical cancer was the second leading cancer for American Indian women residing in New Mexico and Arizona during the period from 1977 to 1983. Age-adjusted cancer rates per 100,000 indicate that American Indian women residing in the states of New Mexico and Arizona have over twice the incidence of cervical

cancer (20.5) than American White women (8.6) during the time period between 1977 to 1983 (Burhansstipanov & Dresser, 1993). However, Seneca women in New York State, during the time period from 1955 to 1984, have the expected rate for cervical (invasive) cancer and half the rate for cervical (in situ) cancer when compared to the cervical cancer incidence rates for the women of New York State, excluding New York City (Mahoney et al., 1989). Due to the small number of observed cancer cases among the Seneca Nation, the confidence intervals may not be statistically significant. Cervical neoplasms in Zuni women occur at almost the expected rate of New Mexico caucasian women with observed-to-expected ratio of 0.8 (Sorem, 1985).

Cervical cancer is the most common cancer among Greenlandic Inuit women; second among Canadian Inuit women; and, third among Alaskan Eskimo women. From 1981 to 1985, cervical cancer among Inuit women in Greenland occurred 64 per 100,000 which is three and half times the incidence among Danish women (Nielsen et al., 1988). During the period from 1970 to 1984, cervical cancer occurred three times as often than expected in Canadian Inuit women (Gaudette et al., 1991). Cervical cancer rates among Canadian Inuit women are stabilizing: 33 per 100,000 in 1970-1974, 42 per 100,000 in 1975-79, and, 26 per 100,000 in 1980-1984. During the period from 1969 to 1983, Alaskan Eskimo women developed cervical cancer twice as often compared to White women in the United States (Lanier et al., 1989).

Cervical cancer was the third leading cancer among Alaskan Native women (Eskimo, Indian and Aleut) with an age-adjusted rate of 28.0 per 100,000 population between 1977 to 1983. Among American White women, the rate of cervical cancer is

8.6. The age-adjusted cancer mortality rate per 100,000 population for cervical cancer among Alaskan women is 12.5 and among White American women is 3.2 (Burhansstipanov & Dresser, 1993).

Among Native women in northwestern Ontario, the risk for developing cervical cancer was less than expected (SIR 0.27) compared to Canadian women between 1972 and 1981 (Young & Frank, 1983). However, there has been a significant increase in cervical cancer among Indian women of Alaska, Manitoba and Saskatchewan. The observed-to-expected ratio is 2.5 for Indian women of Alaska when compared with caucasian women in the United States. Indian women living on Manitoba Indian reserves are one and one half times at risk of developing cervical cancer compared to all women in Manitoba. According to the 1992 Annual Report Statistics for Manitoba Cancer Treatment and Research Foundation, the incidence rates of cervical cancer in Manitoba women during 1992 was 62 per 100,000 (insitu) and 10 per 100,000 (invasive).

Only one Canadian study examined the trends in cervical cancer among aboriginal women during the time period from 1967 to 1986 (Irvine et al., 1991). Age-standardized incidence rates for cervical cancer for registered Indian women of northern Saskatchewan were not only greater than the rates of Saskatchewan women as a whole, but also greater than the rates of women in northern Saskatchewan from 1967 to 1986. Saskatchewan northerners consist of 50 per cent registered Indian people; 30 per cent Métis; and, 20 per cent other ethnic groups. While the incidence of cervical cancer among women in Saskatchewan has declined by 45% during a

twenty year period (from 15 to 8 per 100,000), the incidence of cervical cancer among registered Indian women has increased by 52% (changing from 34 to 52 per 100,000 during the period from 1967-71 to 1982-86). Unlike aboriginal women, the incidence rates for cervical cancer continues to fall steadily among Canadian women (National Cancer Institute of Canada, 1993).

Aboriginal women die from cervical cancer. From 1964 to 1973 age-adjusted mortality rates were analyzed and compared between Native Indian people and the White population of British Columbia (Gallagher & Elwood, 1979). Although overall cancer mortality was similar to the White population, Indian women have a higher mortality rate (a relative risk of 4.5) for cervical cancer than do their non-Indian counterparts. Increased cervical cancer mortality rates among Indian women may be due to advanced stage at diagnosis. From 1977 to 1982, all-cancer mortality significantly decreased for Indian people living on reserves (with the exception of the Territories and the provinces of Newfoundland, New Brunswick and British Columbia) when compared to the general Canadian population. However, deaths due to cervical cancer were significantly elevated among Indian women (Mao, Morrison, Semenciw, & Wigle, 1986).

Age-adjusted cancer mortality rates per 100,000 population during the period from 1977 to 1983 indicated that American Indian women die from cervical cancer at almost twice the rate (5.5) of American White women (3.2) (Burhansstipanov & Dresser, 1993). Native women of North Carolina die twice as often as caucasian women in this state as a result of cervical cancer (Horner, 1990). Similarly, the

mortality rate from cervical cancer among the non-White populations of South Dakota during 1979 to 1983 was 25 per 100,000 while among the White population it was 4 per 100,000. As 88% of the non-White female population over the age of 20 in South Dakota is Indian, the mortality figures closely represent mortality rates for Indian women. Cervical cancer mortality is preventable with appropriate screening and treatment (Skubi, 1988).

Of the women (77%) who participated in a follow-up cervical screening program in an isolated rural community in British Columbia, aboriginal women were most likely to be overdue for follow-up screening (Calam, Bass, & Deagle, 1992). Older women, primarily aboriginal women were under-represented in the adequately screened population. The proportion of women belonging to Indian bands located in school districts with the highest cervical cancer mortality rates in British Columbia who participated in the British Columbia Cervical Cytology Screening Program (CCSP) was analyzed. The proportion of "recent users" of the Program decreased with increasing age beyond the teens, while the proportion of "ex-users" increased, levelling off in the 40 - 59 year age groups (Hislop, Deschamps, Band, Smith, & Clarke, 1992). Aboriginal women participating in CCSP were lower for each age group with a difference of approximately 30 per cent. Beliefs, attitudes and knowledge about cancer prevention and cervical cytology screening, and availability of resources and services on reserves require exploration.

The examination of a cytologic detection program for native women in New Mexico and Arizona (Jordan & Key, 1981) found that screening focused primarily on

the 20 to 30 year age group, and there has been a steady decrease in the proportion of native women screened after the age of 30. Native women older than 30 years of age who are at risk for developing cervical cancer will not have their cancers detected early in the disease process. Cervical carcinoma rates are similar for Indian and Anglosaxon women between the ages of 35 to 39 in New Mexico and Arizona. However, cervical cancer rates are higher in native women in the age groups of 25-34 and 60 years or older. The feasibility of one time screening for the 60 and over age group is a worthwhile consideration since none of the women in this age group had previously received a screening test. Ongoing review of screening effectiveness is required. The aboriginal woman's view of how cervical cancer comes about and how they feel about having pap smears tests are essential elements in appropriate utilization of pap smear screening tests. Research and development of screening strategies and educational programs from the patient's world view of the disease process are needed.

A survey of 50 native women who attend a health clinic in Winnipeg, Manitoba revealed a generally high level of exposure to the known and suspected risk factors for cervical cancer (Young et al., 1991). Just over half of the women (54%) had received pap smears annually while 32% had pap smears less frequently. Some other risk factors surveyed were: presence of cigarette smoking, and a history of contraceptive practices, sexual activity, and genital infections. It was not determined whether the participants had cervical human papillomavirus (HPV) however, 29% of those previously screened had abnormal pap smears.

Of the nine per cent of women in a New Mexico study with evidence of HPV, the incidence of HPV was lower in Native American women (6.6%) than non-Hispanic White women (13.6%) (Becker et al., 1991). The results of a pilot study investigating cervical dysplasia risk factors (sexually transmitted diseases, sexual behaviour, hygienic practices, cigarette use, contraceptive techniques and diet) among American Indian women in southwestern United States, suggests that HPV, vaginal deliveries, and current cigarette smoking were associated with dysplasia (Becker et al., 1993). Since these risk factors for dysplasia among the Native American participants were determined to differ from those in southwestern Hispanic and non-Hispanic White women, further investigation to determine ethnic differences in cervical diseases is required. Also, risk factors for the development of cervical neoplasia in aboriginal women require investigation in various regions in Canada and the United States. The role of men in transmitting HPV also requires investigation.

The five-year cancer relative survival (%) for American Indian women residing in the Arizona and New Mexico are comparable (65.1) to American White women (67.2) during the period from 1975 to 1984 (Burhansstipanov & Dresser, 1993). The relative survival rate compares the observed survival rate for a set of cancer patients to that observed for a group of normal persons of a similar age, race, and sex distribution. The relative survival rate is an estimate of the percentage of the cancer patient population which would be alive five years after diagnosis if there were no other causes of death operating. New Mexico and New York State show significantly poorer survival rates for cervical cancer (Mahoney et al., 1989; Samet et

al., 1987).

### Breast

Breast cancer is significantly reduced for aboriginal women in the United States, Canada and Greenland. Breast cancer among Alaskan Native (Eskimo, Indian and Aleut) women was 44.2 per 100,000 during the period from 1969 to 1983 compared to American White women at 93.3 per 100,000 (Burhansstipanov & Dresser, 1993). Eskimo women experience breast cancer at less than half the rate of American White women (observed to expected ratio 0.4).

Breast cancer was extremely rare among Canadian Inuit women during 1970 to 1984 (Gaudette et al., 1991) and Inuit women in the Northwest Territories (Gaudette et al., 1993). Greenlandic Inuit women were only at half the risk compared to women in Denmark from 1950 to 1969 and became "an intermediate risk" after 1970 (Nielsen, 1986). However, during the period from 1981 to 1984, the risk of breast cancer among Greenlandic Inuit women has returned "to a very low rate" (Nielsen et al., 1988).

Breast cancer among Alaskan Indian (observed to expected ratio 0.7) and Aleut women (O:E 0.6) is almost the rate expected in American White women (Lanier et al., 1989). The significant age-standardized incidence ratios for Indian women residing in Manitoba reserves during 1970 to 1979 experienced half the risk of developing breast cancer compared to all women in Manitoba (Young & Choi, 1985). The rate may have underestimated the number of First Nations women with cancer. Indian people with cancer or symptoms of cancer often relocate to the larger urban



centres in the province for medical reasons. However, the use of "usual address" at the time of diagnosis may have reduced this source of bias. The reduced rate may reflect geographic factors and the level of breast screening available in First Nations communities.

Breast cancer has dramatically increased among Saskatchewan Indian and Northern women (50% registered women; 30% Métis; and 20% other ethnic groups) by 4.4 fold and 3.5 fold respectively, while the incidence of breast cancer among women in the Province remained stable during the time period from 1967 to 1988. The five-year survival rate for Indian women (74%), Northern women (70%) and Saskatchewan women as a whole (77%) are similar (Irvine et al., 1991).

Compared to the total population of women in the United States (84.9 per 100,000), the Oglala Lakota Sioux women experienced a lower annual incidence rate of breast cancer (47.5 per 100,000) from 1970 to 1979 (Justice, 1992). However, among Oglala Sioux women the breast is the primary site for cancer and this may reflect their utilization of breast screening programs. Although most women of the Oglala and Cheyenne River Sioux in South Dakota and the Devils Lake Sioux in the Fort Totten area of North Dakota had at least one mammogram, 38 per cent reported never having had one (Welty, Zephier, Schweigman, Blake & Leonardson, 1993). A higher proportion of Cheyenne River Sioux women reported having had a mammogram. Eleven per cent of women in these three Sioux tribes and 15% of Cheyenne River Sioux women reported having mothers and sisters with breast cancer. Over 40% of the women performed monthly self-breast examinations and over half

reported having had a clinical breast exam in the last two years.

Although the incidence of breast cancer among American Indian women in Arizona and New Mexico was lower (21.7 per 100,000) compared to the total American women population (93.3 per 100,000) during the period from 1977 to 1983, it was the primary site for cancer (Burhansstipanov & Dresser, 1993). In New Mexico, breast cancer occurs in 15 per cent of all new cancer cases in Indian women compared to non-Hispanic Whites. Native American women with breast cancer in New Mexico and Arizona are also diagnosed at a more advanced stage (Black, Bordin, Varsa, & Herman, 1979; Samet et al., 1987). The five year breast cancer survival for American Indian women in Arizona and New Mexico with breast cancer is less than American White women, 48.8% and 75.7%, respectively. Breast cancer risk may include factors around pregnancy and changes in breast tissue. American Indian women in New Mexico have shown a low risk of breast cancer and an earlier shift to less dense breast tissue with increasing age compared to Hispanic and Anglos. These changes in breast parenchymal pattern with age and ethnic groups many reflect factors in breast cancer risks (Hart, Steinbock, Mettler, Pathak, & Bartow, 1989). There was no statistically significant difference in the prevalence of breast cancer when ever-parous and nulliparous status, early age at first full-term pregnancy, and total parity was considered in among 519 Anglos, Hispanics and Indian women in New Mexico and Arizona (Pathak, Pike, Key, Teaf, & Bartow, 1991). Other risk factors for breast cancer require investigation.

### Colon and Rectum

In the United States, Alaskan native people had the highest age-adjusted incidence rate for colon and rectum cancer per 100,000 population for both sexes during the period from 1977 to 1983 when compared with all other racial groups, such as Blacks and Whites (Burhansstipanov & Dresser, 1993). For every 100,000 people, the rate for the Alaskan Native is 62.6 and the rate for other American people is 52.8. The rate of incidence for colon and rectum cancer among Alaskan Native men is 61 which is similar to the rate of White men (64.5). However, Aleut men develop colon and rectum cancer at twice the rate (114.8) of the U.S. White population. Alaskan Native women have the highest rate of incidence for colon and rectum cancer of any racial group in the United States at 65.2 per 100,000 (Burhansstipanov & Dresser, 1993). Black women have the second highest rate at 45.9. Alaskan Eskimo women have the highest rate of colon and rectum cancer (116.1) of any other Alaskan Native group. Among Canadian Inuit colorectal cancers occurred at the expected rate of Canadian people from 1970 to 1984 (Gaudette et al., 1991).

During the period 1977 to 1983, colorectal cancer was the fifth leading cancer site among American Indian people in New Mexico and Arizona with an incidence rate of 10.2 per 100,000 (Burhansstipanov & Dresser, 1993). However, this rate is exceptionally low when compared to the U.S. White population. Colorectal cancer occurs five times more often in U.S. White people with a rate of 52.8 per 100,000.

Although the rate of incidence for colo-rectal cancer is higher among the

American White people, the five-year cancer relative survival is lower among American Indian people. The five-year cancer relative survival is 38% for American Indian people compared with 53.1% for the U.S. White population (Burhansstipanov & Dresser, 1993).

The mean annual incidence rate of colon cancer for Oglala Sioux and Tohono O'Odham is lower than it is for the American population (Justice, 1992). Among the Oglala Sioux the rate per 100,000 is 14.5 for women and 10.8 for men and the rate for American women is 30.4 and for American men it is 35.6. The incidence of colon cancer is lower among the O'Odham than the Oglala Sioux. Among the Tohono O'Odham, the women have not experienced colon cancer (rate is 0) and among the men the rate is 6.7 per 100,000. The differences in these rates may be attributed to the consumption of red meat. The Oglala Sioux are large consumers of meat while the Tohono O'Odham rarely eat red meat.

Although the rate of incidence of colon cancer was lower than the general Canadian population (SIR 0.58) from 1972 to 1981, it was also the third leading cancer site among Indian men living in Sioux Lookout zone of northwestern Ontario. The incidence rate was higher (SIR 0.85) and was the third leading cancer site among the Indian women living in this region (Young & Frank, 1983). However, among Indian people living on Manitoba Indian reserves during 1970 to 1979, the incidence of colon cancer was significantly lower than the general Canadian population (Young & Choi, 1985).

Alaskan mortality rates for colo-rectal cancers are higher among the Native

people (24.6 per 100,000) than the U.S. population (21.3 per 100,000).

#### Stomach

Stomach cancer rates are high among all the Native American groups and these differences are suspected to be related to diet, but specific factors have remained elusive (Horm & Burhansstipanov, 1992, p.33)

#### Liver

The risk for developing liver cancer is high among the Indian, Eskimo and Aleut people in Alaska, but this risk is especially high among Alaskan Eskimo men. Alaskan Indian men develop liver cancer twice as often as the White population in the United States, while Eskimo and Aleut women develop liver cancer three times as often. Alaskan Eskimo men are at risk of developing liver cancer nine fold in comparison with United States Whites (Lanier et al., 1989).

Hepatocellular carcinoma has been observed in people who have had evidence of hepatitis B viral infection, but without cirrhosis (Lanier, McMahon, Alberts, Popper, & Heyward, 1987). Chronic hepatitis B virus infection has been implicated in familial clustering of this cancer (Alberts et al., 1991). Alpha-fetoprotein screening for early detection of hepatocellular carcinoma in HBsAg carriers and hepatitis B viral vaccination of susceptible population has been implemented.

#### Urinary Bladder and Prostate

The incidence of prostate cancer is low among Greenlandic Inuit and Alaskan Eskimo men (Lanier et al., 1989; Nielsen, 1986). Among Canadian Inuit men, prostate and urinary bladder cancer is relatively rare. Both occur at one-tenth the

expected in Canadian men (Gaudette et al., 1991).

Oglala and Tohono O'Odham American Native men have significant deficits in prostate and bladder cancers when compared to American men in general (Justice, 1992). Similarly, American Native men in Western Washington develop prostate cancer half as often as American men in general (Norsted & White, 1989). However, this lower rate could be due to a lower diagnostic rate of asymptomatic tumours. Many of the asymptomatic tumours do not progress to a clinical stage.

The most common cancer site among Zuni Indian men is prostate cancer. And, among status Indian men living in the Northwest Territories prostate cancer was one of the leading cancer sites. However, cancer of the prostate occurred less often than expected among status Indian men when compared to the general population in the Northwest Territories (Gaudette et al., 1993). The second most common cancer site among Indian men in northwestern Ontario is prostate (Young & Frank, 1983). Almost one fourth of the incidence of cancer among Indian men in this Ontario region develop prostate cancer.

According to national death records, American Indian men have low prostate mortality rates at 11.8 per 100,000 when compared to White American rate ie: 21.2 per 100,000 (Burhansstipanov & Dresser, 1993). However, three Indian Health Service areas have elevated prostate cancer mortality rates: Aberdeen with 25.4 per 100,000, Albuquerque with 28.8 per 100,000 and Billings with 31.5 per 100,000 (Burhansstipanov & Dresser, 1993).

The prostate cancer five-year relative survival rate among American Indian

men is the poorest among men living in Arizona and New Mexico (Burhansstipanov & Dresser, 1993). The relative survival rate among the Indian men is 51.4 percent and among White men in this region it is 69.8 percent. Although the incidence of prostate cancer and mortality rates are low among American Indian men living in Arizona and New Mexico, their survival is poorer when compared to other men who live in the same region.

### Melanoma

Inuit women of Greenland and Alaskan Eskimo experience a low risk of melanoma (Lanier et al., 1989; Nielsen, 1986). Skin cancer is also rare among Indian People living in Manitoba reserves and Sioux Lookout Zone (Young & Choi, 1985; Young & Frank, 1983). Similarly, the frequency of melanoma among southwestern American Indian People is very low compared with the observed frequency within the White population residing in the same region (Black & Wiggins, 1985).

Although American Indian People experience only about 6% of the incidence of melanoma as Whites in southwestern United States, they demonstrated an unusual pattern of melanoma site localization (Black & Wiggins, 1985). Examination of clinical and pathologic features of melanoma in 18 American Indian patients revealed the prevalence of subungual, sole/palm, and mucosal tumours. These types of melanomas are rare or absent among White population in southwestern United States but similarities were found in African Blacks, American Blacks, Puerto Rican and non-Whites in Hawaii.

Observations were also made about age and tumour stage at diagnosis in the

study involving 18 American Indian People with melanoma (Black & Wiggins, 1985). The average and median age at diagnosis was higher than for a regional control population of Whites with melanoma. However, this is not only a disease of elderly people. Three of the Indian patients diagnosed with melanoma presented with clinical or advanced tumour stage at diagnosis. Melanoma among American Indian People is in the advanced stage at diagnosis. Nine of the eighteen patients were thought to have died from melanoma.

#### Summary: Specific Cancer Sites

First Nations People have expressed concern about the increasing incidence of cancer in their communities. The overall risk for developing cancer among people living on reserves in Canada was lower than the provincial rates during the period between 1979 to 1983 (Young et al., 1991). Since no national cancer data base exists, patterns and trends have resulted from the analysis of epidemiological studies conducted in various regions in Canada and the United States. The pattern of the frequency distribution of primary cancer sites between First Nations People in various provinces in Canada indicate that each group has unique cancer patterns with respect to each other and the Canadian population. For example, the registered Indian men of Alberta experience a higher percentage of melanoma (12.5) than the Indian people of Manitoba (men 9.9%; women 7.8%) and Sioux Lookout (men 2.5%; women 6.3%). Melanoma has not been documented as a primary cancer site in Saskatchewan Indian people. For Indian men living on Manitoba reserves, 23.4% of all cancer is prostatic and this type of cancer occurs half as frequently (10.9) in Albertan Indian men. One



quarter of all cancer cases among Indian men of Sioux Lookout is kidney (25%).

With the exception of Indian people living on Manitoba reserves (men 8.1%; women 7.0%) kidney cancer is rare among Indian people in other geographical regions. The uniqueness of the cancer experience among aboriginal people also exists in the United States.

Certain types of cancers among aboriginal people exceed the expected rate of the Canadian population. Nasopharyngeal cancer is the primary type of cancer which is higher than expected levels in the Canadian Inuit and Indian people of the Northwest Territories. This pattern is also seen in the Eskimo and Indian people in Alaska. During the period from 1970 to 1984, Canadian Inuit men developed nasopharyngeal cancer 22 times more frequently than the general Canadian population, while Inuit women developed this type of cancer 27 times more frequently (Gaudette et al., 1991). During a similar time period, 1969 to 1983 (Lanier et al., 1989) nasopharyngeal cancer occurred among Indian Alaskan men 10 times and Indian Alaskan women 14 times more frequently than the rate of the White population in the United States. Eskimo men in Alaska developed nasopharyngeal cancer 20 times the rate of the White population in the United States. Eskimo women developed nasopharyngeal cancer 23 times the rate of the White population in the United States. Regional variation in the cancer experience does occur.

Although status Indian people living in the Northwest Territories had higher than expected rates for the total Canadian population for cancer of the nasopharynx, there are no cases of this type of cancer among the Indian people in Sioux Lookout,

Ontario, Canada (Young & Frank, 1983). Rather, for the Indian women in this region there is a nine fold greater risk of developing cancer of the gallbladder. The small number of cancer cases over the nine year period of study provide a challenge to statistical significance. Similarly, Manitoba Indian women had an increased risk of developing gallbladder cancer (three times the risk) when compared to the provincial population (Young & Choi, 1985). Indian women in Manitoba were at three times the risk for developing cancer of the kidney when compared to the general population of Manitoba; Indian men were only at a slightly greater risk than the general Manitoba population. Indian women in Manitoba were almost at one and one half times the risk of developing cervical cancer than all the women in Manitoba. Indian people are at greater risk for developing certain types of cancer than the general Canadian population. However, the types of tumours among the Indian People vary from region to region.

Factors that contribute to increased prevalence of specific cancer types in certain aboriginal groups are not clearly understood. Genetic predisposition, the consumption of preserved foods, exposure to noxious fumes, cigarette smoking and Epstein-Barr viral infection may contribute to the development of nasopharyngeal cancer (Lanier et al., 1980; Yu, 1990). Obesity may contribute to gallbladder cancer (Welty, 1991). Cigarette smoking, diet and environmental factors may be related to kidney cancer (Young & Frank, 1983).

Examination of trends over time indicates an increase in the overall incidence of cancer. First Nations People in Saskatchewan are developing cancer at a significant

rate (Gillis et al., 1991). For all types of cancer, the risk for developing cancer among registered Indian people in Saskatchewan is lower than the Northerners and the total population in province. During the time period from 1967 to 1986 the registered Indian People of Saskatchewan showed a four-fold increase, from 59 to 249 per 100,000 in cancer age-standardized incidence. Northerners who are primarily Indian and Métis ethnic origin showed a two-fold increase (from 126 to 259 per 100,000) and the Saskatchewan population incidence rate increased by only 19% (from 259 to 309 per 100,000). During this twenty year time period the greatest increase in incidence occurred during the last decade of the study in the Indian population and during the first five years among the northerners. The rise in cancer incidence is significant among all population groups. The incidence of cancer is increasing and does not indicate a downward trend among First Nations People in Saskatchewan.

Similarly, the risk for overall cancer sites in Alaskan Native People approaches that of the White population in the United States with none of the frequently occurring cancers in Alaskan Native People showing a downward trend (Lanier et al., 1989; Lanier, 1993). One reason for upward trends in cancer incidence among aboriginal people is the development of types of cancer which result from acculturation. For example, lung, cervical, and colorectal cancers which reflect changes in the acculturation patterns of the Inuit of the Northwest Territories gradually replaced the "traditional" head and neck tumours (salivary gland, nasopharynx and esophagus) (Schaefer et al., 1975). Similarly, cancer of the colon, breast, cervix and lung occur in Indian people residing in Alberta, Saskatchewan,

Manitoba and Sioux Lookout, Ontario.

Cancer of the breast, cervix, colorectum, and lung are considered to be cancers resulting from acculturation. Colon cancer accounts for 8.3% of cancer cases in Sioux Lookout Indian women; 7.8% in Albertan Indian men; 7.5% in Sioux Lookout Indian men; 5.4% in Albertan Indian women; 5.2% in women residing on Manitoba reserves and, 3.6% in men residing on Manitoba Indian reserves. Colorectal cancer constitutes 10.1% of cancer in the registered Indian people of Saskatchewan and 9.1% of cancer in Saskatchewan northerners. Breast cancer and cervical cancer prevail among the women of Alberta: 20% each for breast and cervical cancer. The percentage of breast cancer (19.1) is similar among the Indian women who live on reserves in Manitoba and occurs half as frequently (10.3) in Saskatchewan Indian women. Breast cancer occurs 12.6% in Saskatchewan northerners and 8.3% in Sioux Lookout Indian women. Of all the cancer Saskatchewan women have, 15.5% is cervical while for Indian women living on Manitoba reserves the percentage is 13.9. And Saskatchewan northerners have 6.6% and Sioux Lookout women have 4.2% of tumours which are cervical. Almost 18% (17.8) of cancer cases in Saskatchewan northerners are lung; 13.5% in men who reside on Manitoba Indian reserves; 11.8% in Saskatchewan Indian people; 7.8% in Albertan men; 7.5% in Sioux Lookout men; 5.2% in Indian women on Manitoba reserves; and, 2.7% of Albertan Indian women. Breast, cervix, colorectal and lung tumours reflect the influence Canadian culture has on First Nations Peoples' cultures.

Cancer rates for Indian women in northern Saskatchewan are approaching

those of Indian men largely due to increasing lung, breast and cervical cancer patterns during the period from 1967 to 1986 (Irvine et al., 1991). The deficit in the incidence of lung cancer among Indian women between the years of 1972 and 1981 no longer exists. The lung cancer rates for Indian women exceeded, although not statistically significant, the provincial incidence rates. Similarly, breast cancer incidence rates have dramatically increased over the 20 year period by four and one-half times (4.4) when compared to Saskatchewan women. The age-standardized incidence rates for cervical cancer for Indian women of northern Saskatchewan increased by 52 per cent while the rates of Saskatchewan women declined by 45 per cent during the 20 year period.

The changing pattern of cancer in the aboriginal population warrants explanation (Irvine et al., 1991). Underestimation during the early years of the study could account for the lower incidence of lung and breast cancer. The changing lifestyle of Native people to reflect the Western culture such as smoking habits, diet, alcohol use, exposure to environmental influences and possible changes in sexual intercourse, pregnancy, childbirth and lactation practices. Low socioeconomic status, access to and utilization of pap smear screening and colposcopy also influence the incidence of cervical cancer by detecting carcinoma in situ prior to the development of invasive cancer or treatable premalignant conditions (Irvine et al., 1991). Lack of education and cultural barriers may also contribute to the development of cervical cancer (Jordan & Key, 1981).

### Survival

Only one Canadian study discussed the survival rate or proportion of people who would be alive five years after the diagnosis of cancer (Gillis et al., 1991). The relative survival rate is an estimate of the per cent of the cancer patient population which would be alive after diagnosis if there were no other causes of death operating (Horm & Burhansstipanov, 1992). The poorest survival in the Saskatchewan population was found in northerners (comprised 50% Indian and 30% Métis) and in Indian people 65 years of age and older (Gillis et al., 1991). Fifty four per cent of northerners, 56% registered Indian people and 60% in the general Saskatchewan population survived five years from cancer diagnosis. More specifically, 43% of Indian men and 50% of Indian women who are 65 years of age and older survived 5 years from cancer diagnosis while 55% of men and 60% of women of the general population in Saskatchewan survived cancer five years after diagnosis (Gillis et al., 1991). Monitoring the survival rates in other aboriginal populations would add a dimension of understanding to the cancer experience of First Nations People in Canada.

The five-year survival rates for Saskatchewan northerners and registered Indian people are similar to those found in the United States. American Indian people have among the lowest five year survival rates of any racial group in the United States. For all the cancer sites combined and both sexes combined, the five-year relative survival rate is 33.4 per cent while the rate for the White population in the United States is 51.4 per cent (Burhansstipanov & Dresser, 1993).

The reasons for low survival rates among aboriginal people may reflect the stage at which cancer is diagnosed; language and understanding of treatment; and, medical care access, utilization and compliance with therapy (Gillis et al., 1991). These factors are similarly being considered in the United States and others, including fatalistic attitude about the outcome of a cancer diagnosis and preference for medical assistance from traditional healers rather than Western medicine (Horm & Burhansstipanov, 1992). Although registered Indian people and northerners on social assistance have the assistance of paid medical transportation and can access hospital and physician services when they are required, the nature of access from the First Nations Peoples' experiences require investigation. Understanding perspectives and beliefs about the etiology, characteristics, prevention and treatment of cancer are vital for developing education and cancer screening services for First Nations People.

### Mortality

From 1977 to 1982, the cancer mortality for Indian people living on reserves in Canada significantly decreased (Mao et al., 1986). However, deaths due to cervical cancer were significantly elevated. Also, Indian people experienced four times the expected mortality rate of the Canadian population ( $p < 0.01$ ) while Indian men were observed to have twice the expected rate ( $p < 0.05$ ) for kidney cancer. Lung cancer mortality for Indian women living on reserves was similar to the general Canadian population, but significantly low in Indian men. Indian women experienced about one-third the breast cancer deaths expected when compared to the general Canadian population. Mortality due to gallbladder cancer was rare in Canadian Indian people.

Death attributed to specific cancer sites is suggested to vary from region to region. More studies are required to confirm the findings of this study because the data base may not have considered mobility of First Nations People on and off reserve.

Kidney cancer accounted for 15 per cent of cancer deaths in First Nations People of Sioux Lookout, Ontario compared to only two per cent in the Canadian population (Young & Frank, 1983). Cancer of the uterine cervix, and gallbladder and bile duct present an increased risk of death among Indian women of British Columbia (Gallagher & Elwood, 1979). Mortality can be decreased through early detection/screening programs such as mammography, breast self-examination/clinical examination and Pap testing for cervical cancer (Horm & Burhansstipanov, 1992). Education programs can help people seek medical care earlier. With the diverse responses to cancer among aboriginal people in Canada, cancer prevention and control should be area-specific and based on the cancer epidemiology in each area (Welty, 1992).

#### Cancer Prevention

According to the literature there is an absence of cancer prevention programs which have been developed and implemented for specific First Nations communities. Few programs identifying cancer risk factors in First Nations communities are being implemented to date (Becker et al., 1993; Welty et al., 1993). Published evaluations of newly implemented prevention programs will be helpful for developing programs in regions where community specific programs do not currently exist. Barriers to obtaining Pap smears and follow-up care are being investigated within the North



Carolina region (Dignan et al., 1993).

Lifestyle including diet, alcohol consumption, cigarette smoking, and socioeconomic status are important considerations for developing prevention strategies. Changes in a diet from one of game meat, fish and berries to one that is low in nutrients and fibre and high in fat, carbohydrates and calories may influence the development of colon and breast cancers (Gillis et al., 1991). Certain traditional foods may affect the development of cancers, ie; nasopharyngeal cancer in Canadian Inuit (Gaudette et al., 1991). The impact of traditional lifestyle changes also requires consideration. Poverty, including environmental factors, high occupational risks, sexual and child-bearing practices and the use of preventative medical services warrant further exploration (Horm & Burhansstipanov, 1992). Socioeconomic status has been inversely associated with cancers of the esophagus, stomach, lung (men), and cervix uteri and positively associated with cancers of the breast and corpus uteri.

Cigarette smoking is an important consideration in the development of cancer prevention programs. Cigarette smoking is believed to contribute to increasing lung cancer among certain groups in Canada. Registered Indian people and northerners in Saskatchewan surpassed the provincial lung cancer rates during the time period from 1967 to 1986. Canadian Inuit women developed lung cancer six times more frequently than the general Canadian population, while Canadian Inuit men experienced twice the risk of developing lung cancer from 1980 to 1984. The incidence of lung cancer among Canadian Inuit men is over twice the rate of Greenlandic Inuit men (189.3 and 81 per 100,000, respectively). Canadian Inuit women experience lung cancer three

times as frequently (164.8 per 100,000) as Greenlandic Inuit women (50 per 100,00). Similarly, the incidence of lung cancer is increasing in Alaskan Native People and certain American Native People.

One third of new cancers and cancer deaths among Alaskan Native People are tobacco related (Lanier, 1993). Thirty per cent of cancer deaths among Alaskan Native People are the result of lung cancer. The increased prevalence of cigarette smoking and high rates of cancer mortality among certain American Native tribes are believed to be related (Welty et al., 1993). Cigarette smoking has been linked to lung, cervical, kidney and gallbladder cancers and other diseases such as diabetes that are prevalent in aboriginal communities. The cultural ramifications of cigarette smoking require investigation. The involvement of traditional healers may help communities manage non-ceremonial use of tobacco to prevent cancer. Tobacco is considered a sacred plant and may be smoked as part of traditional ceremonies in certain aboriginal communities in Canada and the United States.

#### Early Detection and Screening

The literature suggests screening for specific types of cancers will decrease their incidence within the Canadian aboriginal population. For example, screening for the Epstein-Barr virus could lead to early detection of people with nasopharyngeal cancer (Melbye et al., 1984).

Education programs to help First Nations People prevent and detect cancer in its earliest stages must reflect the cultural and historical backgrounds of the community with which the program was designed. Few studies have addressed the

cultural ramifications of cancer in First Nations communities. First Nations People in North America are not culturally homogeneous (Antle, 1987; Black Feather, 1992). Describing aboriginal beliefs about the causation and treatment of cancer from a community perspective will provide the context required for health care providers to understand certain practices and beliefs. How First Nations People cope with cancer will add depth to the knowledge that is required to help people manage their cancers (Mechanic, 1986). The role of traditional healers and nurses and other health care providers require investigation. Too few studies are available to provide a meaningful panoramic view of First Nations Peoples' understanding, beliefs and healing practices about cancer. The manner in which research data is obtained will affect the depth of understanding about First Nations Peoples' perspectives about their experiences with cancer.

### Conclusion

The literature reveals that our knowledge and understanding about cancer in First Nations Peoples is incomplete and limited in depth and breadth. First Nations Peoples' cancer experiences from a psycho-social perspective is absent.

Understanding aboriginal people and their cancer experience is largely epidemiological in nature. The overall incidence of cancer among aboriginal groups in various regions in Canada and the United States was explored. Cancer patterns and trends among aboriginal groups, impact of acculturation, survival and mortality rates among aboriginal groups were also examined. There is an absence, in the literature, of cancer prevention programs which have been developed and implemented for

specific aboriginal communities. Statistical understanding provides a limited perspective in understanding the cancer experience among aboriginal people.

The contemporary aboriginal explanation of cancer is absent. The need for a broader and more in depth understanding of aboriginal people and cancer to include the emotional, social, cultural and spiritual perspectives is required. Understanding aboriginal perspectives and beliefs about the etiology, characteristics, prevention and treatment of cancer from a community perspective are vital for developing education and cancer screening services. The role of traditional healers and nurses and other health care professionals will also add depth to the knowledge that is required to help aboriginal people manage their cancers. The third chapter describes the method used to describe First Nations People's experiences with cancer.

## CHAPTER 3

### METHODOLOGY

Ethnography is a method that will privilege the voice of the First Nations People and their experiences with cancer. Ethnography is used to describe the complexity of human experience in its context with the emphasis on people using their own words to portray the daily events in their lives (Lipson, 1989, p. 62). The cancer experiences of First Nations People has primarily been expressed and understood through epidemiological studies. The perceptions First Nations People have about their cancer experiences within the biomedical model have not been heard, nor have their beliefs about the role of the traditional aboriginal healer.

The ethnographic approach accommodates the teaching-learning philosophy of the traditional Native way of learning. Stories have always been a part of the Native oral tradition and are integral to the learning process (Dion Buffalo, 1990). The story teller is the teacher; the listener is the learner. Respect is the first principle in this relationship (Solomon, 1990, p. 79). Ethnography means learning from people; the participant becomes the teacher and the researcher becomes the student (Spradley, 1980, p. 3). Contextual descriptions of the perceptions and experiences of First Nations People living with cancer engender the essence of ethnography.

Ethnography is a process which describes the exploration of complex cancer experiences of First Nations People. The Medicine Wheel, comprised of interacting, interdependent, dynamic, thematic concentric circles and directions guides the exploration of diverse cancer experiences. Some of the interconnecting themes

include the individual, family and community; the emotional, physical, mental and spiritual aspects of a person, family and community; and, the life cycle of the individual. The inter-relationship of these themes and those symbolized by the colours red, yellow, blue and white increase the complexity of First Nations experiences. Ethnography accommodates the intricacy of this conceptual model.

### Study Design

Ethnography is the art and science of describing a group or culture (Fetterman, 1989, p. 11). Culture comprises the ideas, beliefs, and knowledge that characterize a particular group of people (p. 27). First Nations Peoples' understanding about cancer was the focus of this ethnography. Their beliefs and perceptions about the etiology and pathophysiology of cancer; cancer treatment modalities; and, traditional healing practices sought are explored and described in this study.

Clinically oriented ethnography goes beyond the individual experiences with cancer to include the local world or social context of the person with cancer (Kleinman, 1992). A local world is broader than a family and may be a village, a neighbourhood or a social network. The local world of the First Nations People with cancer in this study was the community or reserve in which they resided. First Nations Peoples diagnosed and treated for cancer offered their perspectives about their experiences. Family members as well as community members were also consulted with the intent of understanding the social-cultural context of cancer.

### Participants

The study population was First Nations People who resided in one of four

communities. Originally, two communities comprised the study population. A third and then a fourth community were invited to participate in the study because the number of informants with cancer in the second community was very low. The reasons for the change are presented in the following section under "Participant Access." The participants included people who had been diagnosed with cancer, their families and, key informants from the communities.

The criteria for people who participated in the study were:

1. diagnosis of cancer;
2. eighteen years of age and older; and,
3. ability to understand English.

Criteria for family members participating in the study were:

1. deemed a family member by the person diagnosed with cancer
2. eighteen years of age and older; and,
3. ability to understand English.

The criteria for key informants were:

1. deemed an Elder or traditional healer by a community member; or,
2. deemed by a community member as being knowledgeable about the history of the community
3. eighteen years of age and older; and,
4. spoke English.

The criteria for additional key informants from the community who participated in the study included:

1. employees of the Band ie: community health representative; Chief, Council member, etc.
2. eighteen years of age and older; and,
3. understood English.

#### Participant Access

Four First Nation communities were consulted to access people with cancer,

their families and key community informants for this study. Before inviting First Nation communities to participate in the study, I obtained ethical approval from the Nursing Ethical Review Committee at the University of Manitoba, Faculty of Nursing (see Appendix A).

Each community was approached in the same manner to request access to invite people to participate in the study. I sent this invitation by letter requesting to make a presentation, in person or by telephone, to the Chief and Council of each community (see Appendix B). The intent of the presentation to the Chief and Council was to obtain permission to interview community members with cancer, their families and key members of the community such as Elders, traditional healers, community health representatives, and Chief and Council members. I discussed the purpose of the study; criteria for selecting participants; process of inviting participants; gift-giving protocol; and, the need to hire a community guide.

The guide assisted me in the communities in the following ways: informed and advised on the protocol of behaviour, provided a grand tour of the community, translated during interviews if the participants were more comfortable speaking in their primary language, and assisted in setting meeting locations during the study.

After permission to access a community was provided by the Chief and Council, I sent a letter to the Chief and Council to request: the posting of letters in the community inviting community members to participate in the study; the hiring of a guide; and, the date in which I could enter each community. I requested that letters inviting participation in the study (see Appendices C, D & E) be posted at the Band



Office, community clinic, recreation centre and stores. A sufficient number (15-20) invitations to participate were enclosed with the letter. After restating the job description for the community guide, I asked that a person be recommended by the Chief and Council. The rate of pay for the community guide was \$50 per day. Once in the community I arranged to meet with interested candidates to invite them to assist with the study.

### Community Response

Four communities eventually participated in this study because the participant response for people with cancer was low in the two communities initially accessed. For example, three people with cancer in the first community agreed to participate in this study. The relatives of two of these informants were also interviewed. Other informants included Elders, a Councillor, and community health representatives. An Elder served as a community guide while I was in this community. She accompanied me during the interviews when she thought informants would feel more comfortable speaking in *Saulteaux*, their first language. However, in the second community only one person with cancer and only one family member agreed to participate in this study. The other informants in this community were Elders, the Chief, a community health representative, and family members of people who had died from cancer. An Elder also served as a community guide in this community. He did not accompany me while I interviewed people for this study. All of the informants in the second community spoke English.

A third community was approached in the same manner as the first two and

subsequently agreed to participate in this study. However, only two people with cancer and their relatives agreed to being interviewed. Relating through an Elder, who was also the community guide, other potential informants felt it was too painful to talk about their cancer experiences. I then approached a fourth community.

In the fourth community four people with cancer agreed to participate in the interviews. The relatives of three of these informants were also interviewed. The informants spoke English. A community health nurse served as a guide while I was in this community. He had been a community health nurse in this reserve for many years. In recent years, he provided care to people in the community with chronic diseases such as cancer. Having gone through their cancer experiences with the community health nurse, it is my understanding that the informants wanted to learn more about the study with their nurse present.

The informants seemed to have a trusting relationship with their community health nurse. After I was introduced to the informants, the nurse and I were invited to sit in the living room or kitchen. The community health nurse sat adjacent to the informant and me. The seating arrangements were such that the nurse sat further from the informant than I did. The nurse and the informants engaged in light conversation before I explained the purpose and ethical considerations of the study. During the interview, the informants occasionally looked to their nurse to clarify the date of an event, the name of a procedure or to reminisce. With the exception of the first interview, the dynamics varied little from interview to interview. The informant in the first interview looked at the nurse as he responded to my questions and observations.

However, as the interview progressed, the informant began to face me.

#### Data Collection Methods

While I was in the First Nations communities, the community guides usually arranged times and locations where I could review the ethical nature of the study with the prospective participants and obtain verbal/written consent. These meetings usually took place in the informants' homes. However, when I did not have a community guide for the initial two days in the first community I arranged the meeting places. I suggested that the meetings be held in a place of the informants' choice and comfort such as their homes or in a quiet, private place in the clinic or my suite in the nursing station. The informants chose to meet in the clinic, the boardroom in the place of their employment, and in my suite.

When I met with the informant and I thought that she/he was at ease with me I provided a detailed explanation of the study. The explanation is outlined in the following consent forms: participants diagnosed with cancer (see Appendix F), family members of participants diagnosed with cancer (see Appendix G), traditional Elders and healers (see Appendix H) and community members (see Appendix I).

Two protocols were used to explain the study and obtain consent. The first protocol was for informants diagnosed with cancer, their family members and community members. After explaining the study, opportunities were provided to the informant to ask questions and seek clarification. Then the informant was asked to sign the consent form.

The second protocol was for traditional Elders and healers. I placed a bundle

of tobacco at the traditional person's side and explained the purpose of the interview. Accepting tobacco symbolized a commitment to the conditions outlined between the traditional person and myself. By picking up the tobacco bundle the Elder or healer offered consent to participate in the study (Kiiskeentum, 1992, p.14). I wrote on the consent form that, after the study was explained and questions were answered, the tobacco was accepted by the Elder or healer.

To offer tobacco is to bestow respect for the beliefs of the people in the community. Respect means to feel and show honour for the Elder as a wise person and what the Elder has to say (Bopp et al., 1989, p. 76). Tobacco is one of the four medicines used within the Medawin Society (Ojibway) and Muskego (Cree) traditional way of living. The tobacco offering is used in many native communities in Manitoba.

Once consent was obtained (written or acceptance of tobacco), the informants wanted to be interviewed immediately. Only one informant preferred to arrange to have the interview at another time. I sensed that this person was not sure whether she wanted to participate in the study. Another meeting time was arranged. And her intent to participate was reassessed at that time.

The ethnographer, as a learner, is a human instrument. Relying on all senses, thoughts and feelings, the human instrument is a most sensitive and perceptive data gathering tool (Fetterman, 1989, p. 41). I made observations during the interview session and recorded these on tape immediately after leaving the interview site. Sometimes, particularly while in the last community, I was not able to do this as the interviews were scheduled fairly close together. I recorded my observations after

completing two or three interviews.

In ethnography, the interview is an important data gathering technique (Fetterman, 1989, p. 47). Survey questions elicit a broad picture of the participant's world, develop a model of how it works, and provide a context within which to frame the study (p. 51). Specific questions probe further into an established category of meaning. Where survey questions shape and inform a global understanding, specific questions refine and expand that understanding (p. 52). Open-ended questions elicit long and detailed answers as the question allows the participant to interpret its meaning (p. 54). I used an interview guide because it allowed more flexibility to revise questions for the context of subsequent interviewing sessions.

Face-to-face interviews were completed on an individual basis. Participants diagnosed with cancer and community members including traditional Elders and healers were interviewed separately. A one to two hour family interview was also offered to informants. Two sisters asked to be interviewed together. The time spent during each interview varied from 20 minutes to 2.5 hours. Most of the interviews were 1 to 1.5 hours in length. Once the informants began to talk about their experiences and beliefs, they preferred to complete the interview in one sitting. It sounded as though many of the informants were agreeing to one interview only. Also, it seemed difficult for the informant to stop the momentum of the interview. The informants spoke until they decided the interview was over.

The interview was semi-structured and survey and open-ended questions were used. The interview guides were specific to the participants being interviewed (see

Appendices J, K & L). Some informants found the survey and open-ended questions I asked helpful in guiding the interview. I used specific questions to obtain further understanding about a topic. However, other informants, particularly the Elders, often ignored the questions and set their own agenda. During these times I carefully listened to their messages. The interviews usually took place in the participant's home. Some interviews, however, took place in a room at the informant's place of employment, one of the rooms in the health clinic, or the room in which I was staying. The interview rooms were always private and comfortable for both the participant and me. Generally, the interview sites had minimal extraneous noise so as not to interfere with the recording of the interviews.

Before the interviewing session began I placed a gift bundle beside each of the participants. Gift-giving emphasizes circularity within many Native communities. In a traditional teaching-learning situation, the learner will give the teacher a gift. When the researcher presents a gift to the participant then the circle is complete (Tafoya, 1989, p. 86).

At the beginning of the interview, the participant answered questions from the biographical demographic questionnaire. This questionnaire included information about the participant's gender, age, educational background, work experience and relationship to participant with cancer or role in the community.

Once the biographical data was obtained, I checked with the informants about the placing of the tape recorder. I asked the informants whether they preferred to have the tape recorder covered. Only one informant wanted the recorder covered.

Other informants stated that speaking into an uncovered tape recorder was not a concern to them. The informants were accommodating in having the recorder fairly close to them. The tape recordings provided a reliable method of retrieving information from the interviews. However, some informants spoke in a very low tone of voice. Since I thought that these recordings might be difficult to understand during transcription, I recorded these interviews on a second tape. By listening to the first tape and stopping at appropriate intervals, I recorded the interview on a second tape. I identified the voice tone and important voice inflections in the recording, such as an informant asking a question. Each interview was transcribed verbatim onto a computer disc.

#### Data Analysis

Data analysis is an inductive process in ethnographic research (Fetterman, 1989). It begins with data collection and continues with comparison of themes. Field notes are an important aspect of analysis in the data collection phase of a research study. I recorded my field notes on cassette tape to help guide my data gathering. My field notes were based on observations I made about each community. I included my observations, thoughts and feelings about each informant and interview. The field notes provided some insight into patterns of events or experiences that were emerging from the interviews. I used semi-structured, open-ended questions to facilitate the development of these emerging themes at each subsequent interview.

Once I had completed the interviewing process for all the communities, I ensured that all recorded tapes were transcribed onto computer discs. The transcribed

interviews were categorized into three data sets. The analysis of these data sets provided the basis for describing First Nations Peoples' cancer experiences. The field notes served as a diary and provided further context for each interview and community setting.

Forty-seven interviews which involved fifty-three people were done in four communities. The interviews of seven people were not considered for analysis for a variety of reasons. Three women found it difficult to discuss their experiences with cancer and so their interviews were concluded. One taped interview was inadvertently erased by another recorded interview. Two informants did not discuss cancer. One informant discussed what it was like for her to be a parent of a child with cancer. Aboriginal adults with cancer were the study population. The transcripts of forty six informants were analyzed.

The transcripts from the four Anishinaabe communities were compiled into three data sets, informants with cancer, their families and community members. Then the data sets were coded or assigned meaning. I used this process to analyze the data both with and without the use of an ethnographic computer program. Open coding is the naming and categorizing of phenomena through close examination of data. Each observation, sentence, paragraph is taken apart and each discrete incident, idea and event is given a label to represent a phenomena. The conceptual labels are grouped into categories to identify phenomena. Each category is given a conceptual name (Strauss & Corbin, 1990, p. 57). All the transcripts were read through at least four times. I then engaged in open coding of the transcripts. These codes were put into the



ethnographic computer program for compilation. Coded data were then "pulled out" of the ethnographic computer program and these codes were further analyzed and grouped into categories. Then the categories were compared and clustered into themes. The themes were analyzed for their relationship to each other within the data sets and between data sets.

Ten informants revealed their experiences with cancer. Eight of these informants were women and two were men. Three of the women, Ruby, Sylvia, and Kathy had breast cancer and two of the women, Matilda and Isabel had uterine cancer. Suzanne was diagnosed with leukemia, Joanne with kidney cancer, and Roberta with colon cancer. Samuel had cancer of the prostate and Ebenezer had lung cancer.

Nine family members constituted the second data set for analysis. Jack, Issac and Robert discussed what it was like for them when their wives were diagnosed with breast cancer. They shared, in varying degrees, their thoughts and feelings about their wives' cancer treatments. Elizabeth and Jean poignantly expressed their fears about the return of their mother's cancer and about their role in the family's legacy of breast cancer. Alice talked about the hope and fears she had for her daughter who was in remission from leukemia. Carol and Shannon expressed their dismay about their father having lung cancer. They hoped that both western and Indian medicine would cure their father's lung cancer. And, James spoke about how his wife developed kidney cancer and the role Indian medicine had in helping them deal with her cancer.

The transcribed interviews of twenty seven community members from four

communities was the third data set. Thirteen informants were Elders, five were community health representatives, three were Band Councillors, one was a health clinic administrator, one was a Chief, and four were other community members.

The content of the three different data sets was analysed at varying levels for themes. Analysis began with the content of all three data sets. Themes surrounding cancer causation and metaphor emerged. The historical perspective including cancer prevention and cure was provided by the Elders. The Elders, informants with cancer, relatives and other members from their communities described their views about the impact of industrialization on food and water in the development of cancer. The significance of smoking cigarettes, physical injury, infection, onjine (bad medicine), and destiny were also described from the perspectives of the informants with cancer, their relatives and community members. Various cancer metaphors exist among the Anishinaabe. The prevalent cancer metaphor is "manitoch" which means cancer-as-worm in Saulteaux, the primary language of the Anishinaabe.

The data set consisting of informants with cancer was analyzed and five themes emerged. In the first theme, "Becoming Aware: The Stranger in the Body," the informants with cancer describe their experiences when they sensed they had cancer. In "Becoming A Stranger: Leaving the Community," the informants described their experiences when they had to leave their homes to have their suspicions confirmed and then later to have their cancers treated. The informants' experiences in facing their own mortality and in dealing with their fears that their cancers will return is described in the theme, "The Stranger Apparent." Also, described in this theme is

the silence that surrounds the person with cancer. "Learning to Live with Cancer: Getting to Know The Stranger" is the last theme in which the informants' experiences surrounding their need for spiritual strength and guidance as part of their living with cancer is described.

Analysis of the family members data set revealed there was insufficient data for themes which described their experiences with cancer. However, community members' experiences with cancer were presented in two themes. The community member data base was analyzed collectively and the first theme, "Silence Surrounds The Stranger," described community members' silence about cancer. Also, how the health care providers are seen to be silent about cancer was described by each community. The significance of traditional Indian medicine as one way to manage cancer in each community was described in "Making The Stranger Known: The Healing Journey."

#### Establishing Trustworthiness in the Study

Guba and Lincoln (1989) describe how trustworthiness is used for judging the adequacy of qualitative research. The trustworthiness criteria are: credibility; transferability; dependability; and, confirmability. These criteria will be discussed as they relate to the study.

#### Credibility

A study is credible when a match is established between the constructed realities of the informants and those realities interpreted by the researcher and attributed to the informants (Guba & Lincoln, 1989, p. 237). The interpretation of

these realities is such that people having these experiences should recognize them as being their own (Sandelowski, 1986, p. 30). I used a variety of techniques to ensure that my interpretation reflected those of the informants' experiences and perspectives with cancer. The techniques included establishing rapport and fostering trust; incorporating reflection and reflexivity; peer debriefing; and, triangulation.

Establishing rapport and fostering trust encourages informants to share their experiences and understanding about cancer (Guba & Lincoln, 1989, p. 237). An important element in establishing rapport with First Nations informants was obtaining permission from the Chief and Council to conduct my study in their communities. For example, when I was invited by a Chief to present my study at a community meeting, I went to the meeting well before the time I was scheduled to speak. I asked the Chief who conveyed the invitation to me when I was expected to attend the meeting. I wore a casual dress. I was attentive at the meeting and learned that the Elders were integral to these proceedings. When it was my time to present I acknowledged the Chief, Council members, Elders and members of the community. I spoke clearly and in a pace that was not too quick and not too slow. Questions and clarifications were forthcoming because I encouraged this from the audience. When an Elder stood to speak to my study I listened carefully to the message and was patient to the length of the speech. When I was invited to have lunch I did so. But I waited until all the Elders had a plate of food before getting my own. I sat beside an Elder with whom I felt comfortable approaching. We sat together, quietly at first, and then we talked. I listened more than I talked.

In each community I was never asked about my qualifications as a researcher. Rather, I was asked where the location of my home community and the identity of my family. Knowing that my parents and grandparents were from the First Nations of Fisher River and Peguis provided community members with some knowledge about my cultural roots. It was not unusual for community members to ask for clarification about the identities of my relatives. It seemed reassuring to community members, particularly the Elders, to connect me with a familiar community and family name. The connections community members made between me and my home community and relatives helped to establish rapport.

Trust between the researcher and informant reduces the likelihood that informants will distort information (Guba & Lincoln, 1989, p. 237). I ensured trust was fostered by maintaining confidentiality of data and anonymity of the informants in this study. I promoted trust through confidentiality in various ways. My thesis advisor, the transcriber of the interview tapes and me, were the only people who had access to the data. The informants and their recorded tapes were identified by a coded system. The informants and the communities in which they resided were assigned fictitious names. I did not use distinguishing features that would identify the informants when I wrote the findings of this study.

Incorporating reflection and reflexivity is a technique I used to match the interpretations I made with the informants' experiences and perspectives with cancer. By being reflective I established ownership of my own biases and by being reflexive (Olesen, 1994, p. 165) I used my biases as resources to guide data gathering and

understand my own interpretations and behaviour in the study. Reflection is a process of constructing and managing self images. It describes those instances when we look back on our experiences with the purpose of forming an image or construct (idea) of our earlier work (Rubinstein, 1991, p. 27). Reflexivity is the active analysis and application of experience to improve data collection and interpretation. In other words, reflexivity is the critical examination and use of earlier experience to influence future action (p. 27). By being reflective and reflexive I wanted to use my biases resourcefully to understand my own interpretations in the study.

Peer debriefing is another strategy I used to foster the match between the constructed realities of the informants and those I interpreted on their behalf. To understand my posture, values and role in this study, I engaged in the discussion of findings, conclusions, tentative analysis with a peer who had no contractual interest in the study (Guba & Lincoln, 1989, p. 237).

Credibility in this study was enhanced by triangulation of data sources and methods (Denzin, 1978). Face-to-face interviews were conducted with individual informants with cancer. Then family members of the informants diagnosed with cancer were interviewed individually, or collectively as a family unit. And the community informants were interviewed individually. To ensure that the interpretation of findings was true to the understanding and experiences expressed by the First Nations People in this study, I interviewed people with cancer, their families and their communities. The integrity of the findings of this study are also enhanced by comparing the perspectives of the four First Nations communities.

### Transferability

Transferability occurs when a comprehensive data base is presented so readers can decide whether or not to apply the findings of a study to situations of their interest. It involves an empirical process for checking the degree of similarity between sending and receiving contexts (Guba & Lincoln, 1989, p. 241). To facilitate the judgement of transferability, I extensively described the time, the place, and the context in which the research questions for this study were prominent (p. 241).

Thickly describing emerging themes is similar to weaving a tapestry. Emerging themes are similar to a few strands of thread being woven into the fabric. The design can barely be deciphered. There are gaps on the tapestry. However, as these recurring themes emerged with each interview I sought expansion to obtain context and clarification to obtain detail. Each description obtained was similar to weaving another strand into the fabric. With each clarification the theme was being developed, thickly described. With the weaving of additional threads into the fabric, the design on the tapestry became more distinct and the colours became vibrant. Because of the exploratory nature of the study it was difficult to obtain many thickly described themes. Questions with a narrower focus to guide a study would have been more conducive to the layering of descriptions. Also, some informants talked about aspects of cancer that were most important to them. Some emerging themes were developed more than others. Thick descriptions by layering data obtained with each subsequent interview and verbatim quotations relative to the research questions of the study ensured a meaningful report.

### Dependability

Dependability is the standard used to judge the stability of data over time (Guba & Lincoln, 1989, p. 242). A developing inquiry includes changes in methodology and shifts in construction. I contacted my thesis advisor as necessary to seek clarification and advice about any aspect of this discovery process. For example, I contacted my thesis advisor when people with cancer were not forthcoming in the second community. After discussing the matter with him, I decided to obtain access to a third community. People whose relatives died from cancer were willing to be interviewed while I was in the second community. My thesis advisor helped me examine the implications of interviewing people whose relatives died from cancer. Dependability is enhanced when these changes and shifts are documented so reviewers can explore the process, judge the decisions that were made, and understand the factors in the context that led the researcher to the decisions and interpretations made. Techniques outlined to establish credibility also apply to the stability of data over time.

### Confirmability

The standard of confirmability assures that the integrity of the findings are rooted in the data; the informant's story and the context surrounding the storyteller (Guba & Lincoln, 1989, p. 243). According to Miles and Huberman (1984) and Bogdan and Taylor (1975) confirmability of this study can be judged by reading the findings of this report in relation to the description, explanation or justification of the following: how the researcher became interested in the subject of the study; how the



researcher perceived the study; the specific purpose/s of the study; how informants were approached and how they were included in the study; the impact the informants or data had on the researcher and vice versa; how the data were collected; how long data collection lasted; the nature of the setting/s in which the data collected; how the data were transformed for analysis, interpretation and presentation; how various elements of data were weighed; the inclusiveness and exclusiveness of the categories developed to contain the data; the specific techniques used to determine the credibility and applicability of data (cited in Sandelowski, 1986, p. 34). I will store the interview tapes and transcribed interviews for seven years. If questions arise, the findings can be confirmed. I have access to the tapes and transcriptions.

#### Fairness

Fairness is the extent to which different constructions and their underlying value structures are solicited and honoured within the inquiry process. Since each informant's perspective is value-bound and value-situated the researcher is compelled to both solicit and honour different informants' stories and their underlying value structures (Guba & Lincoln, 1989, p. 246). I explained in detail the ways in which the stories and their underlying value systems were in conflict during the data gathering and data analysis processes.

#### Ethical Considerations

This study is designed to protect the rights of the participants and the researcher at all times. Ethical approval was sought through the Ethical Review Committee, Faculty of Nursing, University of Manitoba.

Informed consent was obtained from all the informants in this study. I provided ethical information, the purpose of the study and discussed my role as researcher. People were informed that they had the option of answering questions. They were informed that they could have refused to participate or withdraw from the study at any time. Maintaining confidentiality was emphasized. I was prepared to withdraw from data gathering at the informant's request. For example, one participant was initially uncertain about participating in the study. After responding to a couple of questions she indicated that the interview was completed. She was not prepared to discuss her experiences with cancer beyond a certain point. I took care to respect her wishes. An important aspect of informed consent is to explain to people interested in participating in the study that they can bring the interview to an end at any time.

Providing psychological support to informants was integral to the interviewing process in this study. I stopped the interview when I assessed that an informant was becoming upset ie: putting head down, eyes becoming reddened, or voice becoming shaky. If the tape recorder was being used I turned it off. Then I was quiet for some moments. The informant then often expressed what she/he thought, or felt about the interview topic. I was prepared to discuss options available to the informant if she/he required further support beyond what I could provide at the interview site. Ethically, the goal was to ensure that no adverse effects occurred for the participants or the investigator during the study.

#### Limitations of the Study

The background of the researcher can be beneficial or detrimental, depending

on the group, situation and the individuals involved. Even if there is no language barrier, there are things an informant can express only to an interviewer of similar background (Lipson, 1989, p. 66). However, problems can arise if the researcher entering the study believes that the culture is already familiar because important pieces of data will be overlooked.

While there is some evidence in studies on bias, the examples are few and there seems to be no evidence of deliberate dishonesty. Further, the risk of such bias occurs in all research. Aamodt (1981) believes that ethnic insiders are generally not as much inside the cultural settings they study, and that because society is formed of many sub groups, with each geographically isolated group differing culturally from its neighbour, no researcher is likely to be a complete native of the group under study.

Dissimilarity between the ethnographer and participant has advantages in other situations. Some participants were more open when they perceived me as a stranger, particularly when gossip was feared. I might have also been perceived as having access to the participant's network of family and neighbours and the concern that I might talk about the interviews may have also affected how I was accepted as a researcher.

While being a stranger to the informants was beneficial to being accepted as a researcher, being a mother and a nurse may have been helpful too. Some informants might have identified with me as a mother and parent. Others may have viewed me as non-threatening in these nurturing roles.

## Conclusion

In this chapter, accessing informants, data collection methods, and analysis were presented. Establishing trustworthiness and ethical considerations were also discussed. The next three chapters describe the findings of this study. In Chapter Four, the perspectives First Nations People have about the causes of cancer and the metaphors they use for cancer are described. In Chapter Five, I describe the cancer experience of First Nations People. And, the cancer experience from the First Nations community perspective are offered in Chapter Six.

## CHAPTER 4

### CAUSATION AND CANCER METAPHOR

This is the first of three chapters which describe the findings of this study. In this chapter, the perspectives First Nations People have about the causation of cancer and the metaphors they use are presented.

#### The Participants

People in four First Nations communities participated in this study. The people in these communities are Anishinaabe (Ojibwa). To help protect the informants' identities, I assigned fictitious names to the communities based upon my experiences, thoughts and feelings at the time I was gathering and analyzing the data. The communities are "The Raven", "The Silent Eagle", "The Nesting Eagle", and "The Medicine Eagle." At the time I was data gathering, I had decided that the names of the communities would be the birds I saw in each community.

While in the community of The Raven, I noticed many ravens were quietly perched in the trees. Seeing these ravens reminded me of a story I had heard a number of years ago. According to the storyteller, the raven served as a symbol for curing cancer. While in The Silent Eagle community I felt the silence surrounding cancer overwhelming. I saw an eagle on one of my initial trips to the community. Although the names of the remaining two communities were based upon my initial experiences in each of these communities, I did not make this decision until after I had almost completed my analysis of the findings.

### The Stranger As Metaphor

Anishinaabe Elders spoke about how European missionaries, hunters and trappers were received by the people in their communities long ago. Uncertain as to the purpose of the intruders, these strangers were looked upon with both curiosity and suspicion. Since Anishinabe communities were well contained, the people were alerted to any newcomers and watched the strangers' movements closely.

The "stranger" metaphor was selected to relate the findings of this study when an informant spoke about the effect of cancer on her family. Three of her five siblings had cancer. The informant considered her family's experience with cancer as being "strange" because every second sibling had cancer. Because it is new and unfamiliar, as were the first European visitors to their communities, cancer is strange to the First Nations People in this study.

The findings have been described in three major areas. First, in "The Presence of a Stranger: The Elders Speak", the Elders provide an historical perspective of the development and prevention of cancer in First Nations communities. Then the Elders, cancer patients, family members and community members present their views about the causes of cancer in "Where the Stranger Comes From: An Overview." The causes of cancer are highlighted under the topics of "The Stranger From The North", "Smoking Cigarettes", "Physical Injury", "Infection", "Onjine", and "Destiny". Thirdly, First Nations Peoples' cancer metaphors are described under the heading, "Manitoch Metaphor: The Stranger As Worm". In this section, the characteristics of Manitoch, the implications of surgery and other cancer metaphors First Nations

People use are presented. I will briefly summarize the chapter.

1. The Presence of a Stranger: The Elders Speak
  - A. Prevention of Cancer: Traditional Ways
2. Where the Stranger Comes From: An Overview
  - A. The Elder Speaks
  - B. Cancer Patients Speak
  - C. Family Members Speak
  - D. Community Members Speak
  - E. The Stranger From the North
    - a. The Impact of Progress on Food Consumption
      - i. Teaching From an Elder
      - ii. A Health Services Administrator's Perspective
    - b. The Impact of Progress on the Nature of Food
      - i. Chemicals and Additives in Food
      - ii. Canned Foods
      - iii. Junk Food
      - iv. Domestic Meat
    - c. Progress: Chemicals in Water
      - i. Ella's Cancer
      - ii. Jacob's Cancer
  - F. Smoking Cigarettes
    - a. Ebenezer's Cancer
    - b. Sylvia's Cancer
  - G. Physical Injury
    - a. Jacob's Cancer
    - b. Sylvia's Cancer
  - H. Infection
    - a. Samuel's Cancer
    - b. Isabel's Cancer
  - I. Onjine
    - a. Joanne's Cancer
  - J. Destiny
    - a. Ebenezer's Cancer
  - K. Summary: Where The Stranger Comes From
3. Manitoch Metaphor: The Stranger As Worm
  - A. Manitoch in the Body: A Difficult Cure
  - B. Manitoch: A Case Study of Roberta's Cancer
    - a. The Surgery
    - b. The Recovery
  - C. Modern Metaphors: Manitoch As Cancer Cell
    - a. Other Metaphors
  - D. Summary: Manitoch Metaphor
4. Conclusion

Figure 6. Cancer Causation and Metaphor Topics

### The Presence of a Stranger: The Elders Speak

Cancer is present in First Nations communities and is being felt by the people. Cancer is also occurring with increasing frequency. It was not always this way. When some Elders think of cancer they are reminded of the initial tuberculosis epidemics in their communities. Like tuberculosis, cancer is an unfamiliar and devastating stranger that the people must contend with and try to understand. Many Elders say cancer was present in the communities long ago, but it remained an uncommon disease. An Elder told me, "Some people had it [before the 1930s]. I know there was two or three women who died of that." Another Elder said that over forty years ago a relative of her husband died from cancer.

The fatal effects of tuberculosis explain, in part, why cancer was rarely observed. An Elder from the community of The Raven recalled, "In the 1930's the most common disease among the native people was TB." Once the ravages of tuberculosis subsided in the First Nations communities, Elders then began to see cancer with increasing frequency, especially during the past three decades.

The Elders told me that there were ways of preventing cancer. They also said that medicine people knew how to cure cancer, however, this highly regarded knowledge has not been passed on to the next generation. Christian authority and the Canadian law prevented First Nations People from assembling to feast, dance or perform ceremonies. Traditional gatherings where knowledge was passed from the Elders and medicine people to the younger generation ceased to take place. Many healers suppressed their medical knowledge fearing retribution and persecution from



the church and Canadian government. During the decades when it was illegal to practice traditional ceremonies, many of the medicine people, who possessed the knowledge to cure cancer, died.

Elders spoke about the history of cancer in their communities. The history of cancer did not arise as a topic during interviews with two Elders from the community of The Silent Eagle. I sensed from the Elders that cancer was something to be ashamed about and so any discussion about cancer should be avoided. Four Elders, two from the community of The Raven and two from the community of The Silent Eagle, thought that people in their communities had cancer long ago. They believed, however, that people did not know their disease was cancer. The number of people afflicted with cancer was few. An Elder in the community of The Nesting Eagle shared that cancer was a recent disease.

Cancer was unknown. We didn't know what cancer was. In fact, we don't even have a name for cancer in our own language. I was just asking about it. We haven't got a name for it. Maybe there's others who might know or have a name for it but that's something new to our people. Not knowing what it was when we heard that someone had cancer, we don't know the symptoms even or how we got it and how to cure cancer. No we didn't. We still don't know about it [703.1.6-18].

The oldest person I talked with in the community of The Silent Eagle was in her eighties. She told me there must have been cancer present in her community:

Because some old people, they used to use bark from the bush for. . . . They scrape. My grandfather, I used to see him scrape some kind of a wood and boil that and use it as a poultice. Put it on a person. Some people you can see the leg leaking like. . . . I think that was cancer to me. But we never knew what it was, eh [612.2.92-102].

Indian medicine was used by her grandfather to cure cancer. Because the cancer was

treated, it remained unknown to most people.

Elders from the community of The Medicine Eagle spoke about Indian medicine people who were able to cure cancer. An Elder who was diagnosed with cancer told me, "Medicine men long ago had medicine for cancer. It's hard to say where the cancer medicine is available." He knows of a medicine man who no longer has cancer. The medicine man was cured. Another Elder in the same community explained how traditional healers helped people who have cancer.

Like if it's not too far gone. . . . Cause I had a cousin. Doctors told her she had cancer. She went to this medicine woman and she had, they gave her medicine to drink. She's still living. Yet the doctors told her it was cancer [810.15.792-799].

Although there is Indian medicine that can cure cancer, it is sometimes difficult to locate. Elders in the same community also believe that Indian medicine is returning, but it is not as potent or good as it used to be.

#### Prevention of Cancer: Traditional Ways

Elders in the community of The Raven spoke about the traditional ways of preventing cancer. An Elder observed that people lived according to the traditional teachings and lived "off the land." This protected them from developing cancer. Deer and moose are still hunted and fish continue to be caught for food. Although the food is considered to be traditional, there is concern about environmental pollution affecting the wildlife, making it a source of cancer. The Elders also observed that the high intake of junk food interferes with a healthy diet for children making them susceptible to cancer.

Another Elder spoke about newborns being given Indian medicine to protect

them from cancer through their growing years. The Elder said, "When a woman gave birth to a child, she would give it something to drink about three days after it was born and this child was protected from getting cancer." Another Elder spoke about the same medicine. This practice is no longer carried out in their communities.

An Elder talked about the "old ways" to prevent uterine and breast cancer. Long ago women used a medicine "so they're cleaned out" after giving birth. The medicine caused the lining of their uterus to shed and this protected the women from uterine cancer. Today, women no longer use this medicine; instead they eventually undergo hysterectomies. Breastfeeding prevents breast cancer. An Elder stated, "I always think that when you breast feed your baby, it's better that way. And it's the ones that don't breast feed their babies . . . those are the ones that have cancer most of the time." The Elders recalled that women used to know how to prevent cancer. They knew how to protect themselves. The practice of taking Indian medicine to prevent cancer, however, is no longer being done in the community of The Raven.

The Elders spoke about Indian medicine men and women long ago who knew how to prevent and cure cancer. However, with the advent of Christianity and Canadian law, the Elders and healers were forced to become clandestine with this highly regarded knowledge and it was not passed onto subsequent generations. Many medicine people took the knowledge of preventing and curing cancer with them to their graves. Today, the Elders believe that medicine to cure cancer is not only difficult to find, but it is not as potent as what it once was.

Elders spoke about some of the "old ways" which prevented cancer. The

women administered medicines to their newborns to protect them from childhood cancers. They knew what medicines to take after childbirth to clean the lining of the uterus. This prevented uterine cancer. However, these measures are no longer practiced. Elders said breastfeeding protected the women against breast cancer. The people have lost their ability to prevent and cure cancer because the knowledge was not transferred from one generation to the next.

The Elders shared their views about the manner in which First Nations People develop cancer. Man-made wastes have contaminated the wildlife and by eating these animals the people may develop cancer. The children are eating quantities of junk food which places them at risk for developing cancer.

#### Where the Stranger Comes From: An Overview

##### The Elders Speak

Cancer was viewed as a recent disease by most people in the First Nations communities. Many Elders observed that cancer was present in the communities long ago. However, it was a rare disease affecting few people. Some Elders believed that the people who had cancer in years gone by did not know what it was. Other Elders believed that cancer was unknown until recently. Currently, the people are very concerned about the rising frequency of cancer in their communities. More and more people are being diagnosed with cancer. The Elders and other community members expressed beliefs about the causes of the increased presence of cancer in their home communities. A listing of the beliefs about cancer causation are listed in Table 13.

The Elders, long-time observers, believe that "progress" has contributed to an

increase in the frequency of cancer in their communities. Progress in the form of modernization has moved into the communities and has influenced the way people live. The traditional ways have been replaced. For example, the practice of breastfeeding babies has been influenced by a modern way of feeding babies. The breast has been replaced with baby formula. The practice of administering traditional medicines to babies for the prevention of cancer also appears to have been affected. The Elders viewed the old ways as having merit in preventing cancer. They talked about cancer as a consequence of progress.

Elders in the communities of The Raven and Nesting Eagles primarily talked about the influence of "progress" on their food. Food causes cancer. Traditional foods such as wild meat and berries were replaced by foods-of-convenience and foods prepared by frying in fat. Foods-of-convenience include products that are processed, high in fat content, and have preservatives and additives. Elders were concerned about "junk food", canned foods, domestic meat, and fried foods. They were worried about the effects of environmental pollution, chemicals such as pesticides, and food additives. They mentioned that cancer thrived on chemicals in processed food.

Progress has also affected the drinking water in the community of The Silent Eagle. The Elders were concerned about the pollution and chemical wastes dumped from the paper mill down river from their community. They believed cancer arises from the polluted waters they have been drinking.

The Elders talked about other ways cancer comes about in their communities. In the community of The Raven, they believed cancer was the result of physical

injury and infection. One Elder questioned cancer-as-contagion. Chicken pox and tuberculosis were contagious diseases that spread devastation through First Nation communities. Cancer, also a devastating disease, may also be considered a contagious disease. Elders in the community of The Silent Eagle spoke about smoking and cancer. Many believed that store-bought tobacco causes cancer. However, kinik-kinik, a natural tobacco prepared from the red willow was believed not to be carcinogenic. An Elder said that everybody is born with a cancer cell. He did not tell me how the cancer cell begins to grow. Another Elder said that whether people get cancer is predetermined. "From the minute you're born your destiny was already fixed." An Elder suggested that taking too many pills causes a disruption in the body and this in turn can cause cancer. He did not elaborate on how disruption causes cancer. Another Elder said heredity plays a role in cancer. Her friend has cancer and so does this woman's daughters.

#### Cancer Patients Speak

Community members diagnosed with cancer shared their beliefs about cancer causation. Almost half of the informants (including one Elder) did not know what caused cancer. For example, one mother asked her daughter's doctors how her daughter developed leukemia. The doctors told her they did not know what caused her daughter's cancer. She asked them if it was hereditary. The doctors told her no. Causes were identified by the other informants. These included: smoking, chemicals in food, canned food, fried foods, physical injury, "bad" medicine and, the possibility of having caught cancer from another person with cancer.

### Family Members Speak

Family members of relatives diagnosed with cancer also had ideas about the causes of cancer. Eight family members presented their beliefs about what caused cancer in their relatives and in their communities. Smoking was the most frequently mentioned cause of cancer. Informants spoke about the role of smoking in cancer causation. One family member whose wife has cancer said, "It's probably the, there's a lot of smoking going on here." Polluted drinking water was mentioned by two people whose relatives had died of cancer (one was an Elder) in the community of The Silent Eagle. A family member whose mother had breast cancer stated that even with a healthy lifestyle there is no guarantee you will not get cancer. "What can you do? I mean I've heard of healthy people that eat healthy foods and exercise regularly and do . . . all the right things and they are the ones that seem to get it."

### Community Members Speak

Other community members identified their beliefs about the causes of cancer. Community members included general members of the community, community health representatives, a health services administrator, a councillor, and a Chief. Of the eleven informants I interviewed, two did not know what caused cancer. The most commonly mentioned cause, however, was "chemicals in food." This cause was identified by people in all the communities. The following causes were also mentioned: heredity, diet including canned foods, fried foods, coffee, chemicals in the drinking water, smoking, physical injury, lifestyle, poor socio-economic conditions, inadequate early cervical cancer detection, and, lingering effects from the diseases

brought by the Europeans.

Community members spoke of progress as having the greatest influence on the development of cancer. More specifically, people identified that the presence of chemicals and additives in the food were the primary cause of cancer. Environmental pollution, the use of pesticides and food additives contributed to the uptake of chemicals in the food chain. Man-made wastes contaminated the produce growing in the soil. When the people ate the produce, they also ingested the chemicals into their bodies.

People in all of the communities, except the community of The Nesting Eagle, cited canned foods as a cause of cancer. Elders from these communities talked about the historical mistrust they have for canned foods. Their community's Elders warned them not to eat canned food because it could cause stomach sickness. Although another Elder used canned food products when she was a young mother, she was cautioned by her mother about the harmful effects of the can on its contents. Other members in the communities who were in their mid-thirties or older, cited canned food as a cause of cancer. A relative whose wife has cancer shared his thoughts about the causes of cancer, "There's quite a lot of change in our diet. We prefer the canned stuff." Other causes of cancer under the topic of food include junk food and fried foods.



Table 13  
Causes of Cancer

<u>Cause</u>	<u>Elders</u>	<u>Patients</u>	<u>Family</u>	<u>Community</u>
Diet			●	●
● chemicals/add	●			●
● canned foods	●	●	●	●
● junk	●			
● domestic meat	●			
● fried foods	●			●
Tobacco	●	●	●	●
Physical Injury	●	●	●	●
Chemicals				
● water	●		●	
Infection	●			
● contagion		●	●	
Heredity			●	●
Onjine		●	●	

### The Stranger From The North

First Nations People voiced that progress had the greatest influence on the occurrence of cancer in their communities. On the Medicine Wheel, the colour white symbolizes the contributions the Euro-Canadian people have made in industrial advancements. Progress however, has benefits and costs.

Elders and community members identified diet as the primary cause of cancer. Progress has also influenced the types of foods consumed by First Nations People. The people have moved away from hunting and fishing for their food to purchasing "store-bought" meats and produce. Elders identified that diets consisting of junk food,

domestic meat, fried foods, and canned foods caused cancer. Environmental pollution, chemicals which enhance the growth of produce, and food processing were also identified as carcinogens. Progress has affected the chemical uptake in produce. Cancer thrives on foods consumed which have been prepared with additives, environmental pollution and chemicals such as pesticides. Elders believe industrial pollution and chemical wastes have also affected the quality of the drinking water in the community of The Silent Eagle.

#### The Impact of Progress on Food Consumption

Progress has influenced First Nations People in the way they obtain food and the types of foods they consume. An Elder and a health service administrator spoke about how progress has contributed to cancer in First Nations People.

Teaching from an elder. An Elder in the community of The Raven explained through an interpreter how progress has influenced the type of foods the people in his community eat. Progress has brought sweets, junk food and, canned food. "The kind of food we eat causes cancer." Few people in his community had cancer "long ago." The people ate the moose and deer they hunted. And, they ate the fish they caught. The people took only the amount of food they needed. They did not hoard their food. Today living is different. With this different living, cancer is more common in his community now. With the availability of processed food the people in his community no longer hunt wild meat. Rather, they hoard and consume store-bought food.

The Elder explained how consuming processed food has contributed to cancer among the people. He listed food-related causes: improperly storing food, eating

canned foods that are past the expiry date, eating too much sweet food, eating too much junk food, and eating on the run. There is confusion surrounding food consumption. He indicated that people do not realize how much junk food they are eating. They do not understand how certain types of food affect their health.

A health services administrator's perspective. A health service administrator from a southern Manitoba community offered his views about the increasing incidence of cancer. His community is closer to larger urban centres in southern Manitoba. Progress has affected the kinds of foods eaten by the people in his community.

I think the transition, the cultural transition of First Nations. . . . We eat a lot of game, deer, and that really has contributed to being more healthy. Now when we have less of that traditional hunting and lifestyle . . . we're into fast foods, high fat, carbohydrates, preservatives and artificial colouring which I think our bodies are really not used to [704.1.23-41].

A lifestyle consisting of eating foods high in fat, carbohydrates, preservatives and artificial colouring contributes to the presence of cancer.

The administrator also talked about other causes of the increased incidence of cancer in his community. They included: "unacceptable social conditions", "high unemployment", "lower standards" of living compared to national average, smoking, inadequate physical activity, chemicals in the food, inadequate early cervical cancer detection, and, lingering effects from the diseases brought by Europeans.

#### The Impact of Progress on The Nature of Food

Many First Nations People influenced by progress have changed how their food is produced, prepared, and stored for consumption. Environmental and food chemicals, canned foods, junk foods, and domestic meat contribute to the

development of cancer in First Nations communities.

Chemicals and additives in food. Foods with additives cause cancer. Air pollution, pesticides and other chemicals cause cancer. An Elder stated that cancer thrives on the chemicals and additives in the food the people are eating.

A community health representative in the community of The Raven spoke about the effect economic development has on food products. "My dad says he blames the White men. All this modernization. That's what he blames it on. Cause there's too many chemicals, all kinds of chemicals even in the food we eat." Store bought meat contains chemicals too. The community health representative (CHR) read that certain vegetables can help prevent cancer. However, she was concerned about buying these foods to eat. "I wonder what little it will help anyways, like they come from the farmers and all that chemicals that are in the farm now." The CHR observed, "The White men invaded the Native people. How strongly it impacted on them. And that's how they look at the cancer. . . . A complete invasion in a different way. . . . His way of modernization."

A band councillor in The Nesting Eagle community linked environmental pollution with the increasing frequency of cancer in her community.

I was very concerned when I was first became councillor in 1987 and my first stop was with the environment because there were three people that acquired leukemia at the same time. . . . All these people had similar diseases yet they had totally different lifestyles, [and lived in] different areas of the community. And then I wrote a memo at that time to our land manager to find out exactly what farmers were putting on our soil, our fields. I never did get a response back but we did get in touch with the Health Environment, the environment officer of MSB [Medical Services Branch, Health Canada] at that time. He came out. . . . It's been a slow process but there's been studies done. Chemicals

tests. The water testing is ongoing. The Health Centre does most of it. And we have that treatment plant now. I still feel the Health Centre should monitor [the treatment plant] along with the environmental officer [705.3.115-142].

Ebenezer, an Elder in The Medicine Eagle community has lung cancer. He spoke about produce which "take up" chemicals used in "the fields." Products such as white flour, vegetables, and potatoes contain cancer causing chemicals.

Canned foods. Elders spoke about the dangers of eating canned foods. With the exception of The Nesting Eagle community, Elders from each of the other communities stated canned foods caused cancer. An Elder explained, "The names on the labels are big and people don't understand what the words mean." The people do not know what is in the canned food. Chemicals and additives speed up the growth of cancer. He also expressed concern about the number of years canned food products sat on the store shelf before being consumed. "People don't what how long those canned foods have been sitting in the store."

An Elder from The Medicine Eagle community asked her grandmother why people have cancer. She was told people eat "too much canned stuff." Her grandmother never opened a can of food to eat, always ate wild meat, never ate bread, and never smoked cigarettes. Her grandmother was over one hundred years old when she died. The Elder spoke about how foods packaged in cans affected the body.

Now [the cans are made] different. There's kind of a coating inside. But a long time ago when you opened a can, like you're not supposed to leave a can of tomatoes in the fridge or whatever. You have to take them out cause the can went black inside. . . . Even canned milk. [My grandmother] used to tell my mamma, "Don't use that Carnation milk." And my mom says, "why?" [My grandmother] said, "Look. Open it. I'll tell you." That can was just black inside. Yet the Pacific [canned

milk] wasn't like that. I don't know what was the difference. And you know what she used to do. My mom was using Carnation. When the baby had a poop, [my grandmother] took a little bit [of the poop] and told my mom to taste it. "Look at the taste of it." My mom said it was just bitter. . . . I don't believe in canned food either. It's very seldom I'll use it. I think the only time I use is soups, you know. Or, if I make cabbage rolls I use tomatoes in the can. But I put them in [a bowl] right away. I don't even squash them in the can. I squash them in a bowl [810.5.223-268].

Isabel had a hysterectomy for uterine cancer. She is from The Medicine Eagle community. Isabel learned from her grandmother that canned food causes cancer. Cancer has not been in her community for very long. "It started about 9 or 8 years ago." Isabel is also not sure whether cancer is contagious.

Junk food. Eating an improper diet causes cancer. The Elders who talked about junk food as a cause of cancer were from the Community of The Raven. An Elder told me that long ago kids were given just a little bit of candy. The children would receive just one stick of candy. If there were two children, they would not get one stick each. They would be given one half of a stick. Today children fill up on candy. There is too much sweets to eat. There is too much junk food. Long ago children were taught to sit down and eat. They did not run around. Now children run around and eat. Habits are hard to break. Today, there are videos and junk food. That is what kids do; watch videos and eat lots of junk food. People do not realize how much candy and junk food they are eating. They do not find out what junk food can do to a person.

Another Elder from the community of The Raven believed cancer "probably has to do with the diet." She remembers,

Long ago the old native people, their diet was consistent and so therefore they stayed rather healthy. Then came along the junk food. Seems to me that's what I noticed long ago. I remember long ago when I was a young girl. We didn't have all this junk food that kids have nowadays, like chips, [soft] drinks [505.3.138-146].

Consuming a diet high in foods such chips and soft drinks place community members at risk for developing cancer.

Domestic meat. Meat from cows and pigs cause cancer. An Elder suggested that cancer may infest pork. "It's O.K. to eat wild stuff [meat]. . . . but bacon is the worst. That's where all the worms eat, like pork." Another Elder suggested that domestic meat is a product of its environment.

Cow, it just rolls in the mud and shit. That's what they send and that's what you buy in the store. But moose, it's in fresh air, everything fresh. But that cows, oh, pigs, they're sloppy. That's why most of these people I say I would rather eat moose or something. Moose out in the fresh air like you know. Nice and fresh. And so clean [508.2.109-119].

The "unclean" environment in which domestic animals live contaminate the meat product.

#### Progress: Chemicals in the Water

Of serious concern for the Elders is the extent of pollution in the river running through their community of The Silent Eagle. One Elder whose sister died from cancer spoke about how the quality of the river water has changed over the years. In the 1930s, the river water was very clear and when you set the nets in the water you could see the fish. The river bottom was visible up to a depth of three feet. The beaches were very nice. Around 1947, the Elder started to buy water for drinking. In 1966, the white fish used to spawn at the mouth of the river. In 1968, the water

began to deteriorate more. The Jenpeg Generating Hydro dam is to blame for destroying the spawning grounds in the river.

In earlier times, an Elder in the community of The Silent Eagle boiled her drinking water. Today she purchases water. "I still have to boil that a little bit. Then I put it in a jar. That's my drinking water for that day." Another Elder talked about the water causing cancer in his community. "And the water I don't drink. Even tap water now. We buy our water. . . . We buy artesian well water." He told me about a man who caught two fish. The fish had growths on their bodies. "That somewhat scares me, you know, the [chemical wastes] spills." He recalls, "In 64, I remember the river, eh. The stuff that was floating down there. Big chunks of sewage. You know we were drinking that. Scary. They [the people in the community] didn't even boil the water." When I told the Elder the river looked beautiful to me, he told me, "Yeah. You go down and see it. It looks blue when you're travelling, eh but you go down and the bloody thing is green. You can't even swim in that water." The Elder told me that most of the people purchase their drinking water.

Ella's cancer. Not all members of The Silent Eagle community purchased their drinking water. Peter's wife, Ella, "was a person that liked drinking water." She died from breast cancer.

Jacob's cancer. Clifford's brother, Jacob died from cancer. Clifford was not sure where cancer came from. But he surmised that it could have come from water pollution and radiation. His community, The Silent Eagle is down river from an atomic plant and a paper mill. The paper mill has been operating for 60 to 70 years.



To process paper, the mill uses more than 100 different chemicals and it has been dumping chemical wastes into the river.

### Smoking Cigarettes

Elders spoke about cigarette smoking and cancer. One Elder stated, "Most of the time smokers get it." A person in the community of The Nesting Eagle talked with the family Elders about the use of tobacco. "We're heavy users of tobacco. But I think before there were less preservatives [no additives] in the tobacco and they used to mix it with kinik-kinik . . . so it was probably more natural, in its natural state." It is believed kinik-kinik weakened the carcinogenic effects of tobacco.

An Elder in this community had heard that smoking caused cancer. A smoker, his co-workers asked him if he knew what cigarette smoke was doing to his lungs. He questioned the link between cancer and smoking, "I don't know that I really believe smoking causes cancer really." He has been smoking since he was a teenager and he has had no problems with his health.

### Ebenezer's Cancer

One of Ebenezer's daughters reflected on the cause of her father's cancer.

When I first knew it was cancer, not him, I thought. He was always active and eating well. So I don't know. But the only thing I thought about was smoking because he smokes. I haven't really kept track of his age. But when I noticed he was 60 I was thinking was he really 60. It sounds old, eh. But considering my dad, he was active [808.6.288-299].

An active man who has a healthy diet can still develop cancer if he smokes cigarettes.

### Sylvia's Cancer

Cancer occurs "because you smoke." It comes from "smoking a lot of

cigarettes." Sylvia has been smoking since she was seventeen. She had breast cancer. She noted that she has cut back on her cigarette smoking. "I don't smoke like I used to."

### Physical Injury

Physical injury causes cancer. An Elder's grandfather died of lung cancer. "He was a carpenter and I guess they were tearing down an old building. One of those big square kind of beams they used to have, fell on his back and that's how it started." It was not long after the beam fell on her grandfather that he was diagnosed with cancer.

An informant explained, "Every one of us has this cancer cell and whatever it is, it could be something in your lifestyle, what you've done, you know, a physical injury or something like that. It's the injury that explodes the cell." A relative of this man was hit in the arm with a baseball. The bruise that developed did not heal. He was eventually diagnosed with cancer.

### Jacob's Cancer

Clifford talked about how the cancer cells in his brother Jacob's body may have been mobilized. Years before developing cancer Jacob was shot in the stomach. This physical insult weakened his body so that his liver, stomach and lungs were damaged; his body became weak. The cancer cells are in the body somehow and they grow rapidly when there's a weakened body. A healthy body would fight the cancer for a while.

### Sylvia's Cancer

Sylvia lives in the community of The Raven. She was diagnosed and treated for breast cancer. She observed that cancer resulted from smoking or "when you hurt somewhere and you get a lump there." Sylvia learned from her mother that if "you get hurt on the breast . . . you get a lump there and from there you get cancer." Sylvia's mom advised her to protect her breasts from injury.

An Elder from Sylvia's community explained how an injury to the breast caused cancer. When the breast is bumped or hit it becomes bruised. "The blood vessels pop, stop the circulation . . . and then from there it develops blood clots and lumps and then it becomes, you know, like the tissue dies. . . . It becomes abscessed and all those tissues around it die."

### Infection

For some informants, cancer occurs as result of infection. Informants also feared that cancer is contagious. An Elder noted that cervical and uterine cancer develops when women hemorrhage a lot. When the blood clots the womb becomes abscessed. This infection causes cancer. Another Elder stated that cancer "starts with a growth . . . and [when] they don't look after it, it spreads." Other informants suggested that cancer was not contagious. Cancer is "like an open sore for long time. . . . Cancer is not contagious. It might run in the family but not contagious. Not like tuberculosis." Her sister got cancer. "She used to have some kind of sores on her hands and then finally she had pain . . . . The [cancer] germ went in through the sores." Although this Elder was definite that cancer was not contagious, another Elder

in her community was not so sure.

### Samuel's Cancer

Samuel is a respected Elder in the community of The Nesting Eagle. He was diagnosed with cancer. Samuel "used to wonder" whether cancer was "something that you catch from somebody." His wife echoed his concern, "Does it catch?" Samuel "used to wonder." He has visited people who died from cancer. His friend had cancer. Samuel visited him every week.

### Isabel's Cancer

Isabel was uncertain whether cancer was contagious. Isabel underwent a hysterectomy for uterine cancer. She revealed her fears of having kissed her uncle and brother; both her uncle and brother had died from cancer.

I was kinda scared. And sometime he [her uncle] wanted me to kiss him when I'd leave him. I didn't want to kiss him because I could get it. Even my brother. I didn't kiss him. I felt so sorry for him. I just wanted to hug him so I did. Not like pneumonia or something like that. I used to kiss him [her uncle] on the face but not on the mouth because I could really get that cancer from breathing and I didn't know. My grandma used to tell me that if you kiss a person when they have cancer, you can't kiss them on the mouth. You can easily get that cancer. It passes to another person. I don't know [802.12.649-665].

### Onjine

Cancer can be brought about by "bad" medicine. In Sauteaux "bad" medicine is known as onjine. A person becomes ill because "bad" medicine was used to bring about the sickness. "Bad" medicine comes from another who is jealous or angry. There are other ways "bad" medicine comes about.

### Joanne's Cancer

James told me how his wife, Joanne developed cancer. At her request, James served as the interpreter during the interview. Joanne's cancer was the result of a jealous relative's use of "bad" medicine. Joanne's aggressor had been jealous of Joanne for some time. The jealousy intensified when Joanne won money at bingo games.

Joanne was preparing food for a community feast when a jealous relative told her to eat some food. Joanne did. Three days after eating the food she went with her husband to play bingo games. They won \$200. James thought his wife's jealous relative was upset about the winnings. On the way home from the bingo games Joanne fell. She felt as though something hit her in the back, knocking her over. The pain stayed with her for a week or so before she went to see a medicine man about it. Joanne's fears were confirmed, she was "struck with a curse." Someone has used "bad" medicine on her. The medicine man stated that there was "white stuff stuck" to her kidney. James and Joanne were reassured the white stuff would go away. However, it did not go away. Joanne developed cancer. With the use of "bad" medicine, a jealous person can inflict a disease such as cancer in another person.

### Destiny

Some informants believed destiny was related to cancer. An Elder stated, "I always think that when somebody dies that is their destiny. . . . From the minute you're born your destiny was already fixed, what you're going to die from and you can't change it." If you get cancer then it was meant to be. The Elder clarified,

"Yeah. Unless there's a cure." An informant said, "I think it just comes. No matter how well you take care of yourself, you'll get it." Both her grandfather and father smoked tobacco.

I think even if you take care of yourself, you know, certain diet, you don't smoke [and you] exercise . . . I think people like that can, will get cancer. So you can never say where it comes from. Because I've seen . . . my grandfather's 72. He's a smoker and, you know, he's o.k. My dad's been a smoker and he's young and he has cancer. So it could happen to anybody [805.5.255-272].

An informant in another community echoed the same belief.

#### Ebenezer's Cancer

Ebenezer has lung cancer. One of his daughters shared her beliefs about the causes of cancer.

I think it comes from everything, like food, smoking, um, your diet and I think anybody can just get it. Like, I think even if you take care of yourself, you know, certain diet, you don't smoke, exercise, I think people like that can, will get cancer. So you can never say where it comes from. Because I've seen older ladies, let's see my grandfather's 72, he's a smoker and, you know, he's O.K. My dad's been a smoker and he's young and he has cancer so it could happen to any body and maybe I should change that. I don't think it comes from everything. I think it just comes. No matter how well you take care of yourself, you'll get it [805.5.253-272].

No matter what their lifestyle, some people are destined to get cancer.

#### Summary: Where The Stranger Comes From

People in the communities expressed concern about the effects of progress on the presence of cancer in First Nations communities. Informants in the three communities of The Raven, The Nesting Eagle, and The Medicine Eagle were concerned about chemicals (environmental pollution, pesticides, food additives) in

their food products and the wild life they hunted. In the community of The Silent Eagle, people were worried about their polluted water supply.

The people believed the predominant cause of cancer was processed food. Elders expressed their concern about the recent change in food consumption. Junk food, domestic meat, canned foods and food thick with additives and other chemicals were part of the every day diet of the people. Community members from The Raven and The Medicine Eagle were particularly concerned about chemicals (pesticides, environmental pollution) in the food.

Canned food was identified as a cause of cancer in all the communities except The Nesting Eagle. People who talked about canned food were 33 years of age and older.

Smoking was the second most commonly identified cause of cancer. The third most frequently mentioned cause of cancer was chemicals in the water. This concern was expressed only by members of The Silent Eagle community. The Elders were particularly vocal about the environmental concern. They had seen many changes in the water system in their community. And then they witnessed an increase of cancer in their community.

#### Manitoch Metaphor: The Stranger As Worm

Metaphors reflect the essential characteristics of a disease and contribute to its understanding. Expressing cancer through the symbol of the worm served to explain the devastating effects of the disease. Cancer-as-worm was a common metaphor used by the informants in the four First Nations communities. Cancer-as-worm is known as

"manitoch" in Saulteaux. Cancer-as-worm was identified by the majority of informants. Other metaphors included: bugs, worm-bug combinations, bug-cell combinations, worm-cells, manicosak (worms or maggots), amogogh (maggots) and cancer-as-germ. Informants spoke of cancer as "eating up something" or komigo (eating away). Outlined in Table 14 is the cancer metaphor and the frequency of its use by informants. The common themes for all the metaphors reflect the infestative, painful, and consumptive nature of the disease.

Table 14  
Cancer Metaphors

<u>Cancer Metaphors</u>	
worm	7
bug	5
worm-bug	1
bug and cells	1
worm and cells	1
worms or maggots	1
maggots	1
"eating up something"	1
"eating away"	1
germ	1
cells	4
other	7

The Elders (including those diagnosed with cancer) used the cancer-as-worm metaphor most frequently. A few of the young adults I talked with referred to cancer as a worm metaphor. Their metaphors also included: bug, black hole, and maggots.



The cancer-as-worm metaphor was revealed in a variety of ways. When I asked an Elder in the community of The Raven, "What does cancer look like?", he told me about the worm-like qualities of cancer. In the same community when another Elder told me the food she eats is also eaten by the cancer in her body, I asked her what the shape of cancer was. She told me, "a worm or a kind of bug that eats your body." In the community of The Silent Eagle, I asked, "What is cancer?" One of the Elders said, "The old people call it Manitosis, a worm."

An Elder from The Raven observed that cancer is like a worm that enters peoples' bodies through open sores. The worm grows by eating the body. An Elder from The Silent Eagle stated:

"It's like a big worm . . . that eats you. That's how my wife used to describe it. It's a big worm. It eats you. Used to mention that quite a lot. I guess she's trying to tell me something. That's how it is, just a big worm eating. . . . It eats you, eats your body . . . eats your cells. Seen her breast here just eaten [611.8.438-453]."

Another Elder said that "the old people called it Manitosis, a worm, a spider-like bug. This bug grows by eating your flesh and bone." He then spoke about an old man he knew in his community who had cancer. The old man had holes in his feet and thighs from cancer. The bug would eat the flesh and leave holes.

An Elder in The Medicine Eagle community spoke of cancer. "It's thought of as little worms of maggots. Manicosak [worms]." Although the Elder did not identify how manicosak affects his body, the image of maggots is formidable. Mary knows cancer as amogogh, "Being eaten away." When she thinks of amogogh she envisions maggots, "Cause I've seen meat decaying with maggots on it." The devastating effects

of amogogh became known to Mary when she was five years old. She heard about an elderly woman in her community who was being eaten away; the cancer was in her eye. Mary recalls, "I could never get this vision out of my head that I could imagine the worms eating away in her eye." In this same community cancer was known as "gamawadaway." "It's something that eats you up" and "komigo" which means "eating away." An Elder in The Raven community said cancer was "like rotting inside your body. It rots and then it grows bigger and bigger until finally it kills you." These images of decay are potent symbols for the reality that cancer produces in the body of First Nations People.

Cancer-as-worm is a symbol for a wasted body. An Elder from the community of The Raven pointed to her stomach where her cancer was located. The cancer eats the food that she ingests; that is why she is losing weight. She said cancer was "a worm or kind of bug that eats your body." The cancer grows all over your body. The word for cancer in her first language is "camagoot." It means "bad bug, bad worm."

Cancer-as-worm is also a source of pain. An Elder from the community of The Silent Eagle stated, "It's like a bug. And the pain that you feel is like the bug eating. If you eat, you feed the bug, and if you don't eat when you're hungry, you get tired." A person can feel manitoch eating; it is painful. It is important to eat however, to feed the cancer-as-worm.

#### Manitoch in the Body: A Difficult Cure

Cancer-as-worm cannot be cured. A woman from the community of The Nesting Eagle stated, "and it's something you can't cure, like you know. It's always

going to be there and if they say there's a cure or whatever, like it's going to go somewhere else in your body. It'll start eating away at something else."

The worm-like metaphor has implications for surgical intervention. An Elder from The Raven community said that there were two kinds of cancer which grow into "all different shapes and sizes." The worst form of cancer has hair-like legs; there is no cure. The second kind of cancer has a black head at the centre with two projections coming from it, one pointing to the south and the other pointing northward. When doctors operate it is impossible "to take out all the cancer." There are "far too many hair-like legs" and there is "always something left behind." It is impossible to rid the body of cancer through surgery.

Another Elder from The Raven community spoke of cancer being like a big worm. Manitoch goes from one end of your body to the other end and when they operate they only take a piece of it. "That's why there is no cure. The rest is left behind to grow again." A member from the community of The Nesting Eagle who was in her twenties explained:

I always pictured it as . . . like a bunch of worms and they're eating up insides, slimy. . . . And just by eating your, whatever it is, you have cancer. Like whatever, they can get a hold, like they seem to be getting bigger. Like they're feeding on your, whatever it is, you have cancer [805.7.342-354].

When I asked, "What happens to the worms during surgery?" she replied:

I picture them as being very quick. . . . Some of those worms tend to squirm away and end up somewhere else. That's when the doctor say, "we couldn't get all of it." Cause those [cancer] worms are too quick and they get away [805.7.342-372].

Peter, a middle-aged man from the community of The Silent Eagle told me

that his wife never mentioned that she had cancer, but he knew. During her biopsy, his wife's breast broke open and the cancer burst forth. He said, "I knew right away. They did . . . a incision and a test. . . . This thing just took off. . . . Just took off. . . . Right away she started breaking as soon as that incision was made." The incision freed the worm and her cancer spread.

In each of the four communities people said that long ago there was a cure for cancer. However, when the healers died, the knowledge to cure cancer passed on with them. Many of the Elders in these communities spoke of poultices used to cure cancer. An Elder from the community of The Raven indicated that poultices were used to draw out the cancer; other herbal medicines were taken to drive out the cancer. I was told about a man who had a poultice placed against a cancer in his hip. As the poultice was being removed a hair-like creature with long legs could be seen coming out from the man's hip. Poultices were used to pull out manitoch completely from the body.

#### Manitoch: A Case Study of Roberta's Cancer

Roberta responded decisively to her oncologist's advice for prompt surgery to remove the cancer from her bowel. The surgery was immediately scheduled. Roberta remembered the urgency.

"We have to do it as soon as we can." He says, "We have to get that out there or else you'll only live a year." He says, "You'll only live a year." He says, "If that starts growing it won't take long." He says, "Before it gets to your lungs. If it gets to your lungs you're gone" [804.1.44-51].

Remembering the surgery, Roberta spoke of her fear that the cancer would

return. On at least three different occasions she recalled that the complete excision of the "cancer worms" was not possible. Recalling her doctor's reassurances that surgery would successfully cut away the fast-growing new growths, Roberta was convinced that some of the cancer worms escaped the knife and hid in another part of her body, but she did not want to think about the cancer worms.

The doctor said, "They're starting eh. Just starting. But they're not ones that'll crawl around. It's raw there and there's swelling there. And that's where they are. Now that busts, it's gonna spread." He says to me, "But we have to get ahead of it. That's the only way we're gonna doctor you is take everything out there and cut your gut out, away from there. . . . That's the only way." He says, "And after that you don't have to worry about it." But still I can't accept that and need to forget about it. I don't have it. I'm just scared all the time thinking it might come back on me or something [804.10.534-552].

Roberta interpreted her physician's explanations using the manitoch metaphor.

After the surgery the packing in Roberta's abdominal wound was removed. She felt the pain about which she was forewarned. Was the doctor removing the stitches? She was not sure. She did not want to look. If she opened her eyes she might see her worst fear—the cancer worms.

The doctor comes in. He says, "We're going to hurt you a little more yet." "Once more," he says, "and that's it." They had that there, the little cheesecloth bandages all stuffed in there where they stitched me up, eh. Oh, that ever hurt. "I'm going to hurt you," he says. . . . "It's pretty hard for us." . . . I was wondering what the heck they were going to do again, take those stitches out or not. And they started. They start pulling them. . . . He was pulling this out like that ever hurt me. I just grabbed on to that bed and just closed my eyes and laid there until they were finished. I thought he was through when he was holding that. It must have been about that long (holding hands apart) and they were counting something on there and they laid it down. . . . I don't know what it was they were counting. How many. I don't know what it was. If it was those worms or what [804.5.243-268]

### The Surgery

Roberta was spiritually prepared for her surgery. She spoke of her resolve to place her fate in God's hands. "I just gave up. If it was God's will for me to live." She consoled her family. "All my family was there. . . . They were all scared. And I told them to not be scared, I'll be o.k."

Then Roberta narrated how she almost died during the time when she was awakening from anesthesia. The excision of the cancer from her bowel was over. "When I woke up . . . I could hardly see these ones [her children] talking to me, but I could hear them. They talked to me and I would go on sleep again, sleep away." Roberta's sister-in-law was also with her during this time. Her sister-in-law stated what she saw and heard. "There was a nurse standing there all the time watching you." The nurse "got scared" because Roberta's "pulse was not working any more." The doctors were called back. Then the sister-in-law left the room and Roberta's side. She did not want to see nor hear that Roberta had died. "I just beat it out of there and I didn't want to say nothing to the girls [children]. . . . They were standing there. I just walked out myself. . . . And I just waited for them to come and tell me . . . you were gone." Roberta "came around again." She was taken to another room and stayed there until she "came around right."

As she continued to recover from the anesthesia Roberta told me what happened to her. Her nightmares expressed her worst fear. The cancer worms had been stirred; they were moving to a new breeding ground in her body. The surgeon had not completely cut away the worms from her colon. Then a change occurred.

Roberta had a vision.

And they kept on like that, eh. I was seeing things on the curtains and everything. I had a nightmare all night for a couple of nights. I didn't know what to do. I couldn't sleep and I'd awaken up and I'd look at the wall and I'd see everything all over, you know, these cancer worms. I'd seen them all over the wall, all over. I couldn't look no place. Oh my God I couldn't look no place. That was just in my (laughter) looking around. Oh, I just went to sleep again, and I closed my eyes. I couldn't open my eyes. When I turned around I woke up again. And I looked up there where they have a TV, the TV stand. I looked up and I looked around again and I seen the Blessed Virgin standing there. She's standing there looking at me, just like these statues and I knew I was going to get better. Yeh, she came to help me. I'll never forget that when I saw her standing there. Well I said to myself if you help me out, I'll never forget you too. I'll pray to you all the time. And then I just got better. And they were surprised that I was getting better so quickly. I was getting better and in no time I was walking around again. "Oh, she ever done well," they said [804.4.179-210]

### The Recovery

While at home, Roberta felt the presence of the cancer worms. Again, her doctor's assurances that the crawling sensation would go away did not appease her. Her physician's words did not address her deepest fears that the cancer worm had found refuge in another part of her body.

After that when I come home. I used to feel them, something crawling around in here where they stitched me up, eh. I used to feel that crawling around in there. Oh that disturbed me and I'd want to sleep. And I told the doctor about this. The doctor told me, "You don't have to worry about that. That'll go away. It's just your nerves. It'll go away. Don't worry about it." Well, it's done now. I don't feel anything. They have moved somewhere else I was thinking. That's what scares me thinking about that [804.11.567-591].

### Modern Metaphors: Manitoch-As-Cancer-Cell

Manitoch is being transformed. With the influence of science and biochemical

knowledge manitoch is metamorphosing into a germ. This germ still has the appearance and characteristics of "manitoch". An Elder from the community of The Raven told me what cancer was.

It's a germ and then it grows on you. If you don't look after yourself right away like and then you start to get sick and finally it goes up and then into, form into a growth and then when that thing bursts, then spreads all over, I guess. That's what I think. . . . According to what I heard this germ has so many legs. . . . It has so many legs and then it spreads over all the whole system of your body. The cancer gets bigger because it eats the flesh. [The germ] eats up everything. It starts to spread like you know. You're just full of it after [509.5.240-302].

This Elder spoke of her mother-in-law who had cancer in her breast. This occurred many years ago when the main disease of concern in her community was tuberculosis. At this time, two or three other women had died of cancer. In those days, the nuns were nurses at the community hospital. One of the nurses told her mother-in-law, "I'll take that. . . . The nurse lanced it a little bit here (pointing to her breast). She was the first one. And got that germ out. . . . A germ about that big (holding fingers apart). Little legs, so many legs." And then the nurse told her mother-in-law, "you won't get sick any more." The Elder's breast healed.

For some informants, manitosis has become a cancer cell. When I asked how the manitoch grows, an Elder from the community of The Raven observed that cancer spreads through the blood stream. "We all have cancer cell." When something triggers the cancer cells they grow out of control. An Elder from The Silent Eagle community also stated that everybody has a cancer cell. She said that some people say that cancer sleeps. And, in time it moves. "The old people say that the cancer cell pops."



I'd say by the movement of cancer. . . . How it spreads, eh. Like a worm, it goes from place to place so that's how come it became to my language what it is now. Cause it doesn't stay in one spot, it moves forward, it moves. . . . It eats by, eats away there the cells in the body [514.4.185-206].

### Other Metaphors

Metaphors help to explain a disease. A health services administrator spoke of cancer as "gamawadaway." To explain how the body feeds on itself, he said, "It's something that eats you up. . . . It destroys, yeah, it destroys. . . . It isn't a virus . . . it could be that your body is reacting . . . your body is defending itself from something. But then it's getting the wrong message. . . . Start killing. Self destructive kind of thing."

Cancer spreads through the blood system. It is impossible to cure. A community health representative explained cancer as being "lumps, big lumps" that do not go away. Breast is the worst cancer. "I think it spreads faster because they say it's where your heart is beating. It seems to move faster than [cancer] in your stomach. Because it is close to where your heart is. The blood is pumping, [the cancer] working its way, spreads faster." Although a woman has a cancerous lump removed from her breast and is told by her physician that she no longer has cancer, she still has cancer. "It is, ah, more hard to detect. It could be hidden somewhere and it could spread, come back." The cancer could spread to other places in the body. "It could return to your other breast. . . . Or if they remove two breasts in the woman it will be still there and will go up. You'll never get rid of it." For the woman who received cancer treatment the cancer is still in her body, some place. "Only it's quiet

and hiding." The treatment is a temporary reprieve.

Metaphors symbolize the fears of having cancer. Family members whose relatives have been diagnosed with cancer spoke about their cancer metaphors. Kathy's daughters each have a metaphor for cancer. Kathy was diagnosed with breast cancer twenty years ago. Both of her daughters fear their mother's cancer will return. One daughter envisioned cancer as "a little grave." For her, having cancer is "a slow death." For the second daughter cancer is "a little black hole." To be diagnosed with cancer is to be "sucked into the black hole."

Once diagnosed with cancer you enter into a world of uncertainty. An informant viewed cancer as "a black spot" which eventually "becomes complete and there's nothing else. Just all black. Death." This informant's brother died from cancer. Samuel has been diagnosed with lung cancer. He has just completed radiation therapy. His daughter expressed her fear that the cancer in her father's chest will return. She sees a small red circle when she thinks of cancer. The red circle is still in her father's lung.

#### Summary: Manitoch Metaphor

Metaphors offer perspectives about the characteristics and process of a disease, and the implications of surgical and medical intervention. Metaphors provide a succinct and powerful understanding about a disease. Cancer-as-worm, which is "manitoch" in Saulteaux, was the most common cancer metaphor used by First Nations People in this study. Other metaphors identified were: bugs, worm-bug combination, bug-cell combination, worm-cells, manicosak (worms or maggots),

amogogh (maggots) and cancer-as-germ. Informants spoke of cancer as "eating up something" or komigo (eating away). The common theme for all the metaphors was the consumptive, painful, and incurable nature of cancer.

The cancer-as-worm metaphor was used most often by the Elders while other metaphors such as bug, black hole, and maggots were used by younger adults.

First Nation cancer patients and their families who understand manitoch-as-cancer interpret the disease and its treatment from this perspective. Their fears and expectations about the management of cancer is a reflection of their understanding of the disease process and treatment outcomes. The incorporation of manitoch-as-cancer in teaching First Nations People about cancer prevention, early cancer detection, and surgical and medical intervention reflects an understanding about cancer patients' perspectives and the implications this has on the management of cancer.

Manitoch grows and breeds by consuming the flesh and bone of its hosts. Cancer-as-worm is manifested by the pain and other signs of decay and devastation. The incurable nature of cancer is depicted in worm's hair-like legs which can grow to enormous lengths within a body. Since cutting one of its many tentacle-like projections is likely, it is impossible to surgically remove cancer in its entirety. The remaining worm pieces migrate to different parts of the body. These remnants may lie dormant or begin to grow.

### Conclusion

The findings in this chapter describe the views informants in this study have about the origins of cancer and the metaphors they use to relate their understanding

about this disease. They believed that the types of foods consumed and chemicals (environmental pollution, pesticides, food additives) in their food products and the wild life they hunted were predominant sources of cancer for First Nations People. A variety of other sources for cancer were also mentioned. The informants in this study identified Manitoch, the cancer worm as a cancer metaphor. Variations of this metaphor were also identified in this chapter. The fifth chapter presents the findings about the cancer experience.

## CHAPTER 5

### THE CANCER EXPERIENCE

This is the second of three chapters which describes the findings of this study.

In this chapter I will specifically address the experience of cancer from the perspective of the person diagnosed with cancer. I will begin by providing an overview of the informants and then present the first of five themes in the cancer experience. "Becoming Aware: The Stranger in the Body" presents the experiences of the informants when they sensed they had cancer. "Becoming A Stranger: Leaving the Community" describes the experiences of the informants when they left their communities to have their suspicions confirmed and then later to have their cancers treated. In "The Stranger Apparent", the informants' experiences in facing their own mortality and in dealing with their ever present fears that their cancers will return is described. Also, the silence that surrounds the person with cancer is described in this section. The informants' experiences surrounding the need for spiritual strength and guidance as part of their living with cancer is described under the topic, "Learning to Live With Cancer: Getting to Know The Stranger." I will conclude by briefly summarizing this chapter.

1. An Overview of The Informants
2. Becoming Aware: The Stranger in the Body
  - A. Sylvia's Awareness
  - B. Kathy's Awareness
  - C. Roberta's Awareness
  - D. Summary: Becoming Aware
3. Becoming A Stranger: Leaving the Community
  - A. Finding the Cancer
    - a. Sylvia's Journey
    - b. Kathy's Journey
  - B. Treating the Cancer: Emphasizing the Stranger
    - a. Sylvia's Experience
  - C. Summary: Leaving the Community
4. The Stranger Apparent
  - A. Seeing The Stranger As Death
    - a. Isabel Sees Cancer As Death
  - B. The Stranger As Always Present
    - a. The Stranger Calls Again: A Case Study
  - C. Silence
  - D. Summary: The Stranger Apparent
5. Learning To Live With Cancer: Getting To Know The Stranger
  - A. Beyond Cure: The Need for Healing
    - a. Indian Medicine
    - b. Christianity: Having Faith
      - i. Test of Faith.
      - ii. Physician As Healer
      - iii. The Gift.
  - B. Summary: Learning to Live With Cancer
6. Summary

Figure 7. Cancer Experience Topics

### An Overview of The Informants

Ten people in four communities spoke with me about their experiences of having cancer. They were diagnosed with various types of cancer. Three women had breast cancer while the remaining women in the study were treated for acute leukemia and cancers of the uterus, kidney and colon. The other two informants were men; one man was diagnosed with lung cancer and the other had prostate cancer.

Eight people were diagnosed with cancer within the last four years. The other two people were diagnosed with cancer in 1960 and the late 1980s. One informant

who was diagnosed with breast cancer thirty years ago, developed uterine cancer. Eight of the ten informants were between the ages of 40 and 68 years of age. A young woman (18) with leukemia and an elderly gentleman (89) treated for prostatic cancer were the "outliers" with respect to age. Outlined in Table 15 is the cancer site, year of diagnosis, gender, and age of the informants.

Table 15  
Informants Diagnosed with Cancer

Site		Year	Treatment	Gender	Age
Ruby	1. Breast	1989	mastectomy chemotherapy	F	60
Sylvia	2. Breast	1994	mastectomy chemotherapy	F	43
Kathy	3. Breast	1970	mastectomy	F	52
Matilda	4. Uterine	1992	hysterectomy chemotherapy	F	40
Isabel	5. Uterine	1993	hysterectomy chemotherapy	F	30
Suzanne	6. Leukemia	1993	chemotherapy	F	18
Samuel	7. Prostrate	1990		M	89
Joanne	8. Kidney	1994	surgery	F	42
Ebenezer	9. Lung	1994	chemotherapy radiotherapy	M	61
Roberta	10. Colon	1991	surgery	F	68

The people I interviewed were at various stages in their cancer experience. All of the women with breast cancer (n=3) had undergone a mastectomy. One of these women was in the process of having chemotherapy treatment at the time of this study. The other two women were treated with chemotherapy or radiotherapy. Informants

diagnosed with kidney, colon and uterine cancer had surgery to remove their cancer. The women with uterine cancer were also treated with chemotherapy. The gentleman diagnosed with prostate cancer was diagnosed subsequent to a prostatectomy. Informants with leukemia and lung cancer received chemotherapy, while the informant with lung cancer also received radiotherapy.

#### Becoming Aware: The Stranger in the Body

Five of the ten informants, all of whom were women, sensed they had cancer before they had any contact with the health care system. They eventually had their fears confirmed. Three of these women were diagnosed with breast cancer, one with kidney cancer, and the fifth was diagnosed with colon cancer. Three women spoke in detail about their awareness of having cancer before receiving an "official" diagnosis.

Sylvia, Kathy and Roberta talked about their awareness of a strange presence in their bodies. Sylvia discovered a lump in her breast while doing a breast self-examination. The cancer pattern had been set in Sylvia's family. Her sister, mother and brother were diagnosed with cancer. Cancer of the breast and pancreas was present in her family. Thus, Sylvia examined her breasts for cancer. She felt a lump in her breast; she was certain it was cancer. Kathy's discovery of a lump in her breast was fortuitous. "I never really bothered with checking myself [doing breast self examinations]." She discovered the lump by chance when she brushed her hand against her breast. Kathy's thoughts about cancer were less immediate, but they were present. The lump in her breast was cancerous. Roberta noticed that her bowel movements were malodorous and uncomfortable. Roberta believed she had cancer



because her bowel movements were so foul smelling.

Sylvia, Kathy and Roberta were concerned about the unexpected changes in their breasts and belly. Something was different. Something was wrong. Sylvia and Kathy closely watched the lumps they each had in their breasts. They palpated their breasts for discomfort and changes in the size of the lumps. Roberta also monitored the level and frequency of her discomfort and checked the colour, form and odour of her stool.

#### Sylvia's Awareness

Sylvia became frightened when she found a lump in her breast. She stated, "I knew I might have cancer." Sylvia had reason for her suspicions. Both her sister and mother had also found strange lumps in their breasts which were malignant.

I think it's the family. . . . I guess it's because, ah, especially when we found out my mom had that, we were pretty sure we were going to get it, all of us. My mom would say that it runs in the family. She used to tell us to watch. But I didn't believe it would be really true. My mom said not everybody would be like that, like the whole family. Maybe some. But then I didn't think that it would be me too. One time when I was looking at myself in the mirror I asked myself, why me? My sisters, I think that's what they think too. But I guess it's done, it's there, there's nothing else to do [501.16.844-864].

After developing cancer, Sylvia's mother tried to alert her children to the possibility of cancer. "My mom used to talk to us about it. Like we shouldn't smoke. 'Don't smoke too much', she would say to us, 'or you'll have cancer.' She said, 'Don't you know that's what causes cancer?'" After her sister was diagnosed with breast cancer, "they [health care providers] always told us to watch ourselves, our breasts. To examine ourselves. That's what I used to do."

I found that lump myself . . . . Well I was scared at first when I noticed that lump there. But I kept a close watch on it and I thought it would go away but it stayed there. And I seen a nurse and checked me and sent me out. And I don't know, I don't know. I didn't know what to think, I got scared right away and I didn't know who to talk to. I talked to my sister, the first one that had it. . . . she had her breast removed and she talked to me about it cause she asked me questions. How I feel and all that and I told her. And I got scared. And she said, "Don't be scared." She said, "Maybe it'll go away." And I said, "I don't think it'll go away." And then she asked me if I was afraid to die. I don't know. I said I think about it, but I try hard not to think about it. I try to keep myself busy. And I talked to my mother about it. I talk about it every day because we are close, me and my sister [501.1.9-41].

Sylvia was uncertain what to do about her discovery. She turned to her sister and mother for guidance and advice. She talked with them about her cancer. Although she examined her breasts for signs of cancer Sylvia did not see the nurse "right away" after she made her discovery. Sylvia waited two to three months before going to the nurse. Frightened, she hoped the lump would disappear. A legacy among the women in her family, cancer generated an awareness in Sylvia before it was diagnosed in her breast.

#### Kathy's Awareness

Thirty years ago, Kathy temporarily relocated with her husband to another community to find work. While they were away from home, Kathy accidentally discovered a lump on her breast. "One day I was doing this [moving her hand toward her breast]. And I felt that lump on this side." Her husband stated the lump was the size of a dime. Kathy tried to understand the strange presence in her breast. She did not know anyone else in the community who had cancer. At first, she thought she might have suffered trauma to her breast. "Maybe I hurt myself or it was just

something like. I didn't really think, I guess I thought about cancer and I didn't really, how would you say that, I didn't really think it would happen to me."

Disbelief. Kathy thought she might have injured her breast. She could not believe that cancer could happen to her.

Kathy left the strange lump on her breast alone. She did not want to disturb whatever was contained in her breast. She thought it might go away if she left it alone. She did not tell anyone else about it. Kathy watched it closely. She felt the lump again. "It was growing bigger." Kathy then became really concerned about the lump. She talked about the growth with her husband.

I think I wasn't really concerned about it. Except I didn't have any pain or anything. It just was sometimes my arm was, sort of an ache, but not really. So I never really thought about it and then I told my husband who says why don't you go to the nursing station so they can see what that is [510.6.286-294].

Kathy noticed other changes in her body. Her arm felt different, but there was no pain. If the lump was cancerous would there not be pain? Two or three months after Kathy made her discovery she went to see the nurse. "When we came home [her community]. . . . then I came to the nurse."

#### Roberta's Awareness

Roberta knew something was wrong with her body. Things were different. "I felt like going to the washroom and I'd go to the washroom and nothing would come. My bowels would not come." Roberta was having a lot of pain and discomfort. She went to her doctor. He was planning to take an X-ray of her bowels. She was told to wait. She waited. Her doctor did not call. She waited some more.

Roberta talked about the changes in her body with her daughter. Her daughter told her, "I'm the same way. That's your piles." Roberta, however noticed things were different. "Once in while I saw blood. . . . It smelt very much. That's why I was thinking that myself. I must have cancer instead of piles." Roberta's only reference to cancer were the stories told by relatives. She heard about an elderly woman who, dying from cancer, was described as being "all rotten. . . . rotting away". A young man with metastatic stomach cancer "was just bent over. He can't straighten up. . . . His stomach is sore all the time." When the pain from Roberta's bowels became unbearable, she made an urgent call to her doctor. "I phoned him from here because I was just crying with pain. I couldn't stop." With the excruciating pain and foul smelling bowel movements, Roberta knew she must have cancer.

#### Summary: Becoming Aware

Sylvia, Kathy and Roberta intuitively sensed they had cancer before they were diagnosed. The women were alerted to cancer because they encountered marked physical changes in their bodies. Sylvia found the lump in her breast when she was examining her breasts. She believed she had breast cancer because her sister and mother both had breast cancer too. However, Kathy accidentally came upon the large lump in her breast. The possibility of having cancer was a remote thought since cancer was rare in her community. Roberta recognized the profound changes that were occurring in her body from the stories she heard about the devastating effects of cancer. For these women, the changes in their bodies were indicative of cancer.

Fear had a paralyzing effect on these women. Although the women sensed they

had cancer, they delayed seeking help from a health professional. Rather, they talked about their fears and sought the advice and reassurances of family members about the strange occurrences in their bodies. They monitored these changes closely and hoped things would get better. Sylvia and Kathy did not seek out medical assistance until they were certain the lumps in their breasts were getting larger. Unbearable pain moved Roberta to call her doctor. Fear of cancer--based on stories circulating through the communities--and a family legacy of breast cancer, prevented these women from seeking medical assistance once they had discovered the stranger in their bodies.

#### Becoming A Stranger: Leaving the Community

By sensing the strangeness in their bodies the informants began to move from places that were well known to them and offered a sense of security to ones that were unfamiliar and filled with doubt. The passage from the familiar to the strange occurred when the informants set out to find and then have their cancers treated. They journeyed into fear and uncertainty both metaphorically and in reality. They had to leave their families and other support systems in their communities and enter strange environments to confirm the presence of their cancers and to receive treatment. Diagnostic tests and cancer treatments took place in large urban hospitals. Informants were strangers in these cancer diagnostic and treatment centres; strangers in a strange land.

#### Finding the Cancer

Informants who sensed the presence of a stranger in their bodies had to leave their communities to find their cancers. Obtaining a cancer diagnosis was a long and

arduous journey. Informants had to travel at least one hour by airplane or by car to reach a diagnostic testing centre. They had to leave their families and other support systems behind.

Informants left the familiarity and security of their home communities and entered a strange environment in a different community to have their cancers confirmed. They were required to stay at the diagnostic testing centre for hours or even days. Other informants were required to have their tests done and then return to their communities to await the results.

Of the ten informants who spoke about their experiences with cancer, two shared in detail what it was like to find their cancers. They were both women treated for breast cancer. The first woman revealed what it was like for her to have repeated biopsies done. Her husband accompanied her during this diagnostic phase of her cancer experience. The second woman talked about what it was like to leave her home and her children to find her cancer. Her husband also accompanied her to a small centre south of her community.

#### Sylvia's Journey

Sylvia's journey, to "officially" find her cancer, took her to Winnipeg five times and she underwent three biopsies before her cancer was proven to exist. Her husband stated these trips to Winnipeg were difficult and expensive. Sylvia spoke about her ordeal.

They didn't take it out right away when they found out I had a lump there. They just put a needle here and took that stuff drain out. There was stuff draining out of there but the doctor never told me that there was nothing there. . . . They didn't feel it, but then a couple of days

later it came back again and then they put a needle in there again and they did it again, and then I went the third time again but that's when they told me to stay there to get that thing out. So I had a little surgery here. They took that lump out. And then they found it I guess. A week later, that's when they told me I have cancer there and I have to have surgery right away [501.4.207-228].

It was perplexing to Sylvia that the physicians seemed puzzled by the lump in her breast. "They weren't sure what it was." She knew the lump was cancerous. To Sylvia it would have been straightforward to immediately cut out the cancer from her body, but the doctors did not do that. Rather, they probed the lump in her breast time and time again. Sylvia was fearful. She was uncertain the doctors were capable of finding the cancer before it spread. Frustrated, Sylvia's husband also questioned her doctors' judgements.

What if they just operated her and took that thing out? Could she still have her breast today? You know it's always in my mind. That first trip we made. All they did was drain that fluid out, eh. It's always in my mind. What if, what if. At that time could that breast been saved. . . . What if they acted upon it right away, what if that lump was just a tiny one [514.12.611-623].

A year lapsed between the first time and second time Sylvia's cyst was drained. After the initial draining of the fluid from the cyst, both Sylvia and her husband inspected her breasts "pretty well every day" for any signs of a lump. Although the doctors were not able to identify the lump as being cancerous, Sylvia with the help of her husband, located the lump as soon as it returned. Sylvia and her husband did not understand why the physicians took so long to remove the cancer from her breast.

### Kathy's Journey

Kathy's experience with cancer occurred thirty years ago. She was fearful of finding cancer. She was afraid to have this devastating disease confirmed. A hospital in a small southern community was the destination to have her cancer diagnosed. Kathy was successful in postponing her journey for two months. The Chief of her community eventually "escorted" her to a craft that took her away from her home and family.

So I came and about a month I guess I had to wait for a doctor to come in. That's when they sent me out to [a hospital in southern Manitoba]. . . . They needed a month. But I kept stalling, eh, because I didn't want to leave my kids and then finally they had to get the Chief to get me at home and put me on the plane because I didn't really want to go, eh. Like I didn't want to leave my kids. So finally I had to go [510.6.294-334].

It was a frightening experience for Kathy to embark on her cancer journey. Being a mother, it was also very difficult for her to leave her children behind, "especially when they are small." Kathy preferred to remain with her family in her own community rather than travel to a hospital in southern Manitoba to confirm the presence of cancer in her breast.

### Treating the Cancer: Emphasizing the Stranger

Many of the informants received chemotherapy or radiation treatments for their cancers. Four women had chemotherapy treatments following a mastectomy or hysterectomy. One informant underwent chemotherapy after being diagnosed with leukemia. One gentleman had additional treatments of radiation because his cancer was not completely stopped by the chemotherapy. One woman also received



radiotherapy following her mastectomy.

All the informants who received chemotherapy and radiotherapy were to leave their communities for treatments in urban centres. Of the informants who spoke about their cancer treatment experiences, two were accompanied by their spouses and one was accompanied by her mother. The fourth went for chemotherapy by herself. Sylvia and Matilda travelled to Winnipeg once a month by plane. Sylvia went for four chemotherapy treatments and Matilda received six treatments. Travelling time aside, their treatments lasted hours and included a physical examination, blood tests and chemotherapy infusion. Ebenezer travelled almost two hours by car for his treatments. He was admitted to a Winnipeg hospital once a month over a period of six months to receive his chemotherapy. Each treatment session lasted four days. After he completed his chemotherapy "there was a spot still showing" on his X-ray so he was consequently started on radiation therapy. Ebenezer and his wife travelled again to Winnipeg for radiation treatments. Roxanne was admitted to the hospital for diagnostic tests. Once her leukemia was diagnosed, she was immediately started on chemotherapy. For each treatment she received, she stayed in the hospital for one month. She was discharged for one month between her treatments.

Cancer treatment reinforced the informants-as-strangers. All of them had to leave their communities and travel to specialized centres to take medication or radiation treatments to rid their bodies of cancer cells. The informants were strangers in these cancer treatment centres. They were unfamiliar with the physical layout, the equipment, and the cancer treatment regime. They were unfamiliar with having

cancer. The cancer treatments were strange; they not only killed the cancer cells but they affected healthy ones too. The informants experienced physical effects from these treatments which emphasized further their strangeness. Having cancer is a frightening experience and having to leave the familiarity of home behind, the cancer treatment experience is overwhelming. The side effects were overwhelming. The informants had no choice but to face the nausea and loss of appetite along with their treatments. The transition to strangerhood continued when the informants took on new physical appearances. The hair fell from their heads and they lost weight.

The physical effects of treatment were formidable. Of the six informants who had chemotherapy, four spoke candidly about their experiences with side effects. Nausea and loss of appetite were most frequently discussed. Hair loss was mentioned as frequently as nausea, but was not discussed to the extent that nausea was. Suzanne anticipated she would be nauseated from her chemotherapy treatments. She had learned that nausea was a common side effect of chemotherapy. "Usually everyone gets sick [vomits] when they have chemotherapy, but I didn't." Suzanne was relieved she was spared from nausea. However, the remaining informants felt the full force of nausea by the time they returned to their homes after receiving their treatments.

Nausea affected the lives of the informants. They were nauseated for four to seven days after receiving their chemotherapy treatments. Informants found the odour of food intolerable. Some found other odours, such as perfume, to be offensive. They could not eat and consequently they lost weight. The informants were apprehensive about going for their treatments. For the majority of informants, post-treatment

nausea was a certainty. It was to be endured. Matilda described living with nausea as a painful experience. The thought of going for treatments was unbearable. She decided not to go for her sixth treatment. "There are times I get really sick. I think it is mostly from chemo. I get really sick. I just hate it." Matilda was scheduled for three more treatments. Uncertain how effective her treatments were in destroying the cancer in her body, Matilda came to the conclusion that the treatments were "a waste of time." "I was going through pain for nothing."

### Sylvia's Experience

Sylvia went to a cancer treatment centre in Winnipeg four times to kill cancer cells that might have broken away and migrated from the original site in her breast. Her husband, Issac, accompanied her on each of these treatment voyages. They travelled for one hour on an eighteen seat, twin engine airplane. By the time Sylvia completed her diagnostic tests, had surgery and chemotherapy Issac and Sylvia had made a total of ten trips by air to Winnipeg. Their length of stay in Winnipeg varied. While Sylvia's travel and accommodation expenses were paid by Medical Services Branch, Health Canada, Issac's were not.

Sylvia did not remark on her experiences in the treatment centre however, Issac observed that the equipment used was "pretty scary." "The nurses nor the doctor said anything [about Sylvia's cancer or treatments]. They just asked me how I felt. That's about it. But to explain more of her condition. I never got any teaching." Issac would have liked to have known more about his wife's condition. The nurses gave him a reclining chair so he could sit beside his wife. Issac sat quietly supporting

Sylvia with his presence.

Issac noticed that Sylvia was reluctant to go for her treatments when she started to lose her hair. At times she actually refused to go for her chemotherapy. However, with Issac's encouragement to continue with the chemotherapy and reassurances that he loved her, Sylvia completed her treatment regime. Going for chemotherapy treatments "was hard for her."

Issac saw his wife change as she went through chemotherapy treatments. "Her hair fell out". But more importantly, "She changed towards me. There was a change in her attitude when she came out of the chemotherapy. Keep away from me." Sylvia became a stranger to her husband. By keeping distance between herself and her husband, Sylvia hoped to keep the shame she felt to herself. She felt "empty" because her breast was gone and she felt "ugly" because a scar replaced her breast. Sylvia was fearful Issac would reject her. "I thought he would leave me." The effects of chemotherapy reinforced the sense of isolation Sylvia already felt as a result of her diagnosis and surgery. She not only looked like a stranger, but Sylvia also felt like a stranger.

Hours after having chemotherapy Sylvia was on the plane heading home to her community. The nausea was setting in and would be with her for four or five days.

I really got sick. I was sick all the time. I lost my hair and I was getting bald like. I lost a lot of hair and I had to wear this thing [turban] which I didn't like and I had to work of course. I worked like that when I was sick. I just kept on working. . . . I would sit there in the hospital for about three hours and I would get that thing done, that chemo. I couldn't even eat and I quit smoking for about four months after that. . . . When I went through that chemotherapy I lost a lot of weight cause I was sick all the time. I couldn't eat. I couldn't stand the

smell of food or anything. Or even perfume, I couldn't smell it. It would get me sick. I would just lay around in bed. I used to work here every day between my treatments. They told me in the hospital to take it easy, that I didn't have to work. But I had to work. We couldn't make up our, the debts we made because we were in Winnipeg for two months. That's why I had to keep working [501.7.325-347].

Each time she left home the chemotherapy reinforced her strangeness. Outwardly, Sylvia as a stranger was obvious to others who knew her. She wore a turban all the time and she had become thin. For Sylvia the nausea was a hardship. She could not eat and she lost weight. She was tired all the time. Being nauseated and tired were not satisfactory reasons for taking time away from work. She had to work to help pay for her husband's travel and accommodation expenses. The emotional support that her husband provided to her on these treatment voyages was financially expensive.

#### Summary: Becoming A Stranger

Once the presence of cancer was sensed, it had to be "officially" confirmed and then treated. Arriving at this confirmation was a trying experience for First Nations People. The informants had to leave their home communities and all the support systems known to them. No one was exempt from leaving the community. A young mother who refused to be separated from her children was forced to leave her community to find her cancer. For some of the informants, repeated trips to the diagnostic centres were necessary.

Many informants were confused about the diagnostic and treatment procedures they underwent for their cancers. With limited explanations about these procedures and processes, many informants did not fully understand how they were progressing along the disease or healing trajectories. The informants' lack of understanding about

a procedure and how it related to their cancers enhanced their anxiety and instilled fear and confusion. With limited explanations some informants expressed mistrust of the healing system.

To many First Nations People invasive diagnostic tests and surgical procedures spread cancer cells. Explanations without considering the informant's view of cancer may enhance anxiety and fear if the procedure contraindicates the removal of cancer in its entirety.

Some First Nations patients return home to their communities after each chemotherapy treatment. This has implications for patients who must travel by car or small aircraft and who return home where there is no running water in their communities. Some informants travelling on small aircraft experienced discomfort. The informants experienced intolerable noise levels, too warm or too cool cabin temperatures and turbulence. Some informants got home before the nausea took its full effect. And others would return home to children or be home alone because others in the family would be working away from the home. People living with nausea and vomiting face the added burden of having to get water from water vats outside their homes and then heating the water to cleanse with it.

First Nations families with relatives who are having diagnostic tests or treatments for cancer may have child care, travel, and accommodation expenses to consider. The parent receiving treatment is responsible for child care expenses of children left behind in the community. Status Indian people who must leave their communities to have diagnostic and treatment procedures for cancer have their travel

and accommodation costs covered by Medical Services Branch of Health Canada. However, these costs create a burden for some families who accompany their relatives during these procedures.

Sometimes travel and accommodation costs are covered for a spouse, partner, or another family member. A supervisor at the Non-insured Health Benefit Unit, Medical Services Branch, Health Canada clarified that the nurse-in-charge in the community health clinic or nursing station determines the medical necessity to request approval for a family member to escort a patient (P. Sasaki, personal communication, May 9, 1996). Non-medical escort services are approved when there is seen to be a requirement for signing consent forms for treatment procedures due to incapacity. For example, a family member may serve as a non-medical escort if the patient she/he is accompanying is insulin dependent and requires assistance in administering insulin injections. Other costs to be considered include child care costs for the patients.

Cancer treatment separates the informants from their families, friends and community. This separation is marked by loneliness. Being away from home and having to go through cancer treatments reinforces the informants' separation from families and friends. Also, they miss the familiar ways of their communities.

Informants returning to their communities after receiving cancer treatments remain separated from other community members. Informants undergoing cancer treatment forego anonymity in their communities. Changes in physical appearance such as weight loss and hair loss do not go unnoticed in small communities. These physical differences serve to separate the informants from the rest of the community.

Also, the community's perception that the informants are going through a "process of dying" reinforces the informants' separation from the community. The lack of anonymity and perceptions that community members have of people diagnosed with cancer are added stressors for people living with cancer.

### The Stranger Apparent

With a cancer diagnosis, informants became strangers as their lives turned dramatically to face uncertainty. The lives they once knew no longer existed. Informants often contemplated their own deaths. Many First Nations People saw cancer as a death sentence. They voiced that the cancer treatments temporarily silenced their cancers. Many people were fearful however, that their cancers would grow at some time in the future. Informants believed that cancer could never be completely removed from the body. The informants' strangeness was reinforced by the silence in their own communities. Community members did not openly speak about cancer, and informants did not break this silence. They believed few people would understand what it was like to have cancer. In their home communities, cancer remained an unknown disease because no one spoke about it. This silence isolated the informants. They became strangers in their own communities.

### Seeing The Stranger As Death

With the diagnoses of cancer, the informants contemplated the possibility of their own deaths. They became aware of time limitations and how these would affect their futures with their children and grandchildren.

Cancer was often viewed as death. Informants spoke about people they knew



who had died from cancer. At the time of their diagnoses, three people had at least two relatives die from cancer. Six other informants spoke about people they knew who had died from cancer. Only three people spoke about knowing of a person who had survived cancer. Thus, thoughts about death surfaced for many informants diagnosed with cancer. With a cancer diagnosis, people were forced to face their own mortality. When they learned of their diagnoses, their lives changed in that their hopes and dreams for the future had to be changed.

Some of the people-as-strangers shared the thoughts they had when they first learned they had cancer. Upon learning she had leukemia, Suzanne's first thought was, "I was going to die." The connection between cancer and death was strong. "I thought that if you're gonna get it then you're gonna die because I saw them all die and they all had cancer." All of Suzanne's relatives who had cancer died. However, Joanne and Ebenezer stated their first thoughts were how cancer would affect their lives as parents and grandparents. Their first thoughts were the "kids" and "our children and grandchildren" when they learned they had cancer. They did not discuss their concerns.

Thoughts about death were inevitable for some informants. Matilda was diagnosed with cancer for the second time after being without symptoms of breast cancer for almost twenty years. She feared that her chances of surviving cancer a second time were next to nothing. "The first thing you know is what is going to do you in. . . . It's just a matter of time." Sylvia was familiar with the fear of dying from cancer. Her mother, brother and sister were diagnosed and treated for cancer. It

was difficult for Sylvia to avoid thoughts about death given the lump in her breast. "I think about it, but I try hard not to think about it." Samuel, an Elder with prostatic cancer explained that if his cancer was the kind that was fast growing he might have thought differently about his mortality. "They told me this is a kind of a slow growing [cancer]. . . . You might live a long time." Samuel avoided thoughts about his death as they interfered with his plans. "I try not to think it's going to kill me. I still want to dance Pow Wow."

Ruby, who was diagnosed with breast cancer, was surrounded by cancer, pain, and death. Her father, aunt and two sisters died from cancer. Thoughts about death surfaced for Roberta as she prepared for surgery. She placed herself in God's hands. "I just gave up. If it was God's will for me to live." Most of the informants did not elaborate on their thoughts about death.

#### Isabel Sees Cancer As Death

Isabel felt despair when she was told she had cancer in her womb. "I felt like I just wanted to end my life." Isabel was familiar with cancer. She became acquainted with it when she accompanied her favourite uncle during his cancer treatments. She went with him to a Winnipeg hospital for four or five chemotherapy treatments. The effects of chemotherapy were observed directly by Isabel. "He lost a lot of hair and he had a swollen face, a swollen leg and he couldn't manage to walk. I had to put him in a wheelchair." When her uncle's cancer was not successfully treated by the chemotherapy, she went with him for radiation treatments.

He went there four times and he couldn't take it anymore. He said he was just getting worse. Then he told me he knew he was going to die. I

kept saying, "Don't say that to me. I'm trying to help you." "I know you're trying to help me," he said. "What do I have," he said. I said, "You have cancer." [801.4.185-201]

In spite of his treatment, Isabel's uncle knew he was going to die from cancer. Her uncle's fate reminded Isabel that if you have cancer, you die. With the death of her uncle Isabel felt her loss. "I was kind of sad, like the world is empty. I was very scared. Like I couldn't stand living alone without him." Isabel saw cancer before. It is a devastating disease. Her father, brother, uncle and grandmother all died from cancer. She had come to expect that if you have cancer you will die.

Now Isabel was diagnosed with cancer. She saw death. Life as she knew it ended. Her plans to have another child were eaten by the cancer in her womb. She was forced to wonder about her own mortality and she was anxious about what her death could mean for her children. "I would have made the kids very fearful. They were scared of me to leave them. . . . I was thinking of my family first, and then, Am I gonna die?"

Isabel's doctor said her cancer "wasn't a very bad one," but she "had to have everything removed" as she had "only had a 50-50 chance" of surviving the cancer if she did not. Isabel prepared for a hysterectomy. "I was so afraid of leaving the kids behind, maybe staying in the hospital forever. . . . And I was kind of very worried all the time." A positive prognosis did not ease Isabel's deepest fears about being overcome with cancer and forced to remain her last days in the hospital. Other people in her community died in the hospital within a relatively short period of time after being diagnosed with cancer. Isabel's fears and anxieties culminated when she had her

cancer excised.

I couldn't remember anything for almost two days. They had a hard time waking me up. I held on the rail and I woke up like this [showing hands in grip position] . . . I seen my sister sitting there. I wasn't sure she was my sister, eh. "Am I dead?" I said to her. I guess I passed out again and six hours time I woke up. I was really sore. I couldn't move anything and I seen a bunch of people standing up, who come and seen me. . . . [The people were] from my dad's family. And so all my girls and my husband, I thought I was gone. And took my, our Chief was there too. He tried to wake me up. If I would have still been out for another couple of hours, I would have been dead. That's what the doctor told me. I felt like I was very, how do you say that, swollen up inside. And I couldn't breathe that much. And every time I moved my stitches would come out. I was scared when I got up and I started to move, what was going to go wrong. . . . Before I woke up too, like you see in heaven, eh. It looks so nice when you're there. When you get there, there's a person standing up there and He said, "It's not time for you to go, go back where you came from" [801.2.100-177].

Isabel clung to life as she awoke from the anesthesia. She could not move. She did not recognize her family and friends standing at her bedside. Were they mourners? Isabel believed the physician was saving her from death as he aroused her from the effects of the anesthesia. She struggled for breath. Isabel was in pain. Her womb replaced by a bloated feeling, Isabel feared her wound would open when she changed her position. She felt that close to death.

#### The Stranger As Always Present

Informants (n=7) who were treated for their cancers believed their cancers would grow again in the future. They lived in fear that the chemotherapy treatments and surgeries had not completely removed their cancers. They believed they would eventually be consumed by their cancers. Although the informants-as-strangers went to their physicians regularly for checkups, their fears were not eased. None of the

informants spoke about the early signs of resurfacing cancers. The informants would always be strangers because they believed that Manitoch [cancer worm] would always be a part of them.

### The Stranger Calls Again: A Case Study

Matilda was diagnosed with uterine cancer. Cancer was not "new" to Matilda as she had "come in contact with it before." Shortly after being diagnosed with breast cancer 17 years ago she "lost" one of her breasts when a cancerous lump was surgically removed from her body. She lived with the fear that "once you have it, it'll keep coming back. Not right away. But over the years it'll move to a different part of your body." With the discovery of a growth the size of an orange in her belly Matilda's fears were confirmed. "It hasn't really ever left me." In her heart she knew that "despite what the doctor says, it'll come back." The cancer in her breast was never completely destroyed. Even with chemotherapy treatments, cancer was not killed; it simply became quiet. This "quiet" cancer stirred and moved to different parts of Matilda's body. Cancer-as-worm found refuge in her womb and began to grow.

At first Matilda thought she was going through menopause.

For two years I was just spotting. It never stopped. I got so about after a year and a half I started really worrying. I thought at first I was going through menopause, early menopause because I started very late with my period. My mom told me that it happens to women when they start late. They're usually the first ones to have menopause. I didn't think anything of it at that time until it really got to me [504.2.44-56].

Matilda went to Winnipeg for a dilatation and curettage. The bleeding from her uterus stopped for about three days and then it started again. "They finally

decided to give me an ultrasound test when they could feel I had this [lump] here."

The ultrasound test revealed that Matilda had cancer. Again. The doctor asked to see Matilda.

So I went. That's when she told me they had seen the growth, that she wanted to operate immediately. And when she told me that, I don't know, I didn't really think anything of it at the time. I thought maybe that something that, you know. She did tell me though that it was, that the chances are, I don't know, about 80, 90 per cent. . . . So I went back to the house. Couldn't sleep that night. I just cried all night. I kept thinking why this. That was the last time I ever cried. The first and last time [504.2.78-94].

With the return of cancer to her body, Matilda's status as a stranger was reaffirmed.

Matilda was in "shock." She wondered why this was happening to her. "I wonder why God would allow this to happen to me of all things, you know. It's something I'll never really understand." Having had cancer before did not protect Matilda from re-experiencing the strangeness of cancer. Matilda felt in between "real and not real" --a state of liminality.

To me right now it's not real and then there are times when it's real to me. Like I'm still in between there. What with the doctors tell me that nothing is coming back because I asked them. How do they know if there is no checkups, just by feeling my tummy and then doing an internal exam. How do they know if it's there or not, you know. I tell them. And then they tell me, if you feel lumps or you'll feel like you're full around that middle area. That means it has come back. I don't know. I'm just telling you that. How do they really know? Because my doctor there, I had a lady doctor, who was telling me before I went in surgery. She says, if we had found it to have spread we'll remove everything. So I had the whole complete (pause). . . . She told me, I'm going to leave you laying maybe for half an hour, after they had taken the lump out for whatever and then they'll remove the whole thing. She says there's no sense in closing up and then removing the whole thing again, you know. I remember when I got up my daughter was there and I asked her if they removed everything. She says yeah. My body is gone, it's completely gone. They took almost

everything. There is a chance it may have spread [504.4.195-232].

Although Matilda was told that her cancer was completely removed, she felt the cancer might have spread. No matter what part of her body might be removed she believed there was still a chance the cancer could spread. Matilda expressed disbelief that she had cancer for the second time, but she knew that, "once you have cancer, you will always have it."

### Silence

Silence about cancer surrounds informants-as-strangers in a variety of ways.

"Not thinking about cancer" is a form of silence on a personal level, as is "not talking about cancer" within the context of family and the community. Silence serves to hide fears about cancer. Only three informants mentioned that cancer was talked about within their families. Most of the informants-as-strangers (n=9) stated that the people in their communities did not openly talk about cancer. From the informants' perspective, the communities of The Silent Eagle, The Nesting Eagle, The Raven and The Medicine Eagle were silent about cancer. Some of the informants (n=5) briefly spoke about their experiences given the various degrees of silence.

### Personal Silence

By not thinking about their cancers informants avoided the fears they had about living with this disease.

Sylvia's cancer. Sylvia had a mastectomy and had undergone chemotherapy. There is a legacy of cancer in her family. Her mother, sister and brother all have been diagnosed with cancer. She recently learned that her sister was diagnosed with

cancer for the second time. One way Sylvia managed her fears about her cancer returning and the possibility of death was by not thinking about cancer. "Pretend that it's not there. . . . Cause if you keep thinking it's there it will stay there." Thinking about cancer beckons its presence. The cancer will not return if you do not think about it.

Sylvia had an ultrasound test done after learning her sister developed cancer again. She was worried about her ultrasound results.

My nurse phoned me from the [hospital] yesterday and told me I had to go back. She told me I had to go see a specialist and I feel kind of, I don't know. I'm expecting something bad. I was just shaking yesterday when she told me I had to go back to see a specialist for that. I guess they checked my results but she didn't say why. She made an appointment for me right away. I try not think about it because I don't know how long it's going to take or if I'm going to die from it. I don't try and think about it, especially when I do something. I like to be around people all the time. You know, I don't want to be alone cause then that's when I start thinking about things like that. I have to keep myself busy. That's why I go to bingos [501.7.361-401].

By not thinking about her cancer, Sylvia avoids fears about her cancer resurfacing and death. To help her keep silent Sylvia kept busy among the people in her community.

### Family Silence

Some family members do not talk about the cancer that is present in their families. Silence contains a family's secrets and fears about having cancer among its members.

Ruby's cancer. Ruby does not usually talk about her cancer experiences with others. Keeping the "cancer silence" is a legacy in her family. Her father, aunt and two sisters died from cancer. "I know they had pain." Her father "took it and never



complained about the pain." Her sisters did the same. "Why should I be the fussy one?" Her father developed a cancerous lesion on his buttock and when the cancer moved "inside him he suffered a lot." He lived in pain for three years before he died.

Ruby does not "want to talk about it and bring out the pain." Having cancer is a physically and emotionally painful experience. "I keep more to myself when I'm in pain." One of Ruby's sisters preferred to stay more to herself when her eyes permanently shifted sideways as a result of a brain tumour. Alone, the sister felt no one should see her while she was in physical pain. Alone, no one could see the shame the sister felt about the changes cancer forced on her eyes. Cancer pain is an oppressive weight that is often carried alone and in silence.

Ruby's husband, Robert found it difficult to talk about his experiences with cancer. "Cancer is hard to explain. . . It is very difficult to talk about this." Even Ruby tried to hide the pain she felt before she was diagnosed with breast cancer. "You can't hide it when you have two boys." Robert felt helpless when it came to his wife's cancer. If he could, he would rather be the one with the cancer. "When she's in pain, I wished it was me and not her." He wondered whether all the cancer was removed from his wife.

Feeling helpless in the presence of cancer was not new to Robert. His mother, two brothers and two sisters have died from cancer. Robert's mother "really suffered from cancer." The physicians could not find his mother's cancer until they operated. "She was filled with cancer." Two weeks after they closed her surgical wound she died. "They opened her and killed her."

One of Robert's brothers survived cancer. Robert was hopeful the surgeons removed the entire cancerous lump on the side of his brother's face. "People with cancer suffer. . . . Some people don't want to admit to having [cancer]. It is something to be ashamed of." There is no cure for cancer. Is Robert fearful of getting cancer himself? He gets a medical check-up each year and "the doctor says there's nothing" [no cancer].

### Community Silence

Informants believe the people in their communities know they have cancer. They also believe the people in their communities do not openly talk about cancer. How does one speak with someone who has a devastating disease such as cancer? Faced with silence, the informants did not talk about their cancer experiences with people in their communities. They felt the people in their communities would not understand. In silence, there is isolation and distance.

Silence in the Community of The Nesting Eagles. Samuel and Suzanne spoke about the silence in their community of The Nesting Eagle. They both believed that people in their community did not talk about cancer because "They don't know anything about it." Both informants did not speak about the role the community health nurses and community health representatives had in caring for people diagnosed with cancer in their community.

Both Samuel and Suzanne keep silent about their cancers for various reasons. Samuel drives his vehicle and walks briskly as he makes his rounds to various community functions and meetings. He greets people with a warm handshake and

smile. He is often seen telling humorous stories to both visitors and people of his community. Samuel's prostatic cancer has spread to his pelvis.

Some days [the pain] gets worse and then my legs get numb on one side. And sometimes it gets so bad that my arm gets numb. I don't like to tell that I'm not feeling very good. I don't like to complain. I don't want people to think [I'm] sick I just like to try to ignore but sometimes I can't help it so I do a lot of rest and I notice that pain is, sharp pain comes out [703.4.187-197].

Samuel is a highly respected Elder who is very active in the affairs of his community. He does not want to be perceived by the people in his community as a complainer or invalid.

Suzanne told a friend she had cancer. However, her friend did not believe her. He thought she was "just kidding around." Her friend did not believe her until Suzanne's sister talked to him. Cancer is an unusual disease and having cancer set Suzanne apart from her fellow community members.

I found it hard to be around people again even though I really wanted to be around them I found it hard to go around [the community]. I felt everything was going to be different and so, I wouldn't go anywhere at all. . . . I thought people aren't going to treat me the same as they did before [I was diagnosed with cancer] and that they'd kind of stay away and everything. So I just stayed home and stayed away instead [708.15.767-783].

Suzanne lived the isolation she felt. She believed the reason people did not want to be near her was their fear she would get sick again and die. It is difficult to lose someone to cancer. She understood this. Rather than risk rejection by the people in her community, Suzanne isolated herself from her community.

Silence in the Community of The Silent Eagle. Ruby explained she did not want to "burden" the people in her community with her cancer. "People have their

own problems. Why would they want to find out about my pain? Why tell them you're sick? Why scare [them]?" Cancer is a fearful disease. Fears about cancer surface when they are discussed openly.

Silence in The Community of The Raven. The people in the Community of The Raven know who has cancer. Matilda believes that "when something's wrong with somebody here everybody knows." News of those who have cancer spreads in a community. "They still treat you the same as before they found out [you had cancer]. They'll say 'hi' and talk to you about whatever, the weather." But the people do not talk about cancer. Cancer, a stranger, is something to be feared.

Both Matilda and Kathy do not discuss their cancer experiences with the people in the community of The Raven. They believe their hopes and fears about living with cancer would not be understood. Kathy believes that when people in the community know you have cancer "they think that you're going to die, that [your cancer] is not going to be cured." Cancer means death in her community. Matilda would like to meet others with cancer. "I want to talk to somebody who is in my situation. . . . A woman with cancer."

#### Summary: The Stranger Apparent

A cancer diagnosis was viewed by informants in First Nations communities as a death sentence. Contributing to this perception was the history of cancer in the communities and within the family context. Informants identified family members (immediate and extended) or friends who had died of cancer. Many of these people died within a relatively short period after being diagnosed with cancer. Witnessing the

deaths of others served to reinforce cancer as deadly disease. Only three of the informants were aware of First Nations People who had survived cancer.

Many of the teachings and understandings of cancer are based on the worm or spider metaphor. Because these creatures can break into pieces, they are difficult to kill. A worm, for example, can be cut into pieces and each piece can survive. Cancer-as-worm has similar properties. Although the informants were reassured by their physicians that the cancer was completely removed from their bodies, they still feared the ability of Manitoch to survive in the body. Fear of cancer recurrence was experienced by all of the informants.

Cancer devastated the lives of all the informants including the elderly. Life as they once knew no longer existed. Some First Nations People may not directly express their sense of loss, uncertainty and fears. These fears and anxieties affected their understanding and retention of treatment and preoperative teachings they had received. An informant interpreted her abdominal incisional pain as dehiscence. Also, informants' traditional understanding of cancer affected the experience of diagnostic and treatment procedures. For example, an informant feared that surgery did not remove all the cancer worms.

Spiritual visions were important to many of the First Nations People in this study. Messages which offer guidance from the Creator are channelled through spiritual visions. These visions, which may or may not be Christian-based, offer the informant reassurance that death is not imminent. A vision offers the informant a sense of peace and understanding about the meaning of their cancers.

Extended members of First Nations families accompany relatives with cancer on their treatment journeys. As with the extended families, the Chiefs are important connections to the communities for the cancer patients who are forced to leave their homes to receive cancer treatments in urban centres.

Some informants spoke about the silence surrounding cancer which occurred at the personal, family and community levels. By not thinking about their cancers the informants avoided fears about their cancers recurring and thoughts of mortality. There was a sense that if informants are preoccupied about their cancers, the cancer will remain with them, both in reality and figuratively.

Families had a "code of silence" -- members did not talk about the cancer that was present among them. The secrets are many and include feelings of fear, vulnerability, helplessness, guilt, shame, pain and loss. If family members discussed their feelings, certain realities about having this disease in the family would surface. The silent family keeps the following secrets among its members: the possibility of the cancer spreading to other members in the family, the family legacy of cancer and the implications for future generations, the limitation family members feel when a relative has cancer.

Informants believed that community members are aware of people with cancer, however, cancer is not discussed in any of the communities. Informants perceived communities were reluctant to "talk about cancer" because its members have limited knowledge about cancer and the information they have about the disease instills fear of the disease. Community members understood cancer to mean pain and death.

Informants-as-strangers felt isolated from other members in their communities partly because they believed community members perceived them to be different. People with cancer were perceived to be dying and in pain. Informants believed they were expected to keep their pain to themselves and in doing so they experienced isolation. Some informants felt they had to protect their community from feeling the fear and pain of their cancer.

The informants-as-strangers kept the code of silence in their community for other reasons. They did not share their cancer experiences with others in the community because they believed they would be misunderstood, while others feared rejection.

#### Learning To Live With Cancer: A Stranger No More

Informants sought the help of western medicine to remove the cancer from their bodies. However, believing their cancers would recur, all informants sought out other sources of healing to help them live with the uncertainty of cancer.

#### Beyond Cure: The Need for Healing

All the informants-as-strangers sought other ways of healing besides the cancer treatment modalities offered by the cancer clinics. Appreciating the limits of western medicine to cure their cancers and believing that once you have cancer you will always have cancer, informants sought the healing of traditional Indian medicine and Christian prayer.

The unknown, of going within, of dreams, of prayer and of meditation is in the direction of the west (Bopp et al, 1989, p. 53). By journeying to the centre of

one's being, it is possible for a person to experience the connection between the human spirit and the rest of the universe, and between the human spirit and the Creator. This experience is the gift of prayer. All people are spiritual beings. All informants identified a part of their cancer experience as being spiritual.

Five informants sought help from traditional Indian medicine men. Two of these informants also referred to their Christian beliefs. Four people sought help from the Christian church. These four informants did not believe in traditional Indian medicine.

#### Indian Medicine

Five informants briefly spoke about their experiences with traditional healers and Indian medicine. The sixth informant was a traditional Elder, however, he did not speak about his own healing experiences with traditional medicine. None of the informants spoke about their beliefs surrounding Indian medicine. All the informants who had consulted an Indian healer before, during, or after being diagnosed with cancer had either done so previous to having cancer or were from families who sought the counsel of traditional medicine people.

Two informants spoke about their use of traditional Indian medicine and expressed their Christian beliefs. Four informants used Indian medicine while receiving chemotherapy or radiation treatments. They each were given medicine tea to drink daily. They did not talk about participating in healing ceremonies. One informant sought the healing of Indian medicine before and after her surgery.

Ebenezer's healing. Seeking the advice of traditional healers has always been a



part of Ebenezer's life. When he learned he had lung cancer he continued to practice his beliefs. During his ordeal with cancer he had the support of his children and friends "to keep on with the Indian medicine."

After receiving his diagnosis, Ebenezer saw an Indian medicine man who advised him not to see a physician. The medicine man explained, "It's just going to make you worse." Ebenezer had intended to follow this healer's advice. Instead, after much thought and in consultation with his wife, he followed his daughter's wishes. "I guess she read it in a book. It said to go for radiation treatment." Ebenezer eventually sought the help of another Indian medicine man.

Ebenezer spoke about the healing effects medical physicians and traditional Indian healers have on cancer. The physicians "just slow the cancer down to keep people alive longer." They do not "cure cancer" and "in a few years time it'll come back." Traditional healers "cure cancer," but "it's hard to say where the cancer medicine is available." I asked Ebenezer whether the Indian medicine he was taking killed the cancer worm. He told me, "It's hard to tell. . . . Once they spread you can't do nothing about it." Ebenezer did not speak further about the healing powers of the traditional medicine he was taking.

Suzanne's healing. Suzanne was diagnosed with leukemia. Before going into remission she developed septicemia. In a critical state, Suzanne was admitted to an intensive care unit. Unconscious and unable to breathe on her own, she was placed on life support. Her kidneys failed and she required dialysis. Suzanne's mother heard the physician say her daughter had a 15 to 20 per cent chance of surviving this crisis.

Suzanne's family remained vigilant outside the intensive care unit. They prayed for her recovery. Sensing the need for further help, Suzanne's grandmother took Suzanne's jacket and moccasins and consulted a medicine man. Her grandmother returned to the intensive care unit with "good news." The healing ceremonies for Suzanne's recovery were done outside the hospital. Also, Suzanne was given Indian medicine to drink. Since she was incapable of drinking "they put it [Indian medicine] on my lips." The physicians and nurses supported this daily ritual. Two days later, the "good news" was being realized, Suzanne started to respond. She came off the respirator and no longer required dialysis. Her mother heard her physician say "something really amazing" has happened to Suzanne. Suzanne's cancer was going into remission.

Suzanne has been in remission for one year. Besides keeping her monthly check-ups with her physician Suzanne takes her Indian medicine every day. Her mother notes that Suzanne "picked up really fast" once she started to take the medicine.

Roberta's healing. After Roberta was diagnosed with bowel cancer she sought the advice of a medicine man.

You just have to depend on the doctor. He says, "It's too late for us. If we knew before that, if you'd come to us earlier we could have did something for you." He says, "We can look after you, after you go to the doctor" [804.15.801-808].

The medicine man advised Roberta to let the surgeon remove the worms from her body.

Upon awakening from the anesthesia Roberta had a vision of the Virgin Mary.

She believed this visitation marked her recovery from cancer. However, Roberta understood how difficult it was to remove cancer worms in their entirety. She feared Manitoch lay silent in her bowels. Two weeks after she was discharged from the hospital Roberta visited the medicine man again.

The medicine man gave her medicine tea to drink. "You'll heal quick. You'll get better soon." Roberta felt reassured. "If there's any left, any worms left in your body, he said, that'll kill them." Roberta drank the preserve jar filled with Indian herbal medicine as she was directed. "I got better." Also Roberta kept her follow-up appointments with the physician. She took the pills prescribed by her physician. "Everything is O.K." She was reassured. All the cancer worms are dead. Roberta hopes the cancer will not return elsewhere in her body.

#### Christianity: Having Faith

Six informants spoke about how their Christian beliefs offered them comfort once they were diagnosed with cancer. Four of these informants did not seek the counsel of traditional Indian healers. Matilda explained that the traditional people do not believe in Jesus and she does. Traditional Indian medicine and Christianity do not "mix" for some. For others like Roberta, both the traditional and Christian ways provided reassurance and comfort when faced with cancer.

Test of faith. Matilda had a hysterectomy to remove the cancer in her womb. She wondered why she developed cancer for the second time. "Sometimes I think it is just a trial I'm going through and that I'm going to come out of it. Other times I think it [cancer] is not here." Matilda is comforted by her belief that God would not let her

go through anything she could not bear. What would the most difficult burden she would be asked to bear? A painful death. Matilda witnessed her fear in the death of a childhood friend. Shortly after her friend was diagnosed with cancer, she was admitted to the hospital. Her friend did not receive any treatment for her cancer.

She must have had pain. I don't know. I asked the nurse if she is in pain. Oh, we're giving her as much morphine as we can. But she was, you know, it wasn't like herself at all. I tried to talk to her. I called her name. . . . It was a shock to see somebody like that. And then I was standing there and I said, am I going to go through this pain too. . . . I don't have no idea what expect of a person who dies of cancer. Is there going to be. . . I don't know. It seems to me she was moving around a lot and getting her nightgown off like that and just stretching it out and flinging her arms back and forth. Almost violent. And screaming. She would hold herself here and just yell [504.11.560-591].

The people Matilda knew died painful deaths. Matilda would like to die with peace.

She spoke about an elderly woman who died peacefully.

They told me she had a hole already. . . . you can actually see her heart pumping, you know. She acts just as if nothing was wrong with her. She would sit on a couch like this and then she would get up and lay like this. And not once did you ever hear moaning pain or anything. And she died peacefully. I wonder about God in his word. He says that he is not going to let us go through anything that we cannot bear, that we cannot handle. . . And then I wonder about myself. I have always been a very, what do I say, I'm not a strong person. . . . I mean in myself you know. I have always been too soft I'll say, very soft. . . . But lately it seems to me I have been getting more and more. . . . Even Jesus doesn't heal everything [504.13.647-690].

Matilda wonders whether she has the strength to deal with this devastating disease.

Cancer eats away at the core of a person's being. She wonders whether she will find peace.

I go to Church a lot. . . . I would go to the alter and I would kneel there and talk to Jesus. . . . It's up to Him, between Him and me. I am

satisfied with how long I have lived because I have seen so many go . . .  
[504.13.711-726].

God does not always cure cancer and Matilda hopes she can bear the burden of having cancer. She finds comfort in His hands.

Physician as healer. A physician, recognising Ruby's powerful belief in spiritual guidance, offered his understanding that the surgery he was about to perform would be guided by God.

Ruby sensed she had cancer in her breast. As she was being prepared for her biopsy Ruby refused to sign the consent form for the surgery. She wanted to see her doctor first. When he arrived at her bedside Ruby told him, "In the O.R. you will be guided. Don't be scared what you find because it was meant to be." Her physician responded by quoting from the Bible, Isaiah 40. He held her hands and then said, "Thank you. I will never forget this."

The gift. Ruby then spoke about a dream she had when she believed she was dying. "Mom and dad came to me when I was so very sick." She saw them from the waist up. Her mom and dad were holding hands. Ruby saw that she was in a place very close to where her parents were. She felt happy. And she wanted to stay with her parents. But a voice told her she could not. Ruby asked, "What is there, what work is there that I have to do?" It was not her time to die. Ruby had work to do. She was given a gift. Her gift was to help people.

People often go to Ruby for guidance. If she feels a heaviness when people approach her, she senses that they need guidance. Ruby then tries to find out what it is they need. When she feels the heaviness leave Ruby interprets this to mean she was

able to help.

Ruby has helped her family over the years. Her father, two sisters and aunt have died from cancer. Ruby spoke about a visit she made to her dying sister's bed. She asked her sister, "What troubles you?" Her sister responded, "You know I'm going to die." Ruby then asked, "Wouldn't you like to tell me something?" Her sister talked about the child she gave away. Ruby reassured her sister. It was not her fault the baby was not accepted into the family.

Ruby reminded her dying sister she had other children and a husband to care for. Her sister said, "I know I won't be here long." Ruby offered the following gift to her sister. "When you go you will be more closer to your children. When you go your children will be lonely. Your daughters will feel alone. Then I will remind them of their mother. I will remind them that their mother will give them help."

#### Summary: Learning To Live With Cancer

Recognizing that their cancers may recur, informants sought various ways to manage their lives. The healing offered by traditional Indian medicine and Christian beliefs goes beyond the physical realm of Western medicine to include spiritual healing. Through prayer, Indian medicine and Christianity offer physical, emotional and spiritual healing. Informants who used Indian medicine sought Indian medicine to "cure" their cancers. None of these informants discussed how this healing would take place. Believing their cancers would recur some informants sought help from the Creator in easing their fears, pain and uncertainties in living with cancer.

Informants, through dreams and visions, received gifts and healing messages

from the Creator. The gifts guided informants to help other people dealing with the challenges in their lives such as losing a loved one through death. Other informants were comforted by messages received through dreams that their deaths were not imminent.

For some First Nations People Christianity and Indian medicine do not "mix". However, for others both Indian medicine and Christian beliefs have a place in their lives. The First Nations People interviewed consulted one or more medicine healers before, during or after obtaining medical cancer treatment. Various traditional healers are consulted depending upon the informants' needs. They may not tell their physicians about seeking the counsel of a traditional Indian medicine person.

Indian healers advised their patients in relation to western medicine. Some Indian medicine healers will avail themselves for healing informants only if medical treatment is not sought. Other Indian medicine people advised their patients to see a physician first for cancer treatment before returning to them for further consultation. And still others will practice Indian medicine while patients are receiving medical treatments.

Traditional healing ceremonies for First Nations in-patients may occur outside the hospital setting. And the patient may be required to drink herbal medicines as part of the healing process.

## CHAPTER 6

### THE COMMUNITY EXPERIENCE

This is the third of three chapters which describes the findings of this study. Before presenting the experience of cancer from the First Nations community's perspective I will provide an overview of the informants. The presentation of the findings begins with the theme "Silence Surrounds The Stranger" in which silence about cancer is described from the community members' perspectives concerning their own silence and the silence they see from the health care provider. The second theme is "Making The Stranger Known: The Healing Journey." In this theme, the informants identified traditional Indian medicine as one way to manage cancer in their communities. I will conclude by briefly summarizing the chapter.

1. An Overview of The Informants
2. Silence Surrounds The Stranger
  - A. Community Silence
  - B. The Silence of Health Care Providers
    - a. Community of the Raven
    - b. Community of The Silent Eagle
    - c. Community of the Nesting Eagle
  - C. Summary: Silence Surrounds The Stranger
3. Making The Stranger Known: The Healing Journey
  - A. Traditional Indian Medicine: Finding The Spiritual Pathway
    - a. Spirituality
      - i. Community of The Raven
      - ii. Community of The Silent Eagle
      - iii. Community of The Nesting Eagle
      - iv. Community of The Medicine Eagle
    - b. Traditional Healer Program
  - B. Summary: Making The Stranger Known

#### Figure 8. Community Experience Topics

##### An Overview of The Informants

Twenty-three people in four communities spoke about their understanding about cancer. Of the informants, nine were Elders; five were community health



representatives; three were councillors; one was an administrator and one was a Chief. Fourteen of the informants were women. Seven of the Elders and all of the community health representatives (n=5) were women. One councillor and a community member were also women. Three community members, two councillors, one Chief, one administrator, and two Elders were men. The Elders were sixty years of age and older. Of the remaining informants, three were in their fifties, six were in their forties, three were in their thirties and one was in her twenties.

Each of the communities were represented by various leaders and health care providers. The number of informants from each community varied. Eight informants were from the Community of The Raven and of these, five were Elders, two were community health representatives, and one was a councillor. Nine informants were from the Community of The Silent Eagle. Of these, four were community members, three were Elders, one was a Chief and one was a community health representative. Four informants were from the Community of The Nesting Eagle. Of these, two were councillors, one was an administrator and one was a community health representative. Two informants, a community health representative and an Elder were from the Community of The Medicine Eagle.

#### Silence Surrounds The Stranger

Cancer is generally not talked about in First Nations communities. The silence is generated from two sources, the community and the health professionals. More than half of the informants (n=13) spoke about the varying degrees of silence surrounding cancer in their communities. Ten stated that "Cancer is not talked about in their

community." In one community cancer was not talked about by some members and in another, cancer was not discussed by members unless they were directly affected by the disease. Another form of silence is the absence of cancer education concerning early detection and prevention of cancer, and the development of community based support groups for cancer patients and their families.

### Community Silence

Modesty and fear were two reasons given to explain the reluctance many First Nations People have in discussing cancer in their communities. For some, cancer is not discussed out of consideration and respect of the Elders' teachings and preservation of their cultures. When talking about cancer, references to various parts of the human body are made. Publicly discussing the human sexual organs and functions is considered "inappropriate" among many First Nations Elders.

When we talk about AIDS [Acquired Immunodeficiency Syndrome] here, some of the older folk don't want to talk about those kinds of things. They were brought up to well, don't talk about things in public. . . . You don't even tell your children. . . . You don't talk about women's affairs that kind of thing. In our culture that was foremost. You don't talk [704.3.137-159].

Modesty is considered an important value in many First Nations communities and the Elders' teachings of Anishinabe ways are revered. Without sanctions from the Elders for open, respectful education about the human body, some informants believe cancer will not be talked about and its prevention and early detection will continue to allude First Nations People.

One informant from each community spoke about the discomfort women feel about participating in early cervical cancer detection programs. In a community health

clinic, pap smears are done and breast self examination are taught annually by predominantly male physicians. A community health representative shared her observations about the cervical detection program in her community. Most of the women in her community who are 40 years and younger know the purpose of having a pap smear done.

The only time they had pap smears done was when they were pregnant or if they had to go for a physical check-up. But they will not go on their own to have it done every year. You almost have to, you know, have it pushed and say, have your physical examination, you know. But we won't say get your pap smear done because they'll refuse to go to the physical examination if we happen to say the word "pap smear". . . . because of their private area that has to be looked at. . . . I think they're uncomfortable to have it done. I think that's the only reason. In our culture it's not appropriate to go and have this thing done every year. . . . It was good one year here we had a female doctor. But in our area its mostly male [doctors] so we don't have a choice. . . . We had a really good turnout with a female [doctor] [809.7.368-430].

Many First Nations women will avoid the embarrassment of having their breasts touched and an internal examination done by a male physician. To preserve their modesty, they will not keep their appointments and will delay seeking help when physical changes have occurred.

With no hope of a cure, community informants fear cancer and understand its disease pathway as one that is progressive and devastating. All informants except one stated they knew a relative or a member of their community who had died from cancer. Most informants (n=17) had witnessed at least one relative die from cancer. And of these, nine had witnessed a husband, wife, sister or brother die from cancer. Eighteen informants believed that being diagnosed with cancer was an inevitable death. "It is a life sentence. There's no cure. Every person that I've known with

cancer has died from it." Also thirteen informants spoke about cancer as a pain-filled disease. Two informants recalled the pain of their dying relatives.

I can see [my mother's] pain and a lot of times I could feel it. I guess because I've seen it so often now with the five [aunts, uncle and cousin who have died from cancer]. . . . But you see them in pain yet they are trying to live normally, like most of them used to like joking and have quite a sense of humour. They keep that up right to the end. Closer to the end, you know, its a bit harder to visit them because you would see the pain behind the jokes and the smiles. I think it's a bit painful to see them trying to keep their spirits despite their pain [601.4.194-213].

It is a pity to see [someone with cancer.] Especially at the end. I guess if they didn't give [my sister] morphine, you know, she would have been suffering. She'd have been yelling, I don't know. A lot of pain. It is very, very painful [509.9.473-477].

First Nations People who have witnessed friends and relatives with cancer have come to know the course of the disease as one filled with pain leading to death. Only one informant, a councillor, did not mention whether he had witnessed anyone experience cancer. He described what it meant to him when people get cancer. "Panic. People who have cancer are definitely going to die." Some of the difficulties that people with cancer face are "knowing that he or she is going to die. Once they find out they have cancer they will die. . . . If I had cancer, I would die drunk, drink myself to death or hope for the best, that treatment will come in time." A community health representative explained that community members do not inquire about cancer as it is considered a "scary subject". However, they ask her about "sexual transmitted diseases, diabetes and hypertension."

Over half of the informants (n=13) spoke about people they knew with cancer who "waited too long" before getting help. "By the time people go to get help the

cancer is too far gone." Knowing the legacy of cancer at the end stages of the disease trajectory, informants were immobilized by fear and were reluctant to seek help when body changes were suspected as being cancerous.

#### The Silence of Health Care Providers

Of the nine people (non-elders) who spoke about the prevention of cancer, three identified cancer prevention education as being required in their communities. Two informants, a community health representative and a community member, believed cancer could not be prevented from occurring. One informant, a health care representative in the Community of The Silent Eagle taught the risks of cigarette smoking at a community health fair. Two informants referred to the type of food consumed as being important to cancer prevention. "I was reading certain vegetables are protectors or fighting against [cancer] but then again I wonder about these store bought vegetables and . . . pesticides." "Start to eat and maybe grow their own . . . fruit and vegetables, instead of going out hunting. . . . Breed your own deer." One informant who had "done a lot of reading on cancer" spoke about lifestyle decreasing the risk of cancer (ie: no alcohol or tobacco consumption; eating a balanced diet; and, keeping physically fit).

Over half of the informants (n=13) suggested that people in their communities should seek help when they first discover physical changes. However, only three informants, a health clinic administrator and two community health representatives, spoke about early cancer detection strategies in their communities. Two briefly discussed the papanicolaou smear testing and three mentioned breast self examination

as being done in their communities.

Four community informants stated support groups and counselling were needed for people with cancer and their families. When sixteen informants were asked how the nurse helps people with cancer, they perceived the nurse's role in providing direct care for the cancer patient in their communities. The responses were similar within communities; they varied somewhat between communities.

#### Community of The Raven

Five informants shared their perceptions of the nurses' role in providing care to people with cancer in their community. The nurses both live and work in the nursing station located in the community. With cancer understood as resulting in inevitable death, informants in this community largely viewed the nurses as being powerless in helping people with cancer. The nurse's role is to "refer" people suspected of having cancer and cancer patients to larger urban centres for diagnostic testing and chemotherapy. They perceived the nurses as "not helpful", "cannot detect cancer", "cannot do much. . . refer [patients] to doctors". A community health representative stated the nurses provided family counselling, "How they are accepting it and what difficulties they have. . . I think there is nothing the [nurses] can do. That's how I see it. Counselling because there is no cure." The hopelessness of cancer is beyond the role of nurses in their nursing station. Cancer is managed outside the Community of The Raven.

#### Community of The Silent Eagle

Six informants spoke about their understanding of the role of the community

health nurse. Two nurses work in the community health centre located on the reserve. Three stated they "don't know" what the community health nurse does for people with cancer. One Elder stated "I never heard them to talk about cancer." The community health nurse helped look after his spouse before she died "once in a while." Another believed the community health nurse to "give needles to kill the pain".

#### Community of The Nesting Eagle

Four informants in this community viewed the community health nurse as providing "counselling" to the people diagnosed with cancer and their families at various stages of the cancer disease trajectory. The nurse "assists the people get their life back in order;" "counsel families stricken with cancer;" and, "administer medication and provide counselling".

#### Summary: Silence Surrounds The Stranger

Community informants identified that health care providers do not talk about cancer in their communities. They also observed that within their communities there is silence concerning cancer. Informants believed that community members' silence about cancer affected their participation in health care prevention education and early detection programs.

First Nations People are reluctant to talk about cancer for a variety of reasons. Modesty is an important value which is fostered by Elders and their traditional teachings. Since concern about breast and cervical cancer is prevalent in First Nations communities, public discussions about cancer prevention and early detection is considered inappropriate according to traditional teachings. First Nations People

consider discussing human sexual functions disrespectful. Women feel embarrassed and uncomfortable about having pap smears, cervical and breast examinations. The data suggest that women feel uncomfortable about being examined by male physicians and nurses. The data were not clear whether certain age groups were more affected by this than other age groups. To avoid embarrassment, women do not keep appointments and delay seeking help when physical changes occur in their bodies.

It is a common belief among First Nations People that they "wait too long" before seeking help when they notice body changes or suspect they have cancer. Since cancer is often considered a death sentence and community members' images of cancer are the end-stage of this disease, First Nations People can be immobilized by fear. Community members' views about the role of the community health and nursing station nurse vary. None saw the community health nurse as teaching about the prevention and early detection of cancer. Indeed the informants in one community believed that the hopelessness of cancer was beyond the role of the nurse. Some informants suggested that referring patients for evaluation and diagnosis to resources outside the community and counselling patients and their families fall short of the informants' expectations for managing cancer in their communities. Knowledge about cancer prevention, early detection are required.

#### Making The Stranger Known: The Healing Journey

Community members identified traditional Indian medicine as a way to help patients and their families manage their cancers.



### Traditional Indian Medicine: Finding the Spiritual Pathway

Twelve informants spoke about the use of traditional Indian medicine in their communities. These informants also believed in traditional healing medicine themselves. They were primarily from the Communities of The Raven, The Nesting Eagle and The Medicine Eagle. Only one informant from the Community of The Silent Eagle spoke about how traditional medicine helps people with cancer. Embarking on a healing journey using Indian medicine is also setting out on a spiritual journey.

#### Spirituality

The beginning of a healing journey using Indian medicine begins with an offering of tobacco to the healer or Elder. To seek "healing" from an Elder or an Indian Medicine person, the patient with cancer places a pouch of tobacco at the elbow of the person from whom he or she seeks help. After the patient states the request, the Elder and traditional healer will pick up the tobacco pouch to signify that they will help the patient. The offering of a pouch of tobacco symbolizes "respect" in "traditional health" and is used by the healers in the healing ceremonies.

[A gift of] tobacco is the way we approach the Elders and the traditional healers. These people are gifted. They were given by the Creator to have the gift [of healing]. And that gift is theirs only as long as they use it to help others. And the way we ask for help is [by offering] tobacco to a healer. And, to me, some of the more genuine healers, that's all they'll ever ask for is tobacco so they can use it in the ceremonies [704.8.419-433].

The gift of healing is spiritually strong. The gift of tobacco that the healer has accepted from the patient is then, in turn, offered to the Creator.

I haven't actually witnessed any treatments but I have heard of people that do go on treatment. It's medicine that they take and it's also spirituality, like their beliefs. You have to believe in order for it to happen. And I know they do drink the medicine and it's also, it's almost like a treatment because they have return appointments. And I don't really have much knowledge as to the way the treatment is done but I know that they have return appointments [809.21.1111-1124].

You have to believe in the Creator if you are to get better. And praying hard is very, very important. Believing in the Creator and praying are very important [506.5.265-272].

The essence of curing cancer is a strong belief in the Creator and prayer. The primary expectation of the traditional Indian healer is to cure cancer. One informant related her experience with a traditional healer the day of the interview.

Healers of cancers are very rare now. And if there is a medicine that heals [cancer] it's kept close to that healer. And yesterday I went to attend a healer right in my own community. . . . I just simply could not believe the difference. Even if he healed my stress. If it was stress related. The pain was real. The pain in my chest was real [705.7.383-394].

People have faith in the curing powers of the traditional healers. Since traditional healers do not advertise their skills, the Indian medicine which can heal people with cancer is often difficult to locate. Besides curing cancer, Indian medicine can help people with cancer in other ways.

Two informants, a woman from the Community of The Medicine Eagle and the other, a man from the Community of The Silent Eagle, explained that traditional medicine help people with cancer by giving them "hope".

Like sometimes they're really sick, eh. They go and see [the Indian medicine people] just the same. Maybe they'll live a little while longer and they have hope. But sometimes the medicine man will just tell you that he can't help you, eh and you have to just live with [your cancer] [810.17.893-901].

Elders give people hope and there's also a calmness, sort of serenity one gets in talking to the Anishinabe Elder. I think they help smooth the worry and the pain. I think, the Elders, that's how they live their lives. I remember visiting another friend of mine that died, she was diagnosed with cancer. And I went to visit her and I had to leave the hospital because I'd seen all her actions and just the way she was talking and the way she looked. I saw that before in my uncle, almost the exact same movements and I knew she was going to die. Yeah. I think she took great solace in listening to an Elder. That's why I believe that. And you have my uncle and aunt [who also died from cancer] believed in traditional healing. They were given hope, they were given strength [602.9.449-474].

People who are dying from cancer and believe in traditional Indian healing ways find comfort, a sense of peace and hope in seeking counsel with the traditional healers.

The use of traditional healing medicine people and Elders from each of the communities' perspective was also examined.

The Community of The Raven. The informants who shared their ideas about the use of traditional healing medicine in this community were five Elders and one community health representative (CHR). Having faith in traditional healing methods, two informants have accessed healers outside their community. One informant believed that she might have cancer herself. Although a physician had told her that she did not have cancer, she remained concerned and consulted a medicine man. Having "faith" in traditional Indian medicine is a comfort to her. Another informant was fearful of developing cancer. He found that by participating in the sweat lodge ceremony to cleanse his total being and taking Indian medicine tea that has prevented cancer from taking over his body.

The Elders in The Community of The Raven Speak. Each of the Elders thought that the people in their community were not getting their cancers diagnosed in

the earliest stages. Consequently, with cancers being diagnosed in the later stages in the disease trajectory there was less chance of recovery. The role of the Elders and traditional healers in relation to helping people with cancer varied. While one Elder was not certain how Elders could help people with cancer in the community, another felt he did not have the necessary knowledge and skills to help a person with cancer. He was the youngest of the Elders, by at least twenty years. Whenever he has been asked to help a person that he felt required skills and knowledge beyond his abilities, he has referred that person to another healer in another community either in Manitoba or Saskatchewan. Not every healer has the skills and knowledge to treat people with cancer. The remaining three Elders who have always lived in this community and were the oldest of the Elders had a different perspective about traditional healing practices in their community.

An Elder best presented the view held by the oldest Elders interviewed in this community. When people get cancer "there is no hope" for them. The people with cancer are diagnosed when the disease is in its advanced stages. Long ago the people in her community were able to get help. "The people knew the medicines" to cure manitosis (cancer). Since these medicines no longer exist, the only option for people with cancer is to see a physician. The Indian medicine is not what it used to be. Elders "can help people with cancer but it is up to the person to ask for help." It is important that the person who is seeking help believes in the traditional ways of healing that the Elder espouses.

An Elder who refers some people to other healers outside the community

talked about the expense of accessing healers. Sometimes it is necessary to consult a traditional healer outside the community and although accommodation and travel expenses are re-imbursed through the Traditional Healer Program, Medical Services Branch, Health Canada, financial resources are required at the outset to pay for the costs. Whether a person consults a traditional healer will depend upon their financial resources. The costs include flights in and out of the community for patient and escort (return appointments to the healer may be necessary). Gifts for the healer are also a financial consideration. There was no mention whether traditional healers were brought into the community under the Traditional Healer Program. The need for financial resources at the outset is thought to alter the use of traditional healers in this community.

The Community of The Silent Eagle. Eight informants responded to the use of Elders in their communities in a variety of ways. They were either silent; stated they did not know about Indian medicine; or, did not believe in Indian medicine to cure people with cancer. Some of the informants knew people with cancer who sought the counsel of Indian medicine people. One informant stated members of her family who were diagnosed with cancer went to Sun Dance ceremonies. Another informant stated his uncle decided to pursue the Indian medicine way rather than the Western medicine for treatment of his cancer. A third informant stated his wife used Indian medicine during previous illnesses, but she did not when she became ill with cancer. Another informant stated:

I don't know if there are any healers in the community. I believe in a spiritual power, God's healing power. The mind is powerful and it's

powerful enough to heal the body if the mind is positive. If you have a healthy spiritual mind your body will follow. If you don't believe your mind will get sick and your body will follow. God is healing. I don't know too much about native spirituality. It has its place in dealing with common illnesses but I have never seen an Indian medicine man heal a person with cancer. I don't believe in the traditional healing practices, traditional medicine. My belief is the Lord and peace of mind. It's a spiritual thing [604.7.318-340].

Not all First Nations People seek the solace in traditional Indian medicine.

The Community of The Nesting Eagle. The councillors and administrator of The Nesting Eagle Community spoke about the frequent use of Indian medicine in their community. Some of the patients will consult the Indian medicine man in the community while others will visit healers in different communities. Aware of the costs involved in travelling to another community or bringing a traditional healer to the community, the Community Health Centre administration provide funding until the patients are re-imbursed for their expenses.

A traditional healer can be brought into the community or people can travel outside the community to see a healer. After a patient arranges an appointment with the healer of his or her choice, the health personnel in their community are made aware of the request. Approval is sought from Medical Services Branch for the proposed travel expenses such as gas mileage, and the number of days ie: meals and accommodation the patient will require to spend with the healer. Meals and accommodation costs for an escort can also be included. The patient and escort must keep their expense receipts for reimbursement. And the healer must also sign a form.

The Community of The Medicine Eagle. A community health representative (CHR) and an Elder spoke about the use of traditional Indian medicine in their

community. The CHR knew about the use of traditional Indian medicine through her work. The Elder has received advice for her own treatment needs from her colleagues who use traditional healing ways in the community.

The community health representative observed "there are a lot of people that go to traditional healers. . . . For the ones that don't believe in the traditional beliefs, they turn to the Catholic way of spirituality." A Catholic Church is on the reserve and is actively attended by the people of Medicine Eagle. People with cancer consult the healer in the community or access healers in Manitoba, Saskatchewan, Alberta or the United States. Some First Nations People who are of the Christian faith do not consult traditional healers.

The community health representative who was originally from another community observed the use of traditional Indian medicine in relation to Western medicine.

Some [people] use both at the same time, the western and the traditional. But I know a lot of [people] who, if they're using the traditional medicine will not take any western medicine while they're finished taking the traditional medicine. . . . And not until they're finished their traditional medicines, you know, finished with their check-ups [with the traditional healer] will they take any western medicine. And some won't [start the western medicine at all] [809.22.1150-1176].

In the community of The Medicine Eagle, some people's beliefs in the traditional healing ways are so strong that they will access "western medicine" only after they have completed their visits with the traditional healer or not use "western medicine" at all.

### Summary: Making The Stranger Known

Traditional Indian medicine is holistic healing. The physical effects of cancer cannot be treated in isolation of the whole person as a thinking, emotional and spiritual being. Strengthening a person's spirituality is believed to be the essence to healing cancer. Those who believe in the healing powers of Indian medicine speak about the Creator as being at the core of these healing ways. Prayer is essential.

The Creator has presented gifts of healing to those known as medicine men and women. Elders are also thought to possess gifts for healing. There is not enough data to distinguish the roles between the medicine people and the Elders. People who seek the counsel of an Indian medicine person or Elder demonstrate their respect for these healing gifts by offering tobacco to the traditional healer. The healer then makes an offering of the tobacco for the purpose of healing.

People with cancer or their families seek the counsel of traditional Indian healers and Elders at various stages in the disease trajectory. Traditional Indian healing affirms one's spirituality and provides comfort, hope and a sense of peace to enhance quality of living. It is also suggested that traditional healing ways can help prepare those dying from cancer and their families for the cancer patients' movement into the next world (death).

Indian medicine is used in all of the communities I visited. There is at least one medicine man and a number of Elders in each community. The experience and skills of each traditional healer varies. It is suggested that healers who do not have the skills to help people with cancer will state that they cannot help or will either refer to



another healer or to a physician.

Those who have faith in Indian medicine believe it can be used to cure cancer, however, this medicine is difficult to locate. It is suggested that locating reputable healers can be accomplished by accessing networks of people who are in close proximity to the Indian medicine healers. Word of mouth is the best way of locating a traditional healer that meets one's needs. Traditional healers may be located in one's own community, in an adjacent community, in another province, or in the United States.

The selection of a healer is dependent upon the needs of the patient. People with cancer seek the counsel of traditional healers before or at the same time as seeing a physician. Some people who are seeing a traditional Indian healer and taking Indian herbal medicine do not consult a physician until the medicine has been completed. Some people do not consult a physician at all. How this selection is done in relation to the stage of cancer was not part of this study. How people decide whether to consult a physician for their cancer was not a part of this study.

It is suggested that some communities' health care providers embrace the services of traditional healers more than others. Recognising the community members' faith in traditional healers, the health care providers support and advocate on behalf of those with cancer and their families who seek traditional healing ways. An example of advocacy is the provision of temporary funds so people can visit a traditional healer located outside the community or bring a traditional healer into the community for consultation. It is suggested that communities are at varying stages in recognising the

services that traditional healers and Elders have in helping people with cancer.

A small group of Elders who possess experience and knowledge about traditional ways of healing suggest that they have a place in their community to help people with cancer. This group consists of the oldest Elders interviewed in a community accessible by airplane. The shift from the traditional ways of healing to the Western ways of curing has undermined their roles as Elders and healers in the community. Elders at one time were consulted by those who needed help with their illnesses including the curing of Manitoch. Knowledge about traditional medicines for curing Manitoch no longer exists. Many people in this community no longer have faith in traditional Indian medicine. They do not use it to the extent they once did in the past. With the loss of knowledge for curing cancer and the loss of faith in traditional healing ways, the potency of the traditional healing ways of Indian medicine has been affected. These Elders also suggest that the present western system of managing cancer is also not helping people with cancer. Although the Elders have ideas about cancer in their community they have not been consulted for their assistance in helping people with cancer.

## CHAPTER 7

### DISCUSSION AND RECOMMENDATIONS

First Nations Peoples' experiences, perceptions and beliefs of cancer from the individual and community perspectives have been presented in Chapters Four, Five and Six. I now compare these findings to those identified in other research studies about aboriginal people and their experiences with cancer and other chronic diseases. The effectiveness of the conceptual framework used in this study is presented. My experience as a researcher will also be highlighted. This chapter concludes with recommendations for nursing education, research and practice.

#### Relationship of Findings to the Literature

A review of the literature about First Nations Peoples' experiences with cancer has revealed a predominantly epidemiological focus of understanding. This review has been presented in Chapter Two of this study. A study about cancer beliefs among Luiseno Indian People which was recently reviewed and was not included in Chapter Two will be compared in this section. Since there has been very little research about First Nations People and cancer, the findings in this study will also be contrasted with those identified in previous research studies about chronic disease experience among First Nations People. Another study concerning Cree health will also be used in this chapter.

#### Overview of Findings in the Literature

Findings in the previous research studies about cancer and chronic disease experiences in First Nations People have been contrasted with the findings in this

study. Similarities and differences between previous studies and this one have occurred in many areas. They include the following topics: cancer, a new disease; cancer causation; cancer as a metaphor; traditional healers, caring and healing; traditional healers and elders; and cancer, a mark of disgrace.

#### Cancer: A New Disease

The Luiseno Indian People living in San Diego County believe cancer to be a relatively new disease which is occurring with increased frequency (Weiner, 1993). The informants in this study also believe this about the occurrence of cancer in their communities. The Anishinaabe further clarified this idea. Some informants believe cancer was present in their communities long ago, but it was a rare disease affecting few people. Moreover, the medicine men and women were able to treat cancer. People were cured and therefore, they did not die from this disease. Tuberculosis and other infectious diseases such as measles were the predominant threats to the health of their community members during earlier times. Other informants believe some people who had cancer long ago did not know what it was. Cancer is considered a new disease because until recently it was largely an unknown disease to First Nations People.

#### Cancer Causation

First Nations People have identified various causes of cancer. I have compared the literature to the findings of this study under two main areas: food and other sources.

### Food: An Origin of Cancer

Food is considered to be the predominant source of cancer among First Nations People. Anishinabe living in a southern Manitoba community view cancer and diabetes as resulting from drastic and uncontrollable change in their diet (Garro, 1991). A traditional diet based on wild foods has changed to one that almost exclusively relies on store-bought foods. Store-bought foods are viewed as inferior to wild foods. Also, substances injected into animals or sprayed onto crops, additives and preservatives added to canned goods and other foods are all seen as causing illness. Subsequently, Anishinaabe consider chronic diseases such as cancer and diabetes to be a "white man's sickness" because these illnesses did not exist "in the old days" and are seen as having been introduced to their communities by Europeans (Garro, 1991). Ultimately, to the people in this community, the presence of cancer and diabetes is one manifestation of ongoing disruption and destruction of the Anishinaabe way of life.

Similarly, the significance of food in the development of diabetes and the loss of traditional values have also been articulated by Cree and Ojibwa Elders in Toronto, Canada (Hagey, 1984). Adelson (1991) related the significance of food to the health of members of the Whapmagoostu Band of Eastern Cree, living in a community approximately 1,200 kilometres north of Montreal in the province of Quebec. "Whiteman's food" is thought to weaken a person and its consumption changes the basic constitution of a Cree person. Cree food is essential to Cree health or "being alive well", miyupimaatissiium. Game and fish are the basic requirement for "being

alive well" and symbolize fundamental aspects of Cree Life. Both the natural and spiritual worlds are integral to Cree Life.

In the natural world "eating well" means to the people in this Cree community that one has been eating bush food and from this it can be assumed that there has been a good hunting season (Adelson, 1991). A good hunting season in turn indicates that one has the physical strength required to work in the bush. "Eating well" is evidence of an experienced hunter and of a woman who has the skills and ability required for the preparation of the meat and the hides. The spiritual aspect of "eating well" is at the moment when the animal chooses to give itself to the hunter. The relationship between a Cree hunter and the animals hunted for food is based upon mutual respect. A cyclical affinity between the Cree person, hunting, the land, and food incorporates all aspects of Cree life and, so, of health and well-being.

A similar view is held by the Luiseno Indian People (Weiner, 1993). To the Luiseno Indian People living in harmony means that peoples' bodies and blood are considered "clean" and are less susceptible to impurities such as cancer (Weiner, 1993). They believe cancer occurs as a result of contact with food, soil, air and water contaminated with impurities such as insecticides, food preservatives, pesticides and chemical wastes associated with manufactured goods. Cancer represents an imbalanced body and society. It has also come to symbolize non-Indian society or "invaders" who allow and/or promote the use of chemical impurities in their communities. The Luiseno People believe that the non-Indian business and government officials and some band council members are destroying their belief

systems, and not protecting their land base.

Similarly, Native People living in a small Alaskan community identified food, water, air and soil contaminated by modernization as causing cancer. Change from traditional to western diet was the third leading cause of cancer in their community (Spratt, 1988). Specifically, they expressed concern that a diet high in processed foods may increase their risk of cancer. The Alaskan native people cited their drinking water as the primary source of cancer (Spratt, 1988). "Bad water," "old water system," "bad tasting water," and "getting sick" periodically from the water, and chemicals (fluoride, chlorine) were their expressed concerns. Fall-out from nuclear testing in China and Russia was the second leading cause of cancer (Spratt, 1988). However, fuller explanation of cancer causation from the Native Alaskan perspective was not acquired. Linkages between cancer and modernization affecting food, water and soil were not made.

In this study, the type and nature of food consumed was identified by the Anishinaabe as the primary source of cancer. Foods believed to cause cancer are the result of progress which is the industrial advancements made by Euro-Canadian People. Progress has also affected the quality of drinking water and spawning grounds within these water systems. The informants identified progress as having the greatest influence in the development of cancer in their communities.

Elders believed that living the traditional Anishinabe way prevented cancer. However, progress has eroded traditional Anishinabe ways of living. Breastfeeding has been replaced by infant formula; traditional medicine given to babies to prevent

cancer in their later years no longer exists; and, traditional foods have been replaced by foods-of-convenience and foods prepared by frying in fat. Foods-of-convenience include products that are processed, high in fat content, and have preservatives and additives. Other foods of concern are "junk food", canned foods, domestic meat, and fried foods. Some informants accorded the presence of chemicals and additives as the primary cause of cancer among Anishinabe people. Environmental pollution, the use of pesticides and food additives contributed to the uptake of chemicals in the food chain.

Progress has also affected the quality of water and has destroyed the fish spawning grounds in the river that flows through The Silent Eagle community. The dumping of chemical wastes by a paper mill, located upstream and close to the community, is contaminating the community's drinking water and altering the supply of fish to the area. Progress has contributed to the development of cancer by affecting the types of foods consumed and the chemical uptake in food and water.

Progress is synonymous with cancer. Cancer consumes not only human flesh but, in the form of progress, consumes traditional Anishinaabe ways of living. Just as the traditional ways were thought to keep cancer at bay, they were also believed to keep the spirit and determination of the Anishinaabe people strong. By eroding traditional values and lifestyles, progress has also eroded the spirit and determination of the Anishinaabe.

Like a cancer, progress has many forms and has evolved over time since the first hunters settled on this land. Colonialism is considered to be the foundation upon



which Canada was developed. Canadian Government policies were designed to assimilate Indian People so that they would cease to exist legally and culturally as First Nations Peoples. The Indian Act is the cornerstone of these policies. In the form of colonialism, progress has "dominated" and has threatened to "take over" and consume Anishinaabe as a people.

The Original People of Canada are similar to other people diagnosed with cancer. First Nations People feel like strangers on the lands in which their ancestors lived. And like people with cancer, Anishinaabe feel uncertain about their futures culturally, economically and socially. Life as they once knew no longer exists. First Nations People feel a sense of loss, uncertainty and fear. They grieve many losses including the land, hunting and fishing rights, spiritual ways of living and traditional Anishinaabe lifestyle. However, there is another movement which is gaining momentum in First Nations communities. The informants in this study are "learning to live with cancer" by getting to know the stranger-as-cancer. Similarly, the Anishinaabe are getting to know the stranger-as-progress. By embracing spiritual ways and looking to the Elders for knowledge First Nations People are getting to know cancer and progress.

#### Other Sources of Cancer

Aboriginal people have identified sources of cancer other than food, water, air and soil affected by modernization. The Luiseno People with indirect experiences with cancer identified tobacco, alcohol, illicit drugs, cancer germs, bruises, and surgical procedures as sources of cancer (Weiner, 1993). The Luiseno People with cancer

believed genetic predilection and/or God's will were the sources of their cancers.

People living in a small Native Alaskan community thought tobacco was one of the leading causes of cancer (Sprott, 1988). In this study, sources believed to cause cancer were sought among the Elders, family members, community members, and people diagnosed with cancer.

Some of the sources of cancer identified by the Anishinaabe in this study were similar to those of the Luiseno while others were different. Illicit drugs and God's will were not expressed as causing cancer however, infection, cancer as a contagion and "bad medicine" were identified. Unlike the Luiseno, the informants directly and indirectly affected by cancer, i.e., Elders, family members, community members believe tobacco and physical injury to be sources of cancer. Some Elders believe cancer occurs as result of infection. This may reflect their experiences with local wound infections. Some people with cancer and their relatives fear cancer is contagious. This belief reflects First Nations Peoples' experiences with tuberculosis which was another disease devastating to Indian People. Heredity is believed to be a source of cancer among family and community members. Bad medicine was identified as a source of cancer among people diagnosed with cancer and their family members. Other sources of cancer identified by community members included poor socio-economic conditions, and inadequate cervical cancer detection.

Comparing the literature to the findings in this study suggest that there are similarities and differences in the beliefs about the sources of cancer between aboriginal communities in North America. When teaching about ways to prevent

cancer certain distinctions between the sources of cancer are helpful to facilitate understanding. For example, the significance of viral infection, cervical and other types of cancer warrant clarification. Also, the susceptibility of the cancer patient to infection deserves explanation. Health care providers' understanding about the significance of "bad medicine", cancer and traditional healing measures will help in developing approaches that will facilitate healing for the Anishinaabe patient and family who hold these perspectives about cancer causation.

#### Cancer As A Metaphor

Metaphors reflect peoples' understanding of a disease. Diseases which are thought to be mysterious, devastating, uncontrollable, and incurable evoke powerful metaphors. The Luiseno people (Weiner, 1993) describe the consumptive nature of cancer as a "fungus" which "eats you away" or a "blob" which "consumes." Sontag (1978) describes the metaphorical evolution of cancer and tuberculosis before a cure was found. Before the discovery of cellular pathology, both were metaphorically identified as "consumptive" diseases. The early figurative definition of cancer was anything that frets, corrodes, corrupts, or consumes slowly and secretly (p. 10).

Military terminology forms a basis for modern cancer metaphors and reflect an understanding of aberrant proliferation of cells.

Cancer cells do not simply multiply; they are "invasive." . . . Cancer cells "colonize" from the original tumour to far sites in the body, first setting up tiny outposts ("micrometastases") whose presence is assumed, though they cannot be detected. Rarely are the body's "defenses" vigorous enough to obliterate a tumour that has established its own blood supply and consists of billions of destructive cells. However "radical" the surgical intervention, however many "scans" are taken of the body landscape, most remissions are temporary; the

prospects are that "tumour invasion" will continue, or that rogue cells will eventually regroup and mount a new assault on the organism. . . . Treatment also has a military flavour. Radiotherapy uses the metaphors of aerial warfare; patients are "bombarded" with toxic rays. And chemotherapy is chemical warfare, using poisons. Treatment aims to kill cancer. (Sontag, 1978, p. 64)

The consumptive theme for the metaphors of cancer in this study correlates with the plant identified in the Luiseno (Weiner, 1993) and those of premodern metaphoric cancer (Sontag, 1978). However, the animal-as-metaphor is unique among the First Nations People in this study. The most common metaphor used by First Nations People in this study is "manitoch" which, in the Ojibwa language, Sauteaux, means cancer-as-worm. Other metaphors used are: bugs, worm-bug combination, bug-cell combination, worm-cells, manicosak (worms or maggots), amogogh (maggots) and cancer-as-germ. Cancer is thought as "eating up something" or komigo (eating away). The cancer-as-worm metaphor was used often by the Elders while other metaphors such as bug, black hole and maggots were used by a few young adults.

The consumptive nature of the cancer-as-worm is a physical manifestation. Manitoch can enter peoples' bodies through open areas on their skin. It grows and breeds by consuming the flesh and bone of its hosts. Cancer-as-worm is manifested by the pain and other signs of decay and devastation. The incurable nature of cancer is depicted in the worms' hair-like legs which can grow to enormous lengths within a body. Since cutting one of its tentacle-like projections is likely, it is impossible to surgically remove cancer in its entirety. The remaining worm pieces migrate to different parts of the body. These remnants may lie or begin to grow. Metaphors provided a succinct and powerful understanding about cancer in this study. They

present a population's perspective about the characteristics and process of a disease, and the implications of surgical and medical intervention. First Nation cancer patients and their families who understand manitoch-as-cancer interpret the disease and its treatment from this perspective. Their fears and expectations about the management of cancer is a reflection of their understanding of the disease process and treatment outcomes.

Metaphors shroud a disease in mystery, making it impossible to understand the disease (Sontag, 1978). Sontag describes metaphors as "punitive or sentimental fantasies concocted" to treat a "mysterious" disease (p. 3). Rather than understanding the disease, people tend to focus on the metaphor and perpetuate the mystery of the disease. Sontag believes that the way to understanding illness is to resist metaphoric thinking.

The metaphor is a powerful resource for learning about a chronic diseases. Animals are important symbols used to learn about life (Bopp et al., 1989). Manitoch, the cancer-as-worm is not only a symbol of the physical manifestation of cancer but also serves as a symbol of traditional ways being consumed by progress. Manitoch is a symbol of an eroded spirit and self determination is a low ebb. Cancer is more than physical symptoms and treatment. It is the prevention and management of this disease which includes the spiritual realm of a person and community.

Contrary to Sontag's assertion, Hagey (1984) stated that the metaphor is important to aboriginal peoples' learning about diabetes and developing effective ways of managing their diabetes. The relationships between the metaphors in "Nanabush

and the Stranger" and diabetes went beyond the physical dimension of diabetes to include the spiritual realm of a people. Nanabush is the legendary figure who represents the teacher in Ojibwa culture and his first encounter with the personified character of Diabetes. Nanabush, a mediator between the Creator and the Ojibwa People, is the embodiment of Ojibwa morality, moderation and balance. "Nanabush is sometimes wise, sometimes bumbling. He gets himself into trouble, he somehow gets himself out of it. He learns by his mistakes. He represents positive and negative, good and bad "(p. 267). Windigo, the opposite of Nanabush represents the physical symptoms of diabetes. Gluttonous Windigo-starvation personified symbolizes disharmony, greed, instinct without reason. "Windigo is purely physical, without spirit" (p. 268). Diabetes is seen as a problem arising from white man's food and environment. Diabetes is envisioned as a problem due to lack of spiritual strength: Windigo is an aspiritual, less than human physical succumbing to external powers. Diabetes is viewed as a threat to aboriginal families and communities. There is a clear resolve to live with diabetes, learn his ways, gain strength from knowing him. This is different resolve than that chosen by many aboriginal people with diabetes. Knowing the ways of diabetes is synonymous to integrating into a white world. Knowing the ways of diabetes and the white world provides hope for aboriginal people in communities where disorder and suffering of whole communities is empirically observed. Unemployment, poverty, family breakdown, alcoholism, diabetes: are all predictable ills reflecting the lack of inner spiritual strength of the Indian People. Nanabush represents internal control in contrast to the out-of-control havoc

represented by Windigo which is seen as an external overpowering force. Diabetes symbolizes "being out of balance." It is "the clan system which is broken down and the Indian people to be out of balance with nature and with each other", "abandoning each other".

In the old days Indian people walked in balance with nature, This was the source of spiritual strength. They were physical fit; they had a balanced diet; each season brought different nutrients that were necessary to stay in balance with nature. Now, if people are over-indulging it is because they are craving for those missing natural elements. (Hagey, 1984, p. 269)

The Nanabush metaphor offers two choices: Either Nanabush, controlled diabetes, internal strength through unity and support, freedom, responsibility and ultimate order and power of aboriginal people as a whole, or Windigo, out-of-control diabetes, isolation and vulnerability, victimization, blame mentality and continued breakdown of the clan system. The choice of Nanabush offers transformation from a purely physical being or Windigo into spiritual being. It is the spirituality which gives individuals and aboriginal communities their strength. The Native culture is the source of their spirituality (Hagey, 1984, p. 270).

In this study, Manitoch is reflective of Windigo, cancer feared. People with cancer feel isolated, vulnerable and not understood. First Nations People with cancer are learning to live with cancer. Understanding the limits of western medicine to cure their cancers and believing that once you have cancer you will always have cancer, informants with cancer sought spiritual healing and rejuvenation through traditional Indian medicine and Christian prayer. Understanding that cancer is now in their communities, informants in First Nations communities have begun to identify ways of

"making cancer-as-stranger known." They are aware that people with cancer in their communities are seeking the counsel of traditional Indian medicine men and Elders for healing. Some community health care providers advocate on behalf of the people with cancer and their families who want to seek the help of Indian medicine men by providing funds so traditional healers can be accessed. Other ways that First Nations People use to get to know the stranger-as-cancer require discussion.

#### Traditional Healers: Caring and Healing

First Nations People diagnosed with chronic diseases seek the counsel of traditional Indian healers to cure their illnesses. Many Indian people have faith in and are actively utilizing the traditional healing system (Gregory, 1989, p. 165). More specifically, in a study with interviews centering around diabetes and high blood pressure, a number of people accessed Indian medicine men and herbalists at some point during the course of their illnesses (Garro, 1991). In this study, people with cancer sought the counsel of Indian medicine men and Elders as sources of healing for people with cancer.

The Indian medicine man is spiritually grounded. The Indian medicine man is "gifted" (Garro, 1990, p. 426). Although the medicine man possesses knowledge and ability to prepare herbal remedies to treat a variety of conditions, their skills "far exceed those of a herbalist." Medicine men "have omniscient powers to ascertain what lies behind an illness or other event." The medicine man's healing gifts are granted through visions and dreams and to strengthen his healing powers he spends time "in the bush" without food and human contact. Medicine men are able to



communicate with spiritual beings, through dream or trance, to diagnose, determine cause, and prescribe a treatment strategy.

The gift of tobacco has spiritual significance in Indian medicine. The gift of tobacco is an important connection between the person seeking help from the Indian medicine man, and the medicine man seeking spiritual guidance (Garro, 1990). It is considered inappropriate for anyone to request help from any Ojibwa healer without a gift of tobacco. Tobacco is used as an offering in all healing activities. Small quantities are placed in areas where medicinal plants are gathered. Cigarettes are often lit and left in a designated place as an offering by medicine men or by people seeking help, or smoked by medicine men when asking for spiritual guidance (p. 448).

Although cancer is considered to be one of the "white man's sicknesses", a patient with cancer would consult a medicine man for two reasons (Garro, 1990, p. 435). First, a physician's treatment had been attempted and was unsuccessful. And second, the cancer was known to be an "Anishinaabe sickness" and could only be properly treated by a medicine man. The Anishinaabe assert that since White man sicknesses were brought to their community by the White man then they are best treated by physicians. However, physicians are thought to be unable to effectively treat Anishinaabe sickness. One of the ways that "Anishinaabe sicknesses" occur is the result of some prior inappropriate behaviour such as mistreating animals, failure to keep a sacred promise, making fun of deformed or retarded people, murder, and practising as a medicine man without possessing the gifts to do so (p. 436). The

person who has violated this code of behaviour, her/his children or grandchildren "pay" for the transgression by becoming sick.

If an illness is resistive to physicians' treatment, the possibility of Anishinaabe sickness is commonly suspected (Garro, 1990). Although physicians may ameliorate symptoms or treat consequences of Anishinaabe sickness, problems may recur and can only be cured by an Anishinaabe healer. If an illness is judged to be an Anishinaabe sickness then a medicine man is consulted. If the medicine man determines the illness to also be Anishinaabe sickness then he will treat accordingly. The patient is also encouraged to consult a physician to have the white man's sickness aspect treated. The spirituality of Indian medicine transcends the boundaries of Christianity in some communities. Garro (1990) did not perceive contradiction, in the Anishinaabe community where she conducted her study, between accepting the medicine man's abilities and the Catholic religion (p.426).

Similarly, in this study, the informants believe the Creator has presented gifts of healing to those known as medicine men. (Similar to Garro's study no medicine women were accessed.) Elders are also thought to possess gifts for healing. There is not enough data to differentiate the healing roles of the Indian medicine people and the Elders. People who seek the counsel of an Indian medicine person or Elder demonstrate their respect for these healing gifts by offering tobacco to the traditional healer. The healer then makes an offering of tobacco for the purpose of healing.

In this study, informants with cancer suggest that Western medicine is limited in its ability to cure cancer. Believing their cancers would recur, some informants

sought the counsel of an Indian medicine man to "cure" their cancers. None of the informants discussed cancer within the context of Anishinaabe or White man's sickness. Other than drinking an Indian medicine tea, none of the informants discussed how this healing took place. As result of visiting with the medicine man, the informants' fears, pain and uncertainties were eased in living with cancer.

Traditional Indian medicine was defined in this study as holistic healing. The physical realities of cancer cannot be treated without considering the person as a thinking, emotional and spiritual being. Strengthening a person's spirituality is believed to be the essence to healing cancer. The community informants who believe in the healing powers of Indian medicine spoke about the Creator as being at the core of these healing ways. Prayer is essential for healing.

From the perspective of community members, people with cancer or their families seek the counsel of Indian healers and Elders at various stages in the disease trajectory. Traditional healing affirms one's spirituality and provides comfort, hope and a sense of peace to enhance quality living. It is also suggested that traditional ways of healing help prepare those dying from cancer and their families for the cancer patients' movement into the next world (death). Of the informants with cancer five sought help from traditional Indian medicine men. Two of these also referred to their traditional beliefs. Four people sought help according to Christian beliefs and, contrary to Garro's study, did not believe in traditional Indian medicine. For others, both the traditional Indian medicine and Christian ways provided reassurance and comfort when faced with cancer.

The selection of a healer in this study is dependent upon the needs of the patient. First Nations People with cancer consult one or more medicine healers before, during or after obtaining medical cancer treatment. From the communities' perspective, people with cancer seek the counsel of traditional healers before or at the same time as seeing a physician. Some people who are seeing a traditional Indian healer and taking Indian herbal medicine do not consult a physician until the medicine has been completed. Some people do not consult a physician at all. How people with cancer determined when to consult a traditional healer and or physician was not part of this study. Whether the disease trajectory of cancer was a consideration in this selection was also not a part of this study.

In the study, Indian healers advise their patients in relation to western medicine. Some Indian medicine healers will avail themselves for healing informants only if medical treatment is not sought. Other Indian medicine people advised their patients to see a physician first for cancer treatment before returning to them for further consultation. And still others will practice Indian medicine while patients are receiving medical treatments.

#### Traditional Healers and Elders

Health care providers recognize the value of traditional healers and Elders in providing healing to First Nations People on an individual and community basis.

#### Accessing Traditional Healers

Some Medical Services Branch (MSB) nurses recognizing the traditional healers' abilities and skills determined which patients would benefit from a referral to

a traditional healer. The majority of nurses (67%) were aware of traditional healing practices in their communities, and 39% reported they had initiated patient referrals to traditional healers (Gregory, 1989). The clients make the decision as to which type of healer should be accessed. MSB nurses referred their patients to traditional healers or contacted the medicine people only when conventional treatment was ineffective ie: when patients experienced a health problem which the nurses could not resolve, or when the patient and/or family experienced frustration with the treatments offered by the Western health care system. Although situations occurred where nurses and traditional healers interacted positively, a truly collaborative relationship was the exception, rather than the norm (p. 164).

In this study, the data suggest that some communities' health care providers embrace the services of traditional healers while in other communities health care providers do not. In each of the communities, traditional healers are accessed for cancer treatment. However, the extent to which health care providers determine which patients would benefit from a referral to a traditional healer is not understood. The reasons why one community's health care providers advocate on behalf of patients who believe in and use traditional healers and in other communities health care providers do not, are beyond the scope of this study. The data suggest that whether the clinic administrator, registered nurses or community health representatives in a clinic or nursing station are aboriginal does not determine the extent of accessing traditional healers. Possibly the personal beliefs about traditional healing practices may be one consideration. Also, whether a community has taken over administrating

its own health care services does not seem to be a factor.

In communities that access traditional healers the health care providers and health clinic administrators recognize their community members' faith in traditional healers. Health care providers support and advocate on behalf of those with cancer and their families who seek traditional healing ways. An example of advocacy is the provision of temporary funds so people can visit or bring a traditional healer into the community for consultation. The Traditional Healer Program is available to all First Nations communities. Adequate financial resources are required at the outset to pay for accommodation and travel expenses for the patient and escort, or to bring a traditional healer to the community for consultation. It is suggested that communities are at varying stages in recognising the services that traditional healers and Elders provide in helping people with cancer.

#### Elders: Role in Community Development

The extent to which Elders are involved in health care service delivery and community development may determine the success of delivering these services and implementing community programs (Gregory, 1986, p. 108). Sole reliance upon the community health representative as an intermediary in developing and implementing health care programs may limit the effectiveness of these programs (Gregory, 1989). The services that Elders can offer in the development and implementation of community health and promotion programs and other traditional First Nations ways of healing may be seriously considered in some communities. The extent to which Elders could provide service in cancer prevention and early detection warrants careful

consideration.

Gregory (1986) related potential services and/or interventions which were similarly identified by community members and Elders. These roles included: counsellors; providers of Indian medicine, domestic advice, and historical/cultural information; role models for the youth; and, community problem solvers. By specifically addressing the Elders' role in helping individual clients and patients he offers insight about the reasons nurses do not involve the Elders in patient care in spite of recognizing the social role and function of the Elders in their communities and willingness to refer clients to Elders. The reasons include: lack of employer policy, inadequate communication between the nurses and Elders, and a lack of understanding of the social and cultural role of Elders. The extent to which traditional healers and Elders were involved in the health care service delivery and community development was not obtained in this study.

In this study, a small group of Elders who possess experience and knowledge about traditional ways of healing suggest that they have a place in their community to help people with cancer. This group consists of the oldest Elders interviewed in a community accessible by airplane. The Elders believe that the shift from the traditional ways of healing to the Western ways of curing has undermined their roles as Elders and healers in the community. Elders at one time were consulted by those who needed help with their illnesses including the curing of Manitoch. Knowledge about traditional medicines for curing Manitoch no longer exists. The Elders believe many people in their community no longer have faith in traditional Indian medicine.

They do not use Indian medicine to the extent they once did in the past. With the loss of knowledge for curing cancer and the loss of faith in the abilities and skills of traditional healers, the potency of the traditional healing ways of Indian medicine has been greatly affected. These Elders also suggest that the present Western system of managing cancer is not helping people with cancer to the extent to which it could. The Elders suggest they have ideas about the care of people with cancer, and the prevention, early detection and management of cancer in their community. However, they have not been consulted by people with cancer, the health care providers or the community's leadership for their assistance that would support Western and traditional Indian medicine. Obtaining the Elders' support and input is suggested as an important strategy for successful cancer prevention and early detection program implementation in the community.

#### Cancer: A Mark of Disgrace

Cancer is a disease of which many First Nations People are ashamed. The stigma of cancer is felt at various levels. These include the individual, within the family and within the community. The mark of disgrace is the physical pathway of destruction left by Manitoch. It is the cancerous growth itself, and the weight and hair loss and other physical manifestations seen in people who are receiving cancer treatment. Many people with cancer feel ashamed about having Manitoch. And families and communities feel ashamed about having cancer among its members. To hide their shame of having cancer, individuals, families and communities adhere to a code of silence. Unfortunately, this code of silence perpetuates the stigma of cancer.



Learning about cancer within the context of the family and community will help to allay feelings of shame about having cancer.

### Overview of Findings Beyond the Literature

Some findings in this study are not discussed in the literature. Spiritual visions and dreams are important to First Nations People with cancer. First Nations People are silent about cancer and this has implications for prevention, early detection education and cancer screening for their communities.

#### Spiritual Visions and Dreams

The spirit is the haven of dreams (Bohm, 1980). Everyone's spirit comes from the spirit world and dreams are the link to this world. Dreams are symbolic messages from the spirit world to the knower. Dreams are the voice of the inner peace which give rise to the Divine. Dreams are a source of knowledge (Irwin, 1994). Dream knowledge reveals the activities of the mysterious powers - their engagement with or relationship to the dreamer. The dream is a medium of knowing, a way of experiencing the reality of the lived-world, a faculty of perception; the religious vision might be regarded as an intensification and heightening of this knowing. Visionary dreams motivate behaviour, shape belief, thought and other types of cognitive processing.

Messages which offer guidance from the Creator are channelled through spiritual visions to the informant. In this study informants were fearful of cancer-worms escaping surgical excision, cancer returning, and imminent death. Their visions, which may or may not be Christian-based offered reassurance that their

cancers-worms had been entirely removed surgically; their cancers were not returning; and, their deaths were not imminent. Dreams and visions are expressions of hope. The sharing of dreams by people with cancer and their families is significant. The expectations of all involved (ie: people with cancer, their families and health care providers) when dreams and visions are shared is worth further consideration.

#### Silence: Cancer Prevention and Early Detection of Cancer

Silence and "not talking about cancer" have implications for cancer prevention, early detection education, and cancer screening programs for First Nations People. First Nations People have various views about preventing cancer. Some believe that there are ways to prevent cancer; others believe that cancer is not preventable; and, Elders believe that the traditional aboriginal ways of living which prevented cancer no longer exist. First Nations People do not seek help from health care providers when they first discover physical changes or suspect they have cancer.

Informants with cancer and community members have reasons for keeping silent about cancer. This silence has implications for prevention and early detection education and cancer screening programs for First Nations People. First Nations People with cancer perceived the people in their communities are reluctant to "talk about cancer" because they have limited knowledge about cancer and the information they do have instills fear about the disease. Community informants agree; cancer is thought of as a death sentence. Discussing cancer is synonymous with talking about dying and death. Immobilized by fear, First Nations People do not seek help when

they first notice body changes or suspect they have cancer.

In this study, First Nations People did not seek help from health care providers when they first noticed marked physical changes in their bodies. The informants believed these changes were indicative of cancer because they heard about the devastating effects of cancer from stories or from cancer experiences in the family. Fear had a paralyzing effect on these informants. Although they intuitively sensed they had cancer, they delayed seeking help from a health professional. The informants with cancer sought assistance when the physical changes in their bodies worsened. Similarly, over half of the community informants advised that First Nations People need to seek help from a health professional when they first discover physical changes in their bodies.

Community informants do not discuss cancer out of respect for Elders and the traditional Anishinaabe teachings. Since cancer affects the breast, cervix and prostate- -discussions about cancer, either privately or publicly, are considered inappropriate according to traditional teachings. First Nations People foster the value of modesty and are reluctant to discuss human sexual organs and their function. Women feel embarrassed and discomfort about having pap smears, cervical and breast examinations. Data in this study suggest that Anishinaabe women feel uncomfortable about being examined by male physicians and nurses. However, the data are insufficient to determine whether women of certain age groups were more affected by this than others. To avoid embarrassment women do not keep appointments and delay seeking help when physical changes occur. Discomfort surrounding the procedure of

breast and cervical examination for all age groups requires investigation.

Aboriginal women were most likely to be overdue for follow-up cervical screening and older aboriginal women were under-represented in the adequately screened population (Calam et al., 1992). Indian women in Manitoba reserves are one and one half times at risk of developing cervical cancer than all women in Manitoba (Young & Choi, 1985). Age-standardized incidence rates for cervical cancer for registered Indian women of northern Saskatchewan were greater than the rates of Saskatchewan as a whole from 1967 to 1986 (Irvine et al., 1991). While the incidence of cervical cancer among women in Saskatchewan have declined by 45% during the twenty year period (from 15 to 8 per 100,000), the incidence of cervical cancer among registered Indian women has increased by 52% (changing from 34 to 52 per 100,000 during the period from 1967-71 to 1982-86). Indian women living on reserves (with the exception of the Territories and the provinces of Newfoundland, New Brunswick and British Columbia) died from cervical cancer with more frequency than the general Canadian population during the period from 1977 to 1982 (Mao et al., 1986). Cervical cancer mortality is preventable with appropriate screening and treatment (Skubi, 1988). Exploration about First Nations women's beliefs and experiences in the cervical cancer screening process would facilitate more effective cervical cancer screening follow-up.

#### Relationship of Findings to the Conceptual Framework

The universal, dynamic, inter-related and multi-dimensional nature of the Medicine Wheel accommodated a wide range of experiences, beliefs and perceptions

First Nations People have about cancer, its origin and disease process, treatment and healing practices, and role of the traditional healer. The Medicine Wheel afforded the analysis of data from the perspective of the informant diagnosed with cancer and community members. Family members' beliefs about the origin of cancer was obtained. However, due to the limited number of participants, the family members' perspectives about their relatives' experiences along the disease trajectory were not explored. Community members related their primary concerns about cancer in each of their communities. This conceptual model was effective in guiding the research questions outlined in Chapter One of this study.

The Medicine Wheel was helpful in developing an understanding about cancer in First Nations communities. It facilitated the interaction between the physical, mental, emotional and spiritual realms of the person with cancer. For example, the hope which visions and dreams offer during recovery from surgical removal of cancer. Also the Wheel accommodated the diversity of First Nations People in celebrating their spirituality within the context of Christianity and/or Indian medicine. The Medicine Wheel has facilitated the understanding of the cancer experience including the awareness of having cancer, having the cancer confirmed and then treated, and then the return of cancer. Also, the Medicine Wheel facilitated the cancer experience as it moved from discovering the stranger-as-cancer in the community, leaving the community to have the cancer diagnosed and treated and then returning home to and learning to live with cancer. The Medicine Wheel facilitated understanding about cancer in First Nations communities.

## Reflection and Reflexivity

Reflection and reflexivity are techniques used to improve all aspects of the research process including data collection and interpretation of findings. Reflection is a process of looking back on our experiences with the purpose of forming an image or construct (idea) of our earlier work (Rubinstein, 1991, p. 27). Reflexivity is the critical examination and use of earlier experiences to influence future action (p. 27). I will begin by sharing what it was like for me to explore the cancer experiences, perspectives, and beliefs of Anishinaabe living in four communities. Then, I will offer suggestions to others who plan to conduct research in First Nations communities.

Studying First Nations People's experiences with cancer has affected me as a writer, researcher, and aboriginal woman. It is difficult, at times, to distinguish between each of these aspects of myself because they are so intertwined. I used some of the teaching symbols in the Medicine Wheel to explain how I have been affected by my thesis work.

The East is a place of new beginnings in the Medicine Wheel. Writing my thesis and going through the process of studying First Nations People and cancer were new and challenging experiences for me. When a path is new, it totally occupies our attention (Bopp et al., 1989). As result of these experiences, I have become a more confident writer and I have learned some very important lessons about doing research and about myself as a person. First, I will briefly share how I developed my writing skills. Then I will present an excerpt, "Making a Quilt: The Storytellers' Gifts and The Listener's Burden", from my thesis experience. The experiences outlined in the

excerpt both presented me with challenges and learning opportunities as a researcher and person.

I struggled with my writing throughout this thesis. There were two aspects to my struggle. First, I was concerned that colleagues would deem my writing unworthy for a masters level thesis. Second, I was concerned that I would not justly write about the informants' experiences with cancer. Both of these fears greatly affected my ability to write the findings of this study. I found some solace when I was reminded that many thesis authors shared my fear of being discovered as imposters. To work through my concerns and fears I found it helpful to look to the South, West, and North of the Medicine Wheel.

The direction of the South on the Medicine Wheel symbolizes physical and emotional expression in ways that are healthy (Bopp et al., 1989). The symbols of the Southern direction served to remind me to keep a broader perspective in my life. My research project was only one aspect of my life. As a way to nurture my physical, emotional, mental and spiritual well-being, I exercised. Much of my exercise was cardiovascular in nature such as walking, and using a stationary bike, row and ski machines. I also did some weight training and have discovered the importance of stretch exercises as a means to relax.

The West is the place of the unknown, of going within, of dreams, of prayer and of meditation (Bopp et al., 1989). West is the direction where I spent the greatest amount of time. There was a period in my thesis work when I found it extremely difficult to put words to paper. I recall moments when I was immobilized by my

anxiety. Finding each of these periods overwhelming, I sought to connect with sacred medicines. I often bathed my work place with a sage smudge to help focus my thoughts. And, I felt safe when I held tobacco in my hand and sought guidance in my thesis work. Thoughts about not doing my thesis never occurred to me. However, at the core of my anxieties was a concern that I might not be able to meet the challenges presented to me.

It is in West where the will is stretched to its outer limits so that the gift of perseverance may be won. For the closer one goes toward a goal the more difficult the journey becomes. The capacity to stick to a challenge even though it is very hard and even painful is an important lesson to be learned in the West. (Bopp et al., 1989, p. 53)

The black bear and turtle, symbolic teachers of the West, served to remind me about the nature of my strength and the importance of introspection (Bopp et al., 1989). The black bear possesses great strengths. Many times, I felt I had to reach deep within me to find the strength I required to go beyond a certain point in my thesis work. The turtle not only teaches to go within but also grants the gift of perseverance to those who learn its ways (Bopp et al., 1989).

By journeying to the center of one's being, it is possible for a person to experience directly the connection between the human spirit and the rest of the universe, and between the human spirit and the Creator. The experience is the gift of prayer. (Bopp et al., 1989, p. 54)

I visited the direction of the West many times during my thesis work. I was reminded about the discovery of human strength and the power of introspection when developing skills such as writing.

In the North of the Medicine Wheel dwells the teachers of intellectual gifts (Bopp et al., 1989). Like many others who look to the North to acquire these gifts, I



lacked the confidence about my intellectual abilities. As there was a point during my thesis work when I hedged about writing (this fear overflowed into other aspects of my life) so too was there a point when I moved beyond my fears. Writing, like any skill, requires practice. This thesis was an excellent opportunity to develop my writing. Consequently, throughout my thesis there are different levels and styles of writing to reflect the various stages I went through in developing my writing.

Going through the process of studying the cancer experiences of Anishinaabe presented me with a variety of challenges. I relate one of these challenges in "Making A Quilt: The Storyteller's Gift and The Listener's Burden."

Making A Quilt: The Storyteller's Gift and The Listener's Burden

We were strangers, the informants and me. They told me how cancer filled their lives with fear, pain, and uncertainty. Some informants told me about their spiritual journeys. When the informants spoke it was as though they were sewing together their cancer experiences like patchwork cloth pieces. After gathering the cloth pieces, I assembled their patchwork pieces into a quilt.

I became aware of the burden of assembling the quilt. As I graciously accepted each quilted piece I could feel the informants' fears and uncertainties which had been sewn into the cloth pieces. So tangible were their anxieties and pain I became apprehensive about holding the cloths too long. Out of respect for the work that went into preparing the patchwork pieces, I placed the cloths for safekeeping in a cedar box which I had in my home. When it was time, I carefully examined each patchwork piece. Holding a cloth piece in my hands, I touched the threads and felt the textures

of the material. The patchwork was beautiful. I was often moved by the informants' strength, courage, and wisdom in dealing with the devastating disease of cancer. I felt compassion for the informants because fear and uncertainty were so much a part of their patchwork pieces. The patchwork pieces were an attest to the realities First Nations People faced when dealing with their cancers.

The patchwork pieces were powerful and evoked within me feelings that I found, at times, overwhelming. Sometimes I was concerned that the feelings of fear I felt were not from the quilt pieces but were my own. It was very difficult for me to face my fears about being touched by the experiences of people with cancer.

I found it difficult to allow thoughts and fears about touching the patchwork pieces to surface because to do so feelings of shame would surface as well. Only after I smudged myself with sacred medicines could I face my fear about being consumed by the energy held within the patchwork pieces. I was comforted and felt protected when I did the smudging ceremony. I often sought the sanctuary of meditation to regain a stronger sense of who I was as a human being. I also consulted an Elder for guidance. The smudging ceremony, meditating and seeking the counsel of an Elder were ways that I used to protect myself and show respect for the quilted pieces the informants left in my trust.

Doing thesis work goes beyond the intellectual processes and reaches into the emotional and spiritual realms. My thesis presented challenges which I chose to take and turn into learning experiences, both as a First Nations person and as a researcher. I have learned more about the Medicine Wheel, ethnography, the research process,

cancer in Anishinaabe communities and about doing research involving First Nations People. One of my initial concerns about becoming a researcher was that I could lose my identity as an aboriginal person. However, my thesis work provided me with rich opportunities to learn more about me as an aboriginal woman.

I have only one suggestion to give to others who plan to conduct research involving aboriginal people. I was often told by colleagues that First Nations communities would be more receptive to me because I was an aboriginal person. However, some Anishinaabe did not respond wholeheartedly to my call for their participation in this study. There were a variety of reasons for this. I would surmise some had nothing to do with my being an aboriginal person. I have always encouraged aboriginal people to conduct research in their own or other aboriginal communities. However, I do not believe that researching in First Nations communities excludes researchers from other ethnic backgrounds. Neither would I recommend that aboriginal researchers conduct studies involving only aboriginal people. Rather, respect for the people who are the focus of study is essential, as is ethically bound research.

### Recommendations

#### Recommendations for Nursing Research

This study has raised many questions about the experiences First Nations People have with cancer. The same research questions that were used to guide this study also deserve consideration among other First Nations communities. The cancer experiences of First Nations People who are Cree, Cree-Ojibwa, Dakota and Dene

may vary from the experiences of the Anishinaabe in this study. Similarly, the experiences of people living in First Nations communities in the more remote areas of northern Manitoba may also vary from the experiences of aboriginal people living in urban centres in Manitoba. Other questions for research include:

1. To what extent do the leadership and health care providers seek the counsel of Elders in developing cancer prevention and cancer detection education programs in their communities?
2. What are the beliefs and experiences aboriginal women have about cervical cancer screening process in their community's health clinic?
3. Explore the significance of dreams and visions and the expectations First Nations People have in sharing dreams and visions with health care professionals.
4. Explore the cancer experience from the family members' perspective.

#### Recommendations for Nursing Education

Nursing educators are in key positions to influence the following points about First Nations People and cancer:

1. Aboriginal people are diverse and so will hold a range of beliefs and perspectives about cancer, treatment and healing.
2. First Nations People seek the counsel of traditional Indian healers.
3. First Nations People have past experiences which will effect their developing initiatives to manage cancer in their communities.
4. The extended family is often present when a First Nations relative is

hospitalized.

In nursing education programs, include the following in course content:

1. Assessment of views First Nations People have about cancer causation and cancer metaphors.
2. Development of cancer prevention and early detection approaches based upon First Nations patients' understanding about cancer through metaphor.
3. Implementing surgical and treatment nursing care based upon assessment of cancer beliefs.
4. Assessment and implementation of nursing care in collaboration with the cancer patient and family.
5. Collaborate with leaders and Elders when developing cancer prevention and early detection programs in First Nations communities.

#### Recommendations for Nursing Practice

1. Do not use pamphlets to teach cancer prevention and early detection of cancer.
2. Teach breast self examination, one on one. Reinforce breast self examination on subsequent visits.
3. Incorporate the patient's beliefs about cancer before explaining invasive diagnostic tests and surgical procedures.
4. Seek the help of Native Services Department within tertiary care centres to develop and implement supportive measures if the cancer patient is planning or using traditional Indian healing practices. These practices may or may not include the use of Indian medicine tea.

5. Allow time for aboriginal cancer patients to speak about their concerns regarding their cancer treatments.
6. Collaborate with community members to develop talking circles or support groups for people with cancer in the communities.
7. Consult with Elders in the communities to learn how they might promote cancer prevention and detection.
8. Consult with Elders to learn how they might support people with cancer and their families.
9. Advocate on behalf of the family members to receive financial assistance for travel, accommodation, child care expenses so that they can accompany patients.

#### Message to First Nations People

I have had the opportunity to listen to the experiences and perspectives First Nations People have about cancer in their communities. I knew that First Nations People have the resources in their communities to determine the management of cancer. This study affirmed my belief. I had the privilege of listening to the wisdom of the Elders, the people with cancer, their relatives and others such as leaders and health care providers in the communities. They provided suggestions for dealing with cancer. They are as follows:

1. It is impossible for communities in southern Manitoba to return to the traditional lifestyle of hunting and fishing. However, certain traditional values such as respect for Elders and their wisdom is essential for cultural survival.

Elders want to actively participate in helping people with cancer in their communities. They have ideas about teaching ways to prevent cancer.

2. First Nations People are spiritual People. Their expression of spirituality may be rooted in Christianity or Indian medicine or both. The spiritual growth of First Nations People is the future of First Nations People.
3. Communities are at various stages in dealing with cancer. Some communities are silent about cancer and others are developing ways to openly discuss cancer.

I have also developed a greater appreciation for the importance of conducting cancer research in First Nations communities. Whether the research is community based or involves temporary partnerships with researchers outside the community, it is expected by all concerned that the research is ethically sound. It is also expected that research findings are given to the participants in the research studies.

## References

- Aamodt, A. M. (1981). Discovering the child's view of alopecia: Doing ethnography. In P. Munhall & C. Oiler (Eds.), Nursing research: A qualitative approaches in nursing research (pp. 163-171). Norwalk, CT: Appleton-Century-Crofts.
- Adelson, N. (1991). "Being alive well": The praxis of Cree health. Arctic Medical Research, Supplement, 230-232.
- Alberta Health. (1995). Strengthening the circle. What aboriginal Albertans say about their health. Edmonton, Alberta: Aboriginal Health Unit, Alberta Health.
- Alberts, S. R., Lanier, A. P., McMahon, B. J., Harpster, A., Bulkow, L. R., Heyward, W. L., & Murray, C. (1991). Clustering of hepatocellular carcinoma in Alaska native families. Genetic Epidemiology, 8, 127-139.
- Antle, A. (1987). Ethnic perspectives of cancer nursing: The American Indian. Oncology Nursing Forum, 14(3), 70-73.
- Becker, T. M., Wheeler, C. M., McGough, N. S., Jordan, S. W., Dorin, M., & Miller, J. (1991). Cervical papillomavirus infection and cervical dysplasia in Hispanic, Native American, and non-Hispanic white women in New Mexico. American Journal of Public Health, 81(5), 582-586.
- Becker, T. M., Wheeler, C. M., McPherson, R. S., Kratochvil, A., Parmenter, C. A., North, C. Q., & Miller, J. A. (1993). Risk factors for cervical dysplasia in southwestern American Indian women - A pilot study. Alaska Medicine, 35(4), 255-263.



Black, W., & Wiggins, C. (1985). Melanoma among southwestern American Indians. Cancer 55(12), 2899-2902.

Black, W. C., Bordin, G. M., Varsa, E. W., & Herman, D. (1979). Histologic comparison of mammary carcinomas among a population of southwestern American Indian, Spanish American and Anglo women. American Journal of Clinical Pathology, 71(2), 142-145.

Black Feather, J. (1992). Cultural beliefs and understanding cancer. American Indian Culture and Research Journal, 16(3), 139-143.

Bogdan, R., & Taylor, S. J. (1975). Introduction to qualitative research methods: A phenomenological approach to the social sciences. New York: Wiley.

Bohm, D. (1980). Wholeness and the implicate order. London: Routledge and Kegan Paul.

Bopp, J., Bopp, M., Brown, L., & Lane, P. (1989). The sacred tree. Reflections on Native American spirituality (3rd ed.). Twin Lakes, WI: Lotus Light.

Brown, G. M., Cronk, L. B., & Boag, T. J. (1952). The occurrence of cancer in an Eskimo. Cancer, 5, 142-143.

Burhansstipanov, L., & Dresser, C. M. (1993). Documentation of the cancer research needs of American Indians and Alaska Natives. Native American monograph no. 1. (NIH Publication No. 93-3603).

Calam, B., Bass, M., & Deagle, G. (1992). Pap smear screening rates. Coverage on the southern Queen Charlotte Islands. Canadian Family Physician, 38, 1103-1109.

Cancer 2000—Manitoba. (1992). Final report of the Manitoba provincial working group, April 1992. Winnipeg: Author.

Clarke, H. F. (1990). Childbearing practices of coast Salish Indians in British Columbia: An ethnographic study. In J. Ross & V. Bergum (Eds.), Through the looking glass: Children and health promotion (pp. 21-31). Toronto: Canadian Public Health Association.

Denzin, N. (1978). The research act (2nd ed.). New York: McGraw-Hill.

Dignan, M., Michielutte, R., Blinson, K., Sharp, P., Wells, H. B., & Sands, E. (1993). Cervical cancer prevention. Alaska Medicine, 35(4), 279-284.

Dion Buffalo, Y. R. (1990). Seeds of thought, arrows of change: Native storytelling as metaphor. In T. A. Laidlaw & C. Malms & Associates (Eds.), Healing voices (pp. 118-142). San Francisco: Jossey-Bass.

Edge, D. S. (1988). A survey of health habits related to cancer in northwest Alaska natives. Arctic Medical Research, 47(1), 632-635.

Fetterman, D. J. (1989). Ethnography step by step. Newbury Park: Sage.

Fortuine, R. (1969). Characteristics of cancer in the Eskimos of southwestern Alaska. Cancer, 23(2), 468-474.

Frost, F., Taylor, V., & Fries, E. (1992). Racial misclassification of Native Americans in a surveillance, epidemiology, and end results cancer registry. Journal of National Cancer Institute, 84(12), 957-962.

Gallagher, R. P. & Elwood, J. M. (1979). Cancer mortality among Chinese, Japanese, and Indians in British Columbia, 1964-73. National Cancer Institute Monograph, 53 (89-93).

Garrett, J. T. (1991). Where the medicine wheel meets medical science. In S. McFadden (Ed.), Profiles in wisdom. Native elders speak about the earth. Santa Fe, NM: Bear & Company.

Garro, L. C. (1990). Continuity and change: The interpretation of illness in an Anishinaabe (Ojibway) community. Culture, Medicine and Psychiatry, 14, 417-454.

Garro, L. C. (1991). Ways of talking about illness in a Manitoba Anishinaabe (Ojibway) community. Arctic Medical Research, Supplement, 226-229.

Gaudette, L. A., & Barreto, L. A. (1988). Development of a cancer registration system for the Inuit of Canada. Arctic Medical Research, 47(1), 624-627.

Gaudette, L. A., Dufour, R., Freitag, S., & Miller, A. B. (1991). Cancer patterns in the Inuit population of Canada, 1970-1984. In B. D. Postl, P. Gilbert, J. Goodwill, M. E. K. Moffatt, J. D. O'Neil, P. A. Sarsfield, & T. K. Young (Eds.), Circumpolar Health 90. Proceedings of the 8th International Congress on Circumpolar Health. Whitehorse, Yukon, May 20-25, 1990 (pp. 443-446). Winnipeg, Manitoba: University of Manitoba Press.

Gaudette, L. A., Gao, R., Freitag, S., & Wideman, M. (1993). Cancer incidence by ethnic groups in the Northwest Territories (NWT) 1969-1988. Health Reports, 5(1), 23-32.

Gillis, D. C., Irvine, J., Tan, L. Chiu, S., Liu, L., & Robson, D. (1991). Cancer incidence and survival of Saskatchewan northerners and registered Indians, 1967-1986. In B. D. Postl, P. Gilbert, J. Goodwill, M. E. K. Moffat, J. D. O'Neil, P. A. Sarsfield, & T. K. Young (Eds.), Circumpolar Health 90. Proceedings of the 8th International Congress on Circumpolar Health. Whitehorse, Yukon, May 20-25, 1990 (pp. 447-451). Winnipeg, Manitoba: University of Manitoba Press.

Giorgi, A. (1970). Psychology as a human science; A phenomenologically based approach. New York: Harper & Row.

Gottlieb, L. S., & Husen, L. A. (1982). Lung cancer among Navajo uranium miners. Chest, 81(4), 449-452.

Gottman, A. W. (1960). A report of one hundred three autopsies on Alaskan natives. Archives of Pathology, 70, 117-124.

Gregory, D. (1986). Nurses and human resources in Indian communities: Nurse perceptions of factors affecting collaboration with elders and contact with traditional healers on Indian reserves and in health centres in Manitoba. Unpublished master's thesis, University of Manitoba, Winnipeg, Manitoba.

Gregory, D. (1989). Traditional healers in northern Manitoba: An emerging relationship with the health care system. Native Studies Review Native Health Research in Canada, 5(1), 163-174.

Guba, E., & Lincoln, Y. (1989). Fourth generation evaluation. Newbury Park: Sage.

Hagey, R. (1984). The phenomenon, the explanations and the responses: Metaphors surrounding diabetes in urban Canadian Indians. Social Science Medicine, 18(3), 265-272.

Hamilton, A. C., & Sinclair, C. M. (1991). Report of the aboriginal justice inquiry of Manitoba: Vol 1. The justice system and aboriginal people. Winnipeg: Queen's Printer.

Hamilton-Dutoit, S. J., Hamilton Therkildsen, M., Nielson, N., Jensen, H., Hart Hansen, J. P., & Pallesen, G. (1991). Undifferentiated carcinoma of the salivary gland in Greenlandic Eskimos: Demonstration of Epstein-Barr virus DNA by in situ nucleic acid hybridization. Human Pathology, 22(8), 811-815.

Hart, B. L., Steinbock, T., Mettler, F. A., Pathak, D. R., & Bartow, S. A. (1989). Age and race related changes in mammographic parenchymal patterns. Cancer, 63(12), 2537-2539.

Hildes, J. A. (1960). Health problems in the Arctic. Canadian Medical Association Journal, 83, 1255-1257.

Hildes, J. A., & Schaefer, O. (1984). The changing picture of neoplastic disease in the western and central Canadian arctic (1950-1980). Canadian Medical Association Journal, 130, 25-32.

Hislop, T., Deschamps, M., Band, P., Smith, J., & Clarke, H. (1992). Participation in the British Columbia cervical cytology screening programme by Native Indian women. Canadian Journal of Public Health, 83(5), 344-345.

Horm, J., & Burhansstipanov, L. (1992). Cancer incidence, survival and mortality among American Indians and Alaska Natives. American Indian Culture and Research Journal, 16(3), 21-40.

Horner, R. D. (1990). Cancer mortality in native Americans in North Carolina. American Journal of Public Health, 80(8), 940-944.

Hurst, E. (1964). Malignant tumors in Alaska Eskimos: Unique predominance of carcinoma of the esophagus in Alaskan Eskimo women. Cancer, 17(9), 1187-1196.

Ireland, B., Lanier, A. P., Knutson, L., Clift, S. E., & Harpster, A. (1988). Increased risk of cancer in siblings of Alaskan native patients with nasopharyngeal carcinoma. International Journal of Epidemiology, 17(3), 509-511.

Irvine, J., Gillis, D. C., Tan, L., Chiu, S., Liu, L., & Robson, D. (1991). Lung, breast and cervical cancer incidence and survival in Saskatchewan northerners and registered Indians (1967-86). In B. D. Postl, P. Gilbert, J. Goodwill, M. E. K. Moffat, J. D. O'Neil, P. A. Sarsfield, & T. K. Young (Eds.), Circumpolar Health 90. Proceedings of the 8th International Congress on Circumpolar Health. Whitehorse, Yukon, May 20-25, 1990 (pp. 452-455). Winnipeg, Manitoba: University of Manitoba Press.

Irvine, J., Tan, L., Janmohamed, M., Robson, D., Beach, D., & Chiu, S. (1993). Cancer in northern Saskatchewan—Trends and survival, 1967-86. Saskatoon, Saskatchewan: Northern Medicine Services, Department of Family Medicine, University of Saskatchewan.

Irwin, L. (1994). Dreams, theory and culture: The plains vision quest paradigm. American Indian Quarterly, 19(2), 229-245.

Joe, J. R., & Justice, J. W. (1992). Introduction: Proceedings of the first national conference on cancer in native Americans. American Indian Culture and Research Journal, 16(3), 9-20.

Jordan, S. W., & Key, C. R. (1981). Carcinoma of the cervix in southwestern American Indians: Results of a cytologic detection program. Cancer, 47(10), 2523-2532.

Justice, J. W. (1988). Contrasting cancer patterns in two American Indian tribes. Native American Research and Training Center Monograph Series. Tuscon, Arizona: The University of Arizona.

Justice, J. W. (1992). Cancer profiles of two American Indian tribes. American Indian Culture and Research Journal, 16(3), 87-116.

Key, C. R., & Becker, T. M. (1992). Data sources for cancer statistics among American Indians/Alaska Natives. American Indian Culture and Research Journal, 16(3), 51-64.

Kiiskeentum. (1992). Spirit seekers 1: Ceremonies. Winnipeg: R. B. Russell.

Kleinman, A. (1992). Local worlds of suffering: An interpersonal focus for ethnographies of illness experience. Qualitative Health Research, 2(2), 127-134.

Krishnamurthy, S., Lanier, A. P., Dohan, P., Lanier, J. F., & Henle, W. (1987). Salivary gland cancer in Alaskan natives, 1966-1980. Human Pathology, 18(10), 986-996.

Lanier, A. P. (1993). Epidemiology of cancer in Alaska Natives. Alaska Medicine, 35(4), 245-247.

Lanier, A. P., Bender, T., Talbot, M., Wilmeth, S., Tschopp, C., Henle, W., Henle, G., Ritter, D., & Teraski, P. (1980). Nasopharyngeal carcinoma in Alaskan Eskimos, Indians, and Aleuts: A review of cases and study of Epstein-Barr virus, HLA, and environmental risk factors. Cancer, 46(9), 2100-2106.

Lanier, A. P., Bulkow, L. R., & Ireland, B. (1989). Cancer in Alaskan Indians, Eskimos, and Aleuts, 1969-83: Implications for etiology and control. Public Health Reports, 104(6), 658-664.

Lanier, A. P., Kilkenny, S. J., & Wilson, J. F. (1985). Oesophageal cancer among Alaskan natives, 1955-1981. International Journal of Epidemiology, 14(1), 75-78.

Lanier, A. P., McMahon, B. J., Alberts, S. R., Popper, H., & Heyward, W. L. (1987). Primary liver cancer in Alaskan natives, 1980-1985. Cancer, 60(8), 1915-1920.

Lipson, J. G. (1989). The use of self in ethnographic research. In J. M. Morse (Ed.), Qualitative nursing research: A contemporary dialogue (pp. 61-75). Rockville, CO: Aspen.

Lowenfels, A. (1992). Gallstones and gallbladder cancer in southwestern Native Americans. American Indian Culture and Research Journal, 16(3), 77-86.



Lowenfels, A., Walker, A., Althaus, D., Townsend, G., & Domellof, L. (1989). Gallstone growth, size and risk of gallbladder cancer: An interracial study. International Journal of Epidemiology, 18(1), 50-54.

Mahoney, M., & Michalek, A. (1991). A meta-analysis of cancer incidence in United States and Canadian native populations. International Journal of Epidemiology, 20(2), 323-327.

Mahoney, M. C., Michalek, A. M., Cummings, M., Nasca, P. C., & Emrich, L. J. (1989). Cancer surveillance in a northeastern native American population. Cancer, 64(1), 191-195.

Malloch, L. (1989). Indian medicine, Indian health. Study between red and white medicine. Canadian Woman Studies, 10(2 & 3), 105-112.

Manitoba Cancer Treatment and Research Foundation. (1992). Annual report statistics. Cancer incidence and mortality in the province of Manitoba during the calendar year of 1992. Winnipeg: Author.

Mao, Y., Morrison, H., Semenciw, R., & Wigle, D. (1986). Mortality on Canadian Indian reserves 1977-1982. Canadian Journal of Public Health, 77, 263-268.

Mechanic, D. (1986). The concept of illness behavior: Culture, situation and personal predisposition. Psychological Medicine, 16, 1-7.

Melbye, M., Ebbeson, P., Levine, P. H., & Bennike, T. (1984). Early primary infection and high Epstein-Barr virus antibody titres in Greenland Eskimos at high risk for nasopharyngeal carcinoma. International Journal of Cancer, 34, 619-623.

Miles, M. B., & Huberman, A. M. (1984). Qualitative data analysis: A sourcebook of new methods. Newbury Park: Sage.

National Cancer Institute of Canada. (1991). Canadian Cancer Statistics. Toronto, Canada: Canadian Cancer Society.

National Cancer Institute of Canada. (1993). Canadian Cancer Statistics. Toronto, Canada: Canadian Cancer Society.

National Cancer 2000 Task Force (1992). The proceedings of Cancer 2000, April, 1992. A report on the work of the national task force. Cancer 2000: Strategies for cancer control in Canada. Toronto: Canadian Cancer Society.

Nielsen, B. B., McMillan, S., & Diaz, E. (1992). Instruments that measure beliefs about cancer from a cultural perspective. Cancer Nursing, 15(2), 109-115.

Nielsen, N. H. (1986). Cancer incidence in Greenland. Arctic Medical Research, 43, 11-168.

Nielsen, N. H., Prener, A., Hart Hansen, J. P., & Jensen, O. M. (1988). Current trends in cancer incidence in Greenland. Arctic Medical Research, 47(1), 640-641.

Norsted, T. L., & White, E. (1989). Cancer incidence among native Americans of western Washington. International Journal of Epidemiology, 18(1), 22-27.

Olesen, V. (1994). Feminisms and models of qualitative research. In N. K. Denzin & Y. S. Lincoln (Eds.), Handbook of qualitative research (pp. 158-174). Thousand Oaks, CA: Sage.

Olsen, S. J. (1993). Cancer prevention and early detection in Native American and Alaska Native populations. In M. Frank-Stromborg & S. J. Olsen (Eds.), Cancer prevention in minority populations. Cultural implications for health care professionals (pp. 3-56). St. Louis, MO: Mosby.

Ontario Ministry of Health. (1994). New directions. Aboriginal Health Policy for Ontario. Toronto, Ontario: Ministry of Health - Aboriginal Health Office.

Pathak, D. R., Pike, M. C., Key, C. R., Teaf, S. R., & Bartow, S. A. (1991). Parity factors and prevalence of fibrosystic breast change in a forensic autopsy series. British Journal of Cancer, *63*, 1005-1009.

Poirier, S., Ohshima, H., De-The, G., Hubert, A., Bourgade, M., & Bartsch, H. (1987). Volatile nitrosamine levels in common foods from Tunisia, South China and Greenland, high-risk areas for nasopharyngeal carcinoma (NPC). International Journal of Cancer, *39*, 293-296.

Rubinstein, R. A. (1991). Reflection and reflexivity in anthropology. In R. A. Rubinstein (Ed.) Fieldwork: The correspondence of Robert Redfield & Sol Tax (pp. 1-35). San Francisco: Westview Press.

Samet, J. M., Key, C. R., Hunt, W. C., & Goodwin, J. S. (1987). Survival of American Indian and Hispanic cancer patients in New Mexico and Arizona, 1969-1982. Journal of National Cancer Institute, *79*(3), 457-463.

Samet, J. M., Kutvirt, D. M., Waxweiler, R. J., & Key, C. R. (1984). Uranium mining and lung cancer in Navajo men. The New England Journal of Medicine, *310*(23), 1481-1484.

- Sandelowski, M. (1986). The problem of rigor in qualitative research. Advances in Nursing Science, 8(3), 27-37.
- Schaefer, O. (1959). Medical observations and problems in the Canadian Arctic, part II. Canadian Medical Association Journal, 81, 386-393.
- Schaefer, O., Hildes, J. A., Medd, L. M., & Cameron, D. G. (1975). The changing pattern of neoplastic disease in Canadian Eskimos. Canadian Medical Association Journal, 112, 1399-1404.
- Skubi, D. (1988). Pap smear screening and cervical pathology in an American Indian population. Journal of Nurse-Midwifery, 33(5), 203-207.
- Solomon, A. (1990). Songs of hope. In M. Posluns (Ed.), Songs for the people: Teachings on the natural way (pp. 75-103). Toronto: NC Press.
- Sonqishe, M., & Levy, L. (1990). Pain control in a patient with myeloma in Zimbabwe. Cancer Nursing, 13(3), 198-200.
- Sontag, S. (1978). Illness as metaphor. New York: First Farrar, Straus and Giroux.
- Sorem, K. A. (1985). Cancer incidence in the Zuni Indians of New Mexico. The Yale Journal of Biology and Medicine, 58, 489-496.
- Spradley, J. P. (1980). Participant observation. Toronto: Holt, Rinehart & Winston.
- Spreitzer, E. (1991). Pain control in a patient with adenocarcinoma of the cervix stage iv in a northern isolated community. Cancer Nursing, 14(3), 155-158.

- Sprott, J. E. (1988). Cancer beliefs in an Alaskan village. Alaska Medicine, 30(5), 155-158.
- Strauss, A. L., & Corbin, J. (1990). Basic of qualitative research: Grounded theory procedures and techniques. Newbury Park: Sage.
- Tafoya, T. (1989). Circles and cedar: Native Americans and family therapy. Journal of Psycho-therapy and the Family, 6, 71-98.
- The Indian Tribes of Manitoba. (1971). Wabung: Our tomorrows. Winnipeg, Manitoba: Manitoba Indian Brotherhood.
- Vachon, M., Lancee, W., Conway, B., & Adair, W. (1990). The needs of people living with cancer in Manitoba. Winnipeg, Manitoba: Manitoba Division of the Canadian Cancer Society.
- Varricchio, C. (1987). Cultural and ethnic dimensions of cancer nursing care. Oncology Nursing Forum, 14(3), 57-58.
- Weiner, D. (1993). Health beliefs about cancer. Alaska Medicine, 35(4), 285-296.
- Welty, T. K. (1991). Health implications of obesity in American Indians and Alaska natives. American Journal of Clinical Nutrition, 53, 1616-1620.
- Welty, T. K., Zephier, N., Schweigman, K., Blake, B., & Leonardson, G. (1993). Cancer risk factors in three Sioux tribes. Alaska Medicine, 35(4), 265-272.
- Young, T. K., & Choi, N. W. (1985). Cancer risks among residents of Manitoba Indian reserves, 1970-1979. Canadian Medical Association Journal, 132, 1269-1273.

Young, T. K., & Frank, J. W. (1983). Cancer surveillance in a remote Indian population in northwestern Ontario. American Journal of Public Health, 73(5), 515-520.

Young, T. K., Orr, P., McNichol, P., & Katz, A. (1991). Prevalence of human papillomavirus infection and risk of cervical cancer in an urban Indian population. A literature review and research proposal. Report prepared for Laboratory Centre for Disease Control, Health and Welfare Canada. Winnipeg: Northern Health Research Unit, Department of Community Health Sciences, University of Manitoba.

Yu, M. C. (1990). Diet and nasopharyngeal carcinoma. Progress in Clinical and Biological Research, 346, 93-105.

Appendix A

Approval Form

The University of Manitoba

FACULTY OF NURSING  
ETHICAL REVIEW COMMITTEE

APPROVAL FORM

Proposal Number N#94/13

Proposal Title: "THE CANCER EXPERIENCE OF FIRST NATION PEOPLE."

Name and Title of

Researcher(s):

FJOLA HART-WASEKEESIKAW

MASTER OF NURSING GRADUATE STUDENT

FACULTY OF NURSING

UNIVERSITY OF MANITOBA

Date of Review: JUNE 06, 1994.

APPROVED BY THE COMMITTEE: JUNE 06, 1994.

Comments: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Date: June 8/94

LORNA GUSE, BHD      ACTING Chairperson  
ASSOCIATE PROFESSOR  
UNIVERSITY OF MANITOBA FACULTY OF NURSING

Position

NOTE:

Any significant changes in the proposal should be reported to the Chairperson for the Ethical Review Committee's consideration, in advance of implementation of such changes.

## Appendix B

**Letter To Chief and Council**

Chief.....and Council Members of the  
.....First Nation.

Dear Chief,

Re: request to make a formal presentation to the Chief and Council

I am a graduate student at the University of Manitoba, Faculty of Nursing. I am also a member of the Fisher River First Nation. For my thesis topic I plan to study the experiences that First Nations people have with cancer. Many Native people have expressed concern about the increasing incidence of cancer in their communities. However, little has been written about the experiences First Nations People have with cancer.

Learning about the cancer experience of First nations People would assist health care providers to develop resources that are culturally relevant in teaching about the prevention of cancer. This study should help health care workers to provide Native cancer patients with the culturally sensitive care that they require.

I would like the opportunity to present the study to yourself and Band Council members. If you require further information please contact me at 7 .

With respect,

Fjola Hart Wasekeesikaw



## Appendix C

**First Nations People Diagnosed with Cancer**

## A Letter of Invitation to Participate in a Study

My name is Fjola Hart-Wasekeesikaw. I am a master of nursing student at the University of Manitoba, Winnipeg, Manitoba, Faculty of Nursing. I would like to find out what experiences First Nations People with cancer have had. You are being invited to be a participant in the study as your views and ideas are valuable to understand what it means to be a First Nations person with cancer.

If you agree to participate, I would like to interview you at two different times in a place that is comfortable to you such as your own home. The interviews will take one hour each and they will be tape recorded.

When I write the report of this study I will not refer to you specifically. Your name will not be used. No one will know that you have given me information.

Although there is no direct benefit to you for participating, I hope to learn more about the ideas and experiences Native people have about cancer and the care they are receiving.

If you think you might be interested in participating please contact me, Fjola Hart-Wasekeesikaw, at the band office on \_\_\_\_\_ (date) between the hours of \_\_\_\_\_ (time).

## Appendix D

### **The Families of First Nations People Diagnosed with Cancer**

#### A Letter of Invitation to Participate in a Study

My name is Fjola Hart-Wasekeesikaw. I am a master of nursing student at the University of Manitoba, Winnipeg, Manitoba, Faculty of Nursing. I would like to find out what experiences First Nations People with cancer have had. You are being invited to be a participant in the study as your views and ideas are valuable to understand what cancer means to the First Nations person.

If you agree to participate, I would like to interview you with other members of your family. The interview will take one to one and one half hours in a place that is comfortable to your family such as your own home. The interviews will be tape recorded.

When I write the report of this study I will not refer to you specifically. Your name will not be used. No one will know that you have given me information.

Although there is no direct benefit to you for participating, I hope to learn more about the ideas and experiences Native people have about cancer and the care they are receiving.

If you think you might be interested in participating please contact me, Fjola Hart-Wasekeesikaw, at the band office.

## Appendix E

**MEMBERS OF A FIRST NATION COMMUNITY**

## A Letter of Invitation to Participate in the Study

My name is Fjola Hart-Wasekeesikaw. I am a master of nursing student at the University of Manitoba, Winnipeg, Manitoba, Faculty of Nursing. I would like to learn about the experiences First Nations People with cancer have.

**ELDERS, TRADITIONAL HEALERS, CHIEF, COUNCIL MEMBERS, COMMUNITY HEALTH REPRESENTATIVES, AND OTHER FIRST NATIONS MEMBERS WHO KNOW THE HISTORY OF YOUR COMMUNITY** are invited to be in the study. Your thoughts and ideas are valuable to understand what cancer means to the First Nations People.

If you agree to talk with me, I would like to do this in a place that is comfortable to you such as your own home. The interview will take one hour. If an interpreter is used then I hope that the interpreter's words can be tape recorded. When I write the report of this study I will not refer to you specifically. Your name will not be used. No one will know your identity. The name of your community will not be used.

Although there is no direct benefit to you for participating, I hope to learn more about the ideas and experiences Native people have about cancer and the care they are receiving.

If you think you might be interested in talking with me please contact me, Fjola Hart-Wasekeesikaw, at the band office.

## Appendix F

## Consent Form For Participants Diagnosed With Cancer

This is to invite you to take part in a study about First Nations People who have cancer. As a result of this study I hope to learn two main things: Ways to teach how cancer can be prevented in the Native people and ways to improve health care to Native people who have cancer. You are being invited to take part in this study since you have expressed an interest in the study.

If you decide to take part in this study, I would like to ask some questions about what it is like to have cancer. The interview will take one hour. You are free to stop at any time during the interview. I would like to tape record the interview. However, if it is uncomfortable to have a tape recorder present, it will not be used. If the tape recorder is used, the tape will be kept in a securely locked place from seven to ten years and then destroyed. The information that is on the tape will be typed.

The written report of this study will not mention your community by name. Your name will not be used in the report. You will be referred to as part of a group of Native people in a First Nations community. Only myself \_\_\_\_\_, and the advisors for this research project will be able to listen to your tapes. They are listed at the bottom of this consent form.

You are free to decide whether or not you want to take part in this interview. Knowledge about Native people and their experiences with cancer has not been done before. The experiences you share will help health care providers develop improved education programs to prevent cancer in Native people. The knowledge that you share will help the understanding health care providers need to give care to Native people who have cancer.

To show respect for the knowledge that is shared with me, I will leave a gift bundle with you.

I am available to answer questions you might have. If you have questions later then I, Fjola Hart Wasekeesikaw, can be reached by telephone at \_\_\_\_\_ or, in writing, at the Faculty of Nursing, Bison Building, Univeristy of Manitoba, R3T 2M7. Or you may wish to call the chairperson of my thesis committee, Professor

David Gregory. He can be reached at

You will be given a copy of this consent form to keep. A report of the study will be given to the Chief and Council. If you would like your own copy of the report please sign below.

Code number \_\_\_\_\_

You are making a decision whether or not to take part in this interview. Your signature indicates that you understand the information provided above and have decided to participate in this study. You are free to stop the interview at any time after signing this form.

\_\_\_\_\_  
Date

\_\_\_\_\_  
Your signature

\_\_\_\_\_  
Date

\_\_\_\_\_  
Fjola Hart Wasekeesikaw

Copy of the report      \_\_\_\_\_yes      \_\_\_\_\_no

Professor David Gregory, Faculty of Nursing, University of Manitoba

Dr. Linda Kristjanson, Faculty of Nursing, University of Manitoba

Dr. John O'Neil, Department of Community Health Sciences, Faculty of Medicine,  
University of Manitoba.

## Appendix G

## Consent Form For Family Members of Participants With Cancer

This is to invite you to take part in a study about First Nations People who have cancer. As a result of this study I hope to learn two main things: Ways to teach how cancer can be prevented in the Native people and ways to improve health care to Native people who have cancer. You are being invited to take part in this study since you have expressed an interest in the study.

If you decide to take part in this study, I would like to ask some questions about what it is like to have cancer. I would like to interview you with other members of your family. The interview will take one to one and one half hours. You are free to stop at any time during the interview. I would like to tape record the interview. However, if it is uncomfortable to have a tape recorder present, it will not be used. If the tape recorder is used, the tape will be kept in a securely locked place from seven to ten years and then destroyed. The information that is on the tape will be typed.

The written report of this study will not mention your community by name. Your name will not be used in the report. You will be referred to as part of a group of Native people in a First Nations community. Only myself \_\_\_\_\_, and the advisors for this research project will be able to listen to your tapes. They are listed at the bottom of this consent form.

You are free to decide whether or not you want to take part in this interview. Knowledge about Native people and their experiences with cancer has not been done before. The experiences you share will help health care providers develop improved education programs to prevent cancer in Native people. The knowledge that you share will help the understanding health care providers need to give care to Native people who have cancer.

To show respect for the knowledge that is shared with me, I will leave a gift bundle with you.

I am available to answer questions you might have. If you have questions later then I, Fjola Hart Wasekeesikaw, can be reached by telephone at \_\_\_\_\_ or, in writing, at the Faculty of Nursing, Bison Building, Univeristy of Manitoba, R3T

2M7. Or you may wish to call the chairperson of my thesis committee, Professor David Gregory. He can be reached at

You will be given a copy of this consent form to keep. A report of the study will be given to the Chief and Council. If you would like your own copy of the report please sign below.

Code number \_\_\_\_\_

You are making a decision whether or not to take part in this interview. Your signature indicates that you understand the information provided above and have decided to participate in this study. You are free to stop the interview at any time after signing this form.

\_\_\_\_\_  
Date

\_\_\_\_\_  
Your signature

\_\_\_\_\_  
Date

\_\_\_\_\_  
Fjola Hart Wasekeesikaw

Copy of the report \_\_\_\_\_yes \_\_\_\_\_no

Professor David Gregory, Faculty of Nursing, University of Manitoba

Dr. Linda Kristjanson, Faculty of Nursing, University of Manitoba

Dr. John O'Neil, Department of Community Health Sciences, Faculty of Medicine,  
University of Manitoba.

## Appendix H

## Consent Form For Traditional Elders and Healers

In accordance with the traditional ways of the community I will place tobacco at the Elder's side while I present the consent form.

This is to invite you to take part in a study about First Nations People who have cancer. As a result of this study I hope to learn about the experiences Native people have with cancer. I would like to learn from the Elders about cancer. Where does it come from? How does it grow? What do people have to do when they have cancer? The Elders and healers will not be asked to share their knowledge about medicine herbs. You are being invited to take part in this study because you have been identified by the Chief and Council as being an Elder in your community.

To show respect for the knowledge that is shared with me, I will leave a gift bundle for the Elder.

If you decide to take part in this study, I would like to ask some questions about cancer. The questions and talking will take one hour. You are free to stop at any time during the teaching. I would like to use a tape recorder to tape the interpreter if English is not spoken. A tape recorder will be used only if you agree to have it present during our talk. If the tape recorder is used, no one will know it is you sharing your experiences. The tape recording will be kept locked in a safe place from seven to ten years and then it will be destroyed. The information that is on the tape will be typed.

The written report of this study will not mention your community by name. Your name will not be mentioned in the report. You will be referred to as an Elder in a First Nations community. Only myself \_\_\_\_\_, and the advisors for this project will be able to listen to your tapes. They are listed at the bottom of this consent form.

You are free to decide whether or not you want to take part in this teaching session. Knowledge about the beliefs Native people have about cancer has not be done before. The teachings you share will help nurses better understand Native people and their beliefs about cancer. The knowledge that could be identified with you will be



kept confidential.

I am available to answer questions you might have. If you have questions later then I, Fjola Hart Wasekeesikaw, can be reached by telephone at \_\_\_\_\_ or, in writing, at Faculty of Nursing, Bison Building, University of Manitoba, R3T 2M7.

You will be given a copy of this consent form to keep. A report of the study will be given to the Chief and Council. If you would like your own copy of the report you may contact me.

Code number \_\_\_\_\_

You are making a decision whether or not to take part. Your signature or mark indicates that you understand the information provided above and have decided to participate in this study. You are free to stop the teaching at any time after signing this form.

\_\_\_\_\_  
Date

\_\_\_\_\_  
Elder signature or mark

\_\_\_\_\_  
Date

\_\_\_\_\_  
Interpreter

\_\_\_\_\_  
Date

\_\_\_\_\_  
Fjola Hart Wasekeesikaw

Copy of the report \_\_\_\_\_yes \_\_\_\_\_no

Professor David Gregory, Faculty of Nursing, University of Manitoba

Dr. Linda Kristjanson, Faculty of Nursing, University of Manitoba

Dr. John O'Neil, Department of Community Health Sciences, Faculty of Medicine,  
University of Manitoba.

## Appendix I

## Consent Form For Community Members

This is to invite you to take part in a study about First Nations People who have cancer. As a result of this study I hope to learn two main things: Ways to teach how cancer can be prevented in the Native people and ways to improve health care to Native people who have cancer. You are being invited to take part in this study since you have expressed an interest in the study.

If you decide to take part in this study, I would like to ask some questions about what it is like to have cancer. The interview will take one hour. You are free to stop at any time during the interview. I would like to tape record the interview. However, if it is uncomfortable to have a tape recorder present, it will not be used. If the tape recorder is used, the tape will be kept in a securely locked place from seven to ten years and then destroyed. The information that is on the tape will be typed.

The written report of this study will not mention your community by name. Your name will not be used in the report. You will be referred to as part of a group of Native people in a First Nations community. Only myself \_\_\_\_\_, and the advisors for this research project will be able to listen to your tapes. They are listed at the bottom of this consent form.

You are free to decide whether or not you want to take part in this interview. Knowledge about Native people and their experiences with cancer has not been done before. The experiences you share will help health care providers develop improved education programs to prevent cancer in Native people. The knowledge that you share will help the understanding health care providers need to give care to Native people who have cancer.

To show respect for the knowledge that is shared with me, I will leave a gift bundle with you.

I am available to answer questions you might have. If you have questions later then I, Fjola Hart Wasekeesikaw, can be reached by telephone at \_\_\_\_\_ or, in writing, at the Faculty of Nursing, Bison Building, Univeristy of Manitoba, R3T 2M7. Or you may wish to call the chairperson of my thesis committee, Professor

David Gregory. He can be reached at

You will be given a copy of this consent form to keep. A report of the study will be given to the Chief and Council. If you would like your own copy of the report please sign below.

Code number \_\_\_\_\_

You are making a decision whether or not to take part in this interview. Your signature indicates that you understand the information provided above and have decided to participate in this study. You are free to stop the interview at any time after signing this form.

\_\_\_\_\_  
Date

\_\_\_\_\_  
Your signature

\_\_\_\_\_  
Date

\_\_\_\_\_  
Fjola Hart Wasekeesikaw

Copy of the report \_\_\_\_\_yes \_\_\_\_\_no

Professor David Gregory, Faculty of Nursing, University of Manitoba

Dr. Linda Kristjanson, Faculty of Nursing, University of Manitoba

Dr. John O'Neil, Department of Community Health Sciences, Faculty of Medicine,  
University of Manitoba.

## Appendix J

## Interview Guide For Participants With Cancer

1. What is it like to have cancer?
2. How do people know they have cancer?
3. Where does cancer come from?
4. What does cancer do in the body?
5. Does it grow? If so, how?
6. Is it worse to have cancer in certain parts of the body?
7. Is cancer different in Native People?
8. Is cancer different in children? adults? elderly?
9. How did you find out that you had cancer?
10. What did you do once you knew you had cancer?
11. Can you tell me about your treatment? What happened to you?
12. What must you do to feel better?
13. How do Elders, traditional healers, physicians, nurses help people with cancer?
14. Are there some things that the Elder or traditional healer can do but are asked not to do by the physician? the nurse? the hospital?
15. What does your family say about you having cancer?
16. What do your friends say about you having cancer?
17. What do other people in the community say about you having cancer?
18. How do family, friends, community members help people with cancer?
19. What are some of the difficulties that people with cancer face?

## Appendix K

## Interview Guide For Family Members of Participants With Cancer

1. What is it like to have a relative with cancer?
2. How do people know they have cancer?
3. Where does cancer come from?
4. What does cancer do in the body?
5. Does cancer grow? If so, how?
6. Is it worse to have cancer in certain parts of the body?
7. Is cancer different in Native People?
8. Is cancer different in children? adults? elderly?
9. How did you find out that your relative had cancer?
10. What did you do once you knew your relative had cancer?
11. Can you tell me how it was for you when your relative had treatment? What happened?
12. What must you do to help your relative feel better?
13. How do Elders help people with cancer?
14. How do traditional healers help people with cancer?
15. How do physicians help people with cancer?
16. How do nurses help people with cancer?
17. Are there some things that the Elder or traditional healer can do but are not asked to do by the physician? the nurse? the hospital?
18. What does your relative who has cancer say about having cancer?
19. What do your friends say about your relative having cancer?
20. What do other people in the community say?

## Appendix L

## Interview Guide For Community Members

1. How do people get cancer?
2. What is cancer?
3. What does cancer do in the body? Does it grow? If so, how?
4. Is it worse to have cancer in certain parts of the body?
5. When did cancer first start in native people?
6. Is cancer different in Native people?
7. Is cancer different in children? in adults? in the elderly?
8. What is like to know someone with cancer?
9. What does it mean when people get cancer?
10. How do people know they have cancer?
11. What do people have to do when they know they have cancer?
12. What can people do so they will not get cancer?
13. How do Elders help people with cancer?
14. How do traditional healers help people with cancer?
15. How do physicians help people with cancer?
16. How do nurses help people with cancer?
17. How do community health representatives help people with cancer?
18. Are there some things that the Elder or traditional healer can do but are asked not to do by the hospital? the physician? the nurse?
19. What are some of the difficulties that people with cancer face?
20. What is it like to know someone with cancer?