

THE LIVED EXPERIENCE OF ANISHINAABE PEOPLE WITH CANCER:
A FOCUS ON INDIGENOUS HEALING,
WESTERN MEDICINE AND MINOBIMAADIZIWIN

by

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Abstract

Cancer is a leading cause of death in Anishinaabe people and the incidence is increasing. Despite reported successes of integrating Indigenous healing and Western medicine in the treatment of addictions, domestic violence, mental health, palliative care and chronic illness, there is a paucity of such information for cancer. A number of studies highlighted the need for awareness for policy makers and physicians of the contribution of Indigenous healing to cancer care, as well as the need for cultural safety.

This Indigenous inquiry examined potential benefits and challenges of including Indigenous healing in cancer care. Using a participatory approach, I investigated how the cancer experience was affected when Anishinaabe people included both Indigenous and Western medicine in treatment and when they did not. This inquiry also examined how Indigenous healing assisted in achieving *Minobimaadiziwin*, an Anishinaabe understanding of health.

Interviews were conducted with thirteen adults diagnosed with cancer from five Manitoulin First Nation communities. Seventeen key informant interviews were conducted with those working from Indigenous and Western health perspectives. A conversational method was employed in this Indigenous research as it honoured the oral tradition of the Anishinaabe and was concerned with co-creating knowledge in a relational context. Understanding stories involved Indigenous knowledge and Western theory, framed as two-eyed seeing.

Participants recognized that *Minobimaadiziwin* could not be realized with Western medicine alone. With the inclusion of IH/TM and recognition of the spiritual component of life, a person can approach *Minobimaadiziwin* despite the obstacle of cancer along their path. This is best

facilitated by braiding the two types of healing. Dissemination of results took two forms: a collective, teaching story for the Anishinaabe people concerning cancer and Minobimaadiziwin and publications concerning potential benefits of and challenges with pluralistic medicine for Anishinaabe cancer care.

Keywords: Aboriginal Health, Cancer, Indigenous Healing and Traditional Medicine, Indigenous Methods, Indigenous Knowledge, Participatory Action Research, Two-Eyed Seeing

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I would first like to acknowledge my family. The completion of this dissertation would not have been possible without their support and love. It is a well-known fact that undertaking a PhD is not without sacrifice and inherent challenges beyond the academic fold.

It has been shared in Christian and Anishinaabe teachings that “a little boy will lead them” and my son exemplifies this for me. As an educator, I started my PhD studies with the aim of honouring my parents with a teaching meant to be shared with Anishinaabek concerning cancer and Minobimaadiziwin. I realized that this will also help my son learn about the beauty and importance of our teachings and what Anishinaabek have to offer the rest of the world. He is a child intent on learning from his Elders, he appreciates their wisdom and I am in awe of the knowledge he holds, considering his short time on this path. He has been a teacher and has led me to look closely at the twin to physical self - that is, spirituality. This direction comes through his questions and his appreciation of and interest in our language and community. Miigwech, Colin.

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Chapter 1: Introduction

Locating myself in this research¹

It is customary within the Anishinaabe culture and with Indigenous research design to introduce and locate oneself as a measure of respect (Absolon & Willett, 2004; Geniusz, 2009; Hart, 2002; Kovach, 2009; Lavallee, 2009; Linklater, 2011; Weber-Pillwax, 2004). Anishinaabe people usually begin by declaring their Spirit name, clan and community: *M'skwaa Beedabeno kwe n'dishnikaas* [Translation: My name is Red Dawn Woman]. *Name dodem* [Translation: My clan is the Sturgeon Clan]. *Wikwemikong n'doonjiba* [Translation: I am from Wikwemikong]. The purpose of identifying the researcher and the purpose for conducting this research is two-fold. One purpose is to maintain authenticity, transparency and to conduct this work in a “good way.” This research is intended to be respectful, valid, useful and meaningful to both academe and the Anishinaabe people. The notions of transparency and validity are especially relevant as a researcher-in-relation who intends to study within her home community. A second purpose for this introduction is to begin conveying an Anishinaabe worldview which is becoming re-learned by many, including myself.

I recently came across a book written by Wendy Makoons Geniusz. Her work, entitled *Our Knowledge is Not Primitive: Decolonizing Botanical Anishinaabe Teachings* has been a guidebook, of sorts, for my research. I am thankful for all of those Indigenous scholars who came before me, not only to clear a path, but for ensuring that our Anishinaabe *gikendassowin* is always respected. Geniusz cites a song by Huron Smith (1932) which was cited in what is

¹ Elements of the section on *Locating Myself in this Research* were previously published in the *Anishinaabewin Niswi Deep Roots, New Growth* 2012 conference proceedings (Peltier, 2013).

believed to be the first known published research on ethnobotanical knowledge and Anishinaabe *gikendaasowin*. The lyrics for this song have no date associated with them because they are believed to be based on the original instructions from *G'Zhe Manido* [Translation: The Creator] to the Anishinaabek on how to gather medicines.

Nin b aba odji'bîke o'o'we'dasa'ssema

I go to gather roots; here is tobacco;

mînode ni nowi nîmîcîn gi wedji'bîkei'en

Give me direct guidance, you, maker of roots

da mino wi dji'bîkei'an.

That I may get the proper roots (Smith as cited in Geniusz, 2009, p. 62).

The words in this particular song represent what I set out to do in my dissertation and I believe this song is a metaphor for my work. On a daily basis, I asked the Creator for direction in my work. I sought permission and gathered stories (collected the data). I always offered tobacco and asked for direct guidance so that the stories were presented in an honest and respectful way. The Grandfather teaching of honesty is critical in research to ensure that when searching for that Anishinaabe *gikendassowin* (Indigenous knowledge) from the stories that we interpret and represent them in the most respectful way, hopefully free of any bias and full of learning to be shared with others.

My doctoral work coincides with a personal journey to re-learn and gather the teachings of my ancestors. As Rheault (1999) eloquently stated: "In the case of research dealing with the way of a good life [Minobimaadiziwin], knowledge and identity, it not only develops the necessary structures for the investigation, but also ultimately provides a degree of self-revelation for the investigator" (p. 16). Similarly, I believe it is necessary to begin with an understanding of the

researcher's perspective, as well as the drivers for the research. In her article on developing great research questions, Lipowski (2008) states that researchers should formulate research questions by keeping personal experiences in mind as opposed to thinking only in terms of data. My research questions were conceived as a result of familial and community experiences with cancer and Indigenous healing.

Throughout my doctoral thesis journey, I have had the pleasure of meeting and learning with academics from a variety of disciplines. Some of the most insightful conversations have been with other Indigenous researchers who have informed me that I cannot complete this work without telling my own story. This is congruent with being authentic and follows our Grandfather teaching of Honesty. It also speaks to the difference between my experiences as an Anishinaabe graduate student working and living within her own community, in comparison to someone who is coming at their work from a purely etic or even from the non-Indigenous, *insider* perspective.

My story is about a disease that has no single blueprint or road map. For some people, cancer treatment is successful and the cancer was curable but, unfortunately for others, it remains a lethal disease that is relentless in its progression. I have experienced the extremes of this disease with my parents and my grandfather. By telling my story, it is my hope that the readers understand that some cancers, for instance, breast, cervical and colon cancer, may be treatable and curable. It takes an informed health advocate to take a preventative approach to their health. This can be approached through many avenues including the use of Western medicine or Indigenous healing/traditional medicine, but what is central to good health is balance. Minobimaadiziwin is a central theme within this work and it involves maintaining balance in the physical, mental, emotional and spiritual aspects of ourselves. Those stories that have been

gathered in this work include examples of how Anishinaabek are dealing with cancer in their own way.

My first encounter with cancer was through the experience of my grandfather, David Lewis (Takwadjiwan). My own memories of my grandpa were of a kind, generous, hardworking man for whom family meant everything. I remember my grandpa, a long-time smoker, coming to visit and in his own way, attempting to teach my dad about the dangers of smoking and cancer. I knew this teaching was meant for me, too, because he was speaking English. He and my dad always visited using *Anishinaabemowin* [Translation: Anishinaabe language]. It was very rare to hear them using the English language in any of their conversations. I remember them sitting at the table one evening and my Grandpa taking a cigarette right out of my dad's mouth. He broke it in half and threw it into the ashtray, telling my dad that this would kill him one day. Incidentally, my dad, always a comedian, just chuckled and lit another one. At the time, he seemed unconcerned about how important this teaching would become.

My grandpa was an independent man and although he did work as a caretaker of the Wikwemikong Nursing Home building, he rarely, if ever, visited the doctors, the community health clinic or the hospital for his own medical treatment. According to my aunt, who is a community nurse, my grandpa was not on any other form of Western medication with the exception of the occasional use of Aspirin or cough syrup when his congestion and coughing were becoming problematic. My eldest aunt Liz and my uncle Mike happened to be visiting when my grandpa's coughing and congestion were a growing cause for concern. Aunt Liz offered to drive him to the hospital to get checked by a doctor and he reluctantly agreed to go. My grandfather was diagnosed with cancer and he also had pneumonia. He was given six months to a year to live but being the strong man that he was, he lasted two years after this diagnosis was

given. My grandpa did agree to go through systemic therapy and radiation treatments at the former Northeastern Ontario Regional Cancer Centre in Sudbury, Ontario. For someone who did not use the health care system very often, I often wonder what went through my grandpa's mind when he endured cancer treatment at this facility and what this experience was like for him.

My dad had shared with me that my Grandpa did have knowledge of traditional medicines. This knowledge, however, was not forthcoming perhaps because of mistrust or fear of criticism. My dad told of a time he remembered going to harvest a certain type of medicine with my grandpa and his good friend, Wilfred Kimewon. They spoke about and reminded each other about doing things "in a good way" and offered *Semaa* [Translation: tobacco] for the medicines that they were about to pick. I remember my grandpa sharing our medicines - *Abzeechigun* [Translation: a medicine that corrects illness/brings you back to health/immune boosting] when I was sick with a cold and, more discretely, a stone he placed in my mother's hands before she underwent surgery for her back problems. Despite the apparent *zhagwenmowin* [Translation: imposed shame] on his beliefs, he meant to share what he believed would be helpful to others. It seemed that my grandpa was someone who was able to blend Anishinaabe *Gikendaasowin* with Catholicism, another strong Wikwemikong spiritual tradition, as he attended mass regularly, without fail.

My grandfather, always a hardworking man, was not one to sit around and dwell on his illness. I remember that on the day of his death he was repairing the roof of the house he built and shared with my grandmother, Josephine Lewis (nee Gabow) in Wikwemikong. He wanted to continue doing the things he did on a daily basis, but when this became too difficult and his body was not cooperating anymore, he accepted his death and seemed content with the life he led, living in Minobimaadiziwin until his spirit left this realm. My aunt Monica, a community nurse, often served as a caregiver for my grandpa. She told me that she remembered him telling her prior to

the day he died, in *Anishinaabemowin* [Translation: Anishinaabe language], “I would like to die tomorrow.” My grandpa died of lung cancer on May 3, 1998. On that day, my dad was called to my grandparents’ home. My dad shared with me that when he arrived, he saw that my grandpa needed help, he picked my grandpa up and when he lifted him, he could literally feel his spirit leaving to begin his journey to the Spirit World.

Our family had another cancer experience when my mother was diagnosed with breast cancer. Her story is one where early detection and screening were successful. My mom, Lynda Lewis (nee McLeod-Shabogesic), is a member of the Nipissing Nation. She is of the Crane Clan where her clan responsibilities lie in leadership and planning. My mother was a leader in Wikwemikong education for over 30 years leaving, her community when she was only 19 years of age to pursue her teaching career in Wikwemikong. She served as an elementary school principal, teacher and special education resource teacher at Wasse-Abin Pontiac School and at Kaboni School for the early part of her teaching career. She enjoys reading and journaling, but is an extremely private person. She preferred to write her experiences in response to some of my questions. I asked my mom for permission to share her story and I wanted to honour that story privileging her voice, rather than mine.

It was a stroke of luck that I broke my wrist because I wouldn’t have gone for the mammogram which detected my breast cancer. I was in denial of how this could have affected my life. I had gone for mammograms in the past and they had never found anything, thankfully. As a result of my broken wrist, I had to go for a bone density test and at around that same time I also received a notice to go for a mammogram. I thought I would get it over and done with and I went for my mammogram at the same time. I never thought I would have cancer ... actually I

thought the mammogram might be a waste of time, since they had never found anything before. I went for the mammogram and as it turned out, it saved my life.

I never really was what I'd call an informed health consumer maybe because I had been relatively healthy my whole life. When I was sent for an x-ray in Little Current and the hospital staff member asked who my family doctor was ... I wasn't sure because I had never had a family doctor. I named Dr. Barss because my husband had been under his care. Dr. Barss came in to see me in x-ray. He told me that my wrist wasn't healing properly and that I'd have to go to Sudbury but that, unfortunately, he couldn't take me on as a patient because he had so many patients on his list already. When I went for my x-ray in Sudbury, I made the appointment for my mammogram. Dr. Barss called me one night while I was painting my kitchen with my sister-in-law, brother-in-law and husband. He told me that they had found something on my mammogram, but that I shouldn't be worried, that it was probably nothing. He must have felt sorry for me, at that point, because he took me on as a patient.

For me, the treatment phase was very quick. Within five weeks of the mammogram I had been booked for surgery. On my next trip to Sudbury, for another wrist x-ray, Dr. Brule, a surgeon, booked an appointment for me to see her. She arranged to have a biopsy done that afternoon. She called me shortly after the biopsy and told me that the first step would be surgery.

I didn't want my family to know about the cancer diagnosis. I didn't want them to worry, so I didn't tell them anything. I drove myself to the biopsy appointment,

but Dr. Brule made me promise that I would have someone drive me for the surgery. So the next time, I asked my sister-in-law to drive me. At this time, I was also driving back-and-forth to Nipissing, looking after my mother who was ailing. Dr. Brule tracked me down at my mother's home. She called to tell me that I had an appointment with Dr. Hearst for chemotherapy and with Dr. Want for radiation. Dr. Want told me I should have someone with me when I saw the chemotherapy doctor. Only then did I decide to tell my husband because he had to come with me.

I went through chemotherapy treatment in Mindemoya and my husband drove me to every appointment. The treatment I received at the Mindemoya hospital was excellent. The environment was comfortable and the staff members, the doctors and nurses, were supportive. They always asked if I had any questions and clarified everything for me. When I finished this stage of treatment, I went to stay at the Daffodil Terrace Lodge in Sudbury for radiation treatments. The other patients and staff at the Lodge were really supportive. You were able to see the doctor every week. Dr. Want was there to provide information and to oversee my care. For the questions I had, the patients would always have kind suggestions for dealing with cancer on a day-to-day basis. The Daffodil Terrace Lodge had all kinds of activities, resources and speakers who provided information on how to deal or cope with cancer, treatment and side effects. The Lodge provided accommodation and improved my access to the treatment facility. Otherwise, it would mean me travelling four hours to-and-from my treatment daily. So, I really appreciated that service. I finished my treatments in June of 2006.

My care continued with follow-up appointments every six months with Dr. Brule and Dr. Want. I have also continued with having my mammograms every year. I'm now a firm believer in screening and early detection. The screening caught the cancer when it was in the early stages ... it saved my life. I have 14 sisters and I've encouraged all of them to have a mammogram. Shortly after finishing my radiation treatment, my sister Jeanette was also diagnosed with breast cancer. She has gone through successful cancer treatment and a mastectomy. We both have been cancer-free for 6 years.

My mother recovered fully from the cancer and decided to retire after 36 years of dedicated service to the community of Wikwemikong. This decision was timely because later that year our family was about to face another bout with another cancer. My dad's health began to decline very quickly and my mom spent the next two years caring for my dad. As it turns out, my dad had cancer. His cancer could not be treated successfully, despite at least two years of diagnostic testing and surgery. My dad had been visibly ill from 2007 to 2009 with what we later learned, but had suspected, was cancer. My father, like many other Anishinaabe people, also suffered the misfortune of having diabetes, which he originally thought was the root of his illness.

In July of 2007, my dad was showing signs of serious illness. He was very weak, had lost a tremendous amount of weight, was sleeping all the time and began losing his voice. His family physician, Dr. Barss, had ordered a battery of tests from August to November which involved several blood tests, ultrasounds, a stress test, a scope, x-rays and finally a CT scan. Within those three months a formal diagnosis was still not forthcoming. I have since learned that this is common when a tissue diagnosis is lacking. On November 17, 2007, I took my dad to see a healer who was visiting Wikwemikong from Whitefish Bay, Ontario in the Lake of the Woods

area. The healer told him he had a growth in his stomach and back and that he would eventually be told it was cancer. In the following weeks, my dad was initiated in the Midewiwin Lodge and he participated in many healing ceremonies surrounded by family members, close friends and community members. One of the ceremonies included the “Shaking Tent or Shake Tent.” It was in preparation for this ceremony that my father first learned that he had cancer. The healer did not even have to touch my father but ran his hand over his back and stopped in the area around his kidney. He said: “It’s here, it’s black and it’s growing and they’re going to say that it is cancer.” Without any form of technology this man identified for my father the root of his physical problems and provided medicines for healing.

On November 21, 2007, my dad was informed that he had a tumor that was 8-10 centimeters in size located in his right kidney. He was scheduled for surgery in January of 2008. Soon thereafter, we were told that the surgery could not be accomplished because of a risk of complications and that the surgery would be too dangerous. My dad was informed that before the surgery to remove the tumor could have been completed he would have to undergo another type of preparatory surgical procedure at St. Michael’s Hospital in Toronto. The surgery occurred on February 12, 2008 and, at first, appeared to be successful. My dad was a changed man. He was alert and no longer wanted to sleep all day. He thought his medical issues were successfully treated and he appeared to be feeling much better. We also continued with his instructions from the healer and things seemed to be going very well.

My dad missed his work at the school, the children, his colleagues and feeling productive. He decided to go back to work in September of 2008. He was principal of Wasse-Abin Junior School, an elementary school in Wikwemikong. He remained devoted to his work and Anishinaabek education. My dad exemplified of the roles and responsibilities of the Fish Clan in

serving his people. He was an avid reader and a true intellectual in constant pursuit of learning new things including Anishinaabe *Gikendaasowin*. My dad had been attending ceremonies including sweats and fasting in the years prior to his illness. The teachings of the clan system tell us that those of the Fish Clan are wise people and they carry the responsibilities of conflict resolution, being the voice of reason and participation in intellectual pursuits such as meditation and philosophy. My dad was always reading about the great philosophers, and he was a proponent of Anishinaabek language and education. As a school leader and family go-to person, he was often the (very stern) voice of reason. He did not take any of these roles and responsibilities lightly. We could not convince him to retire early.

His relatively good health was maintained until the Christmas break of 2008. Early in the school year he was already experiencing memory loss but he tried to persevere in his work. During the Christmas break, my dad experienced numbness in his arm. We had originally thought he was having a stroke. My mom wanted him to go to the hospital to get checked out and he reluctantly agreed. He ended up being admitted for further testing. My dad was sent to Sudbury for another computerized axial tomography (CAT) scan the next morning. A day later, we received the crushing news the cancer had spread to his brain.

January of 2009 was spent preparing for more healing ceremonies with the visiting healer and making trips to Sudbury for specialist care. At one point, I remember meeting with a radiologist who drew a picture for my dad and told him that the cancer had spread not only to his brain but to his lungs, kidneys, stomach ... basically it had spread throughout his entire torso and on to his brain. There was not much that could be done, medically, at this point. It was the first time that I can ever recall my dad showing any emotion about his physical state. My dad spent the last six months of his life with his family and community, living in Minobimaadiziwin. He prepared

himself for his journey to the Spirit World and through the use of Indigenous healing we were brought closer together as a family for a purpose ... for healing and acceptance of my dad's inevitable spirit journey. My Dad's name was Henry Lewis (Takwadjiwan) '*Bemaasige*' – a light for all to see' and he passed away on August 1, 2009 at the age of 62.

Through my doctoral work, I would like to bring the cancer experiences of Anishinaabe people to a place where we can learn from them. In doing so, we can learn about how we are dealing with this disease and how we are striving for *Minobimaadiziwin* (the good life). I am inspired by my family's experiences with cancer and believe that each is a lesson in and of itself. My doctoral work has coincided with my personal journey of re-learning about our Anishinaabe *Gikendaasowin*. As a family, we were awakened to the power of Indigenous medicine and ceremony. Our family went through a process of learning the beauty of our own healing methods and became stronger as a result. We can attribute this to our Indigenous medicines, ceremony, and learning the importance of balance in all aspects of our lives, including that ever-important element of spirituality. Our story is echoed throughout this dissertation and thus speaks to the importance of a collective narrative that should be shared with others facing cancer.

Background

Cancer is the general name for a group of more than 100 diseases. Although there are many kinds of cancer, all cancers start because abnormal cells grow out of control. Untreated cancers can cause serious illness and death (American Cancer Society, 2014).

Epidemiological research concerning Aboriginal peoples² in the early 1990s (Young as cited in Canadian Partnership Against Cancer, 2011) and the early 2000s (Marrett & Chaudhry, 2003) highlighted trends over the past fifty years which suggested an overall shift away from infectious to chronic diseases, such as diabetes and cancer. Cancer itself has become one of the leading causes of death and there is a growing trend of incidence in the Canadian Aboriginal population (Canadian Partnership Against Cancer, 2011; Cancer Care Ontario, 2002). It has been commonly stated that cancer-specific data concerning incidence and mortality are sparse or are not available for Aboriginal populations, especially for First Nations populations in particular (Canadian Partnership Against Cancer, 2011; Cancer Care Ontario, 2012; Gracey & King, 2009; Marrett & Chaudhry, 2003). This is due, in part, to the fact that data to support adequate cancer surveillance has not been collected. For one thing, nationwide health surveys are not typically conducted in First Nations and any data collected off-reserve has a negligible influence on meaningful conclusions (Cancer Care Ontario, 2012). However, some generalizations have been posited regarding cancer in First Nations and Canadian populations. It has been stated that First Nations people are diagnosed with, and die from,

² In this dissertation, the terminology used to describe the population of interest changes often and thus, can be considered interchangeable. In Canada, the term Aboriginal is inclusive of three cultural groups: First Nations, Inuit and Métis. Aboriginal is often used when discussing research in the Canadian and Australian context. Researchers in the global context have also used the terms Native, Indigenous or Indian to describe this population. In the local context and within my study's purpose, methods and results, I use the term Anishinaabe (sing.) or Anishinaabek (pl.) to refer to the original person or people of Manitoulin Island. The Anishinaabek are of Ojibwa, Odawa and Pottawatomi descent.

cancer less often than other groups (Marrett & Chaudhry, 2003; Young & Choi, 1985; Young & Frank, 1983). As one key informant stated, anecdotally,

...we know that cancer is primarily a disease of the aged, of the older people... According to the statistics, Indians don't get cancer at the same rate as white people because it is a disease of the Elderly. The reason they don't get it is they don't live long enough to get it. So it was good news, bad news. (IHP01)

In one study that observed cancer incidence and mortality trends in Ontario First Nations from 1968 to 1991, it was reported that incidence rates for all cancers increased and colorectal and lung cancer rates were approaching the provincial incidence rates (Marrett & Chaudhry, 2003). In a recent publication addressing Cancer Care Ontario's *Aboriginal Cancer Strategy II*, it was stated that, "Cancer incidence is increasing more rapidly and cancer survival is worse among Ontario's First Nations, Inuit and Métis (FNIM) populations than among other Ontarians" (Kewayosh et al., 2015, p. 33). At a national level, the incidence of common cancers has also increased and the Canadian Partnership Against Cancer (2012) has reported that in some Aboriginal populations, the rates are now at, or above, those for the general Canadian population. Where cancer mortality rates for First Nations people are lower than in the general Canadian population due to lower incidence, First Nations people are more likely to die sooner from this disease (Canadian Partnership Against Cancer, 2012). Overall, it has been suggested that there has been a shift in disease trends within Indigenous populations to one that resembles Euro-American disease patterns, which are laden with chronic conditions (Gracey & King, 2009; Marrett & Chaudhry, 2003). Cancer is now among the top three causes of death in

Aboriginal peoples in Canada (Canadian Partnership Against Cancer, 2012). These alarming statistics are cause for action and have prompted a closer examination of health determinants, inequities, policy implications and improvements.

The statistics and the future burden of cancer have been attributed to a variety of factors which shape health. Canadian health researchers have labelled these factors, the social determinants of health. They have identified fourteen key factors, one of which is Aboriginal status (Mikkonen & Rapheal, 2010). Czyzewski (2011) cited the 2007 International Symposium on the Social Determinants of Indigenous Health. It was found that Indigenous determinants of health differed from those of mainstream populations due to varied understandings of health and colonialism as a distal determinant. In their landmark reviews of Indigenous health, Gracey and King (2009) and King, Smith and Gracey (2009) elaborated on these determinants of health and changing disease patterns in Indigenous populations. These authors emphasized the effect of colonization and the social and political context from which the abysmal health trends and overall health inequities between Indigenous and non-Indigenous peoples have emerged (Gracey & King, 2009; King, Smith & Gracey, 2009). As such, researchers Loppie-Reading and Wein (2009) have specified the Indigenous determinants of health and have grouped these according to distal, intermediate, and proximal levels. Poverty is an example of one of the determinants of health which is a cross-cutting factor and compounds the detriment to health. In effect, if someone is poorly educated they are at a disadvantage for finding and sustaining gainful employment. This often forces the individual and their dependents to contend with poorer housing conditions and poorer food options, which is likely to have a negative influence on their health. Loppie-Reading and Wein's (2009) model of

Indigenous determinants of health is further elaborated upon later in this chapter and is connected with my theoretical model.

This dissertation employs this understanding of the Indigenous determinants of health, and underlying inequities in how they apply to the cancer experience and the goal of improving cancer services for the Manitoulin Anishinaabek. Some of the determinants have direct impact on Anishinaabek people and their access to support within the current system of cancer care. For instance, complex jurisdictional issues affect people diagnosed with cancer, as health care is the responsibility of three distinct parties: the federal government through Health Canada – First Nations and Inuit Health Branch’s Non-Insured Health Benefits Program (e.g., drug benefits, medical supplies and equipment benefits, medical transportation and access to traditional healers); the provincial government through the Ontario Ministry of Health and Long-Term Care (e.g., cancer screening, OHIP, Northern Health Travel Grant Program); and the First Nation health centre services which devolved through the Health Transfer policy (e.g., access to primary care services, medical transportation and home care) depending on the services required. This complexity in service delivery may create barriers for accessing diagnostic and treatment services for cancer and for health care access in general (Cancer Care Ontario, 2002; National Collaborating Centre for Aboriginal Health, 2011). Other barriers related to the Indigenous determinants of health include, but are not limited to, the understanding of disease management and the inherent power, cultural and class relationships between patient and health professional (Loppie-Reading & Wein, 2009).

With the anticipated increase in cancer rates in the growing Aboriginal population, cancer has become a priority with a focus on policy implications and improvements. There have been numerous national, provincial and local efforts to strategically plan for the expected rise in cancer incidence. In 2011, the *First Nations, Inuit and Métis Action Plan on Cancer Control* was introduced as a recent action plan introduced by the Canadian Partnership Against Cancer, an organization funded by the government of Canada to address cancer control for Canadians. At the Ontario provincial level, Cancer Care Ontario implemented the Aboriginal Cancer Control Strategy which culminated in the publication, *Aboriginal Cancer Strategy II* (2012). At the local level, a consultation project that focused on the input of Aboriginal communities examined how to engage Aboriginal communities in long-term cancer research. With this community-based strategy in mind, researchers hoped to identify local priorities for future cancer research. In general, efforts from all agencies have been focused on risk reduction and prevention through screening, cancer surveillance and improving cancer care services with a holistic focus in mind. There appears to be a consensus from all agencies that the plans directed at cancer control should have a holistic focus and respond to the distinct needs of Aboriginal peoples, including culturally-responsive solutions.

This research hypothesized that a culturally-responsive solution to cancer care include Indigenous healing and traditional medicine in the treatment and in the maintenance of physical, mental, emotional and spiritual well-being. Upon conducting the background research for the present study, it was found that in much of the literature published on cancer and Aboriginal peoples, there is a dearth of information concerning the use of Indigenous healing/Traditional medicine (IH/TM) in the treatment of cancer (Struthers

and Eschiti, 2004). However, there have been studies published concerning the use of IH/TM and Western medicine in other areas of health and illness (Clarke & Holtslander, 2010; Maar & Shawande, 2010; Puchala, Paul, Kennedy & Mehl-Madrona, 2010; St. Pierre-Hansen, Kelly, Linkewich, Cromarty & Walker, 2010).

Plans for cancer control or cancer strategies often mentioned the need for culturally-responsive resources and services, but there was little mention of IH/TM or the importance of addressing the emotional and spiritual aspects in patient's lives. For instance, Cancer Care Ontario's (2002) *It's Our Responsibility* document which informed the development of Cancer Care Ontario's (2012) *Aboriginal Cancer Strategy II* contained a chapter on traditional healing, but the *Aboriginal Cancer Strategy II* made no further reference to this form of health care for Aboriginal peoples. This has been attributed to an overall lack of awareness about Indigenous healing and traditional medicine. The need for improved awareness of Indigenous healing is evident in current government policies (Canadian Partnership Against Cancer, 2012; Jacklin & Warry, 2004). For example, it is the current policy of the First Nations Inuit Health Branch (FNIHB), which administers Aboriginal health policy in Canada, not to fund traditional medicine programs, services and associated costs of ceremonial expenses, traditional medicines or honoraria for healers (Jacklin & Warry, 2004). This study addresses the gap in evidence concerning the incorporation of both Western medicine and Indigenous healing to promote holistic healing for cancer and supports the need for qualitative data about the lived cancer experience of Anishinaabe people. The study will also contribute to the health service knowledge base with policy implications in mind.

Research questions

With its focus on an examination of IH/TM and Western medicine, the present study furthers the literature with its foci on cancer in a rural, northern Ontario setting. In order to avoid homogenizing the Aboriginal population, this research was specific to Anishinaabe people in northeastern Ontario with informants, both Indigenous and non-Indigenous, from northeastern Ontario and Minnesota. Anishinaabek from Manitoulin Island have long maintained connections to their relations (i.e., blood families and Midewiwin families) across Ontario, Manitoba and in the northern United States, including Michigan, Wisconsin and Minnesota. Anishinaabek who strive to hold onto the Anishinaabe way of life have travelled between these regions for teachings, support and sharing.

The study was guided by the following research questions:

Primary Question: What is the lived experience for Anishinaabe adults of Manitoulin diagnosed with cancer and their use of either Indigenous healing with Western medicine or only Western medicine?

Secondary Questions: Does the inclusion of Indigenous healing bring an Anishinaabe person closer to Minobimaadiziwin? How does this relate to the overall cancer experience?

Calls for improved understanding for cancer and IH/TM

The *Aboriginal Cancer Care Needs Assessment*, a precursor to the *Aboriginal Cancer Strategy II*, discussed aspects of traditional healing within the Ontario Aboriginal

population. The report identified a widespread desire to access traditional healing by Aboriginal people and noted that patients tend to participate in both traditional healing methods and Western treatment options at the same time. Moreover, traditional methods were felt to be particularly helpful with the patient's spiritual, emotional, mental and physical needs (Cancer Care Ontario, 2002). In addition, the report pointed to the need for education and awareness within the Ontario Aboriginal population regarding cancer and IH/TM.

It was found that there is a lack of basic information about traditional healing methods, as well as conventional cancer treatment options and other post-diagnosis services (Cancer Care Ontario, 2002). There is a need for straightforward educational materials which address specific Aboriginal concerns and include positive messages (Cancer Care Ontario, 2002). A message of optimism is required to counteract the pessimistic views and beliefs about cancer in Aboriginal communities. Furthermore, information and education are required to promote the benefits of traditional healing for health professionals (Cancer Care Ontario, 2002; Maar & Shawande, 2010; Manitowabi, Williamson & Shawande, 2009).

In 2009, an Aboriginal cancer research report was produced for the Manitoulin area which was instrumental in identifying priorities and strategies for long-term cancer research for Aboriginal communities (Maar, Lightfoot, Sutherland, Strasser, & Wilson, 2009). The overall objective of the Maar et al. study was to explore how Aboriginal communities could ethically engage in long-term cancer research. The communities involved in the study outlined research and information needs that would improve

understanding, outcomes and patient care. There were two research recommendations coming from this study that were specifically relevant to my research. The first concerned the need for in-depth qualitative research to learn more about the lived experience of Aboriginal cancer patients and their families. The second saw the need for research on the lived experience of Aboriginal patients and the impact of the use of traditional approaches to health. These recommendations, in part, provided further impetus for the present study for the Anishinaabe people of Manitoulin Island.

What are Indigenous healing and traditional medicine?

Traditional medicines have been used for thousands of years by Indigenous peoples in Canada, with demonstrated efficacy in treating a wide range of health issues ... Traditional medicines are still first-line healthcare for 75 percent of the world's population (National Aboriginal Health Organization, 2012).

Indigenous healing and traditional medicine have been defined in various ways. Two popular definitions of traditional healing and traditional medicine, respectively, have been put forth by the Royal Commission on Aboriginal Peoples as:

practices designed to promote mental, physical and spiritual well-being that are based on beliefs which go back to the time before the spread of Western 'scientific' bio-medicine. When Aboriginal Peoples in Canada talk about traditional healing, they include a wide range of activities, from physical cures using herbal medicines and other remedies, to the promotion of psychological and spiritual well-being using ceremony, counseling and the accumulated wisdom of Elders (Indian and Northern Affairs Canada, 1996, p. 325)

and the World Health Organization as:

the sum total of knowledge, skills, and practices based on the theories, beliefs, and experiences Indigenous to different cultures, whether explicable or not, used in the maintenance of health as well as in the prevention, diagnosis, improvement of treatment of physical and mental illness (WHO, 2000, p. 1).

It has been acknowledged by many that traditional medicine is a complex notion and it is difficult to articulate this domain of Indigenous knowledge because it is external to Western paradigms of understanding (Martin-Hill, 2003). Upon her review of the literature on traditional medicine and in consulting knowledge keepers, Martin-Hill (2003) attempted to describe and frame traditional medicine within a contemporary context. She cautioned researchers when they review literature on traditional medicine to consider that the term “traditional” was imposed on Indigenous peoples by scholars who referred to practices that were not typical of their own, European culture.

Upon consulting an Elder prior to conducting this research, I was advised that ‘Indigenous healing’ and ‘traditional herbal medicine’ were different but related concepts where Indigenous healing may involve ceremonial aspects that are not always involved in taking traditional herbal medicine. Other Elders have shared with me that the spiritual component of traditional medicine can never be omitted. It is for this reason that the two conceptions, taken together, as Indigenous healing/Traditional medicine (IH/TM) was the preferred terminology for the present research. Ideally, Anishinaabe terminology, *mshki ki* [Translation: healing powers of the earth/medicine] would have been more appropriate

in defining this phenomenon for the Manitoulin region. It is also appropriate to articulate this concept as something that remains very much a part of the Anishinaabe way of life rather than a lost 'tradition' regardless of the terminology used (Maar & Shawande, 2010; Manitowabi & Shawande, 2011; Martin-Hill, 2003; Waldram, Herring, & Young, 2006).

Other research on traditional medicine and healing in North America has focused on descriptions of traditional healing in an effort to define and describe the concept (Broome & Broome, 2007; Struthers, Eschiti & Patchell, 2004). There have been qualitative studies about traditional healers and how they conduct their work (Nauman, 2007; Struthers, 2000; Struthers, 2003; Struthers, Eschiti & Patchell, 2008). Researchers have also documented use of traditional healing and healer services among Native Americans (Kim & Kwok, 1998; Marbella, Harris, Diehr, Ignace & Ignace, 1998) and have compared the use of Western and traditional medicine (Broome & Broome, 2007; Gurley, Novins, Jones, Beals, Shore & Manson, 2001). Despite the attempts at description and understanding, Indigenous healing/Traditional medicine remains an enigma.

Indigenous knowledge itself has been fragmented and repressed, and colonialism has prompted knowledge keepers to hide what has been cultivated for fear of persecution or, alternatively, exploitation (Lux, 2001; Martin-Hill, 2003; Waldram et al., 2006).

Researchers are reminded that it was only recently, in the 1970s, that legal bans against Indigenous healing ceremonies still existed (Lux, 2001; Martin-Hill, 2003; Waldram et al., 2006). Lux, as cited in Martin-Hill (2003), shares how institutions contributed to the demise of Indigenous healing/traditional medicine:

The stated rationale for repressing the dances was that they interfered with farm work and ‘unsettled’ the people. In truth Native people’s special knowledge of healing, which they gained through visions and experience and passed on through the transfer of bundles at ceremonial dance camps, was being actively suppressed ... The construction of the healer as a quack and the dances as a barbaric waste of time served to justify the repression of both (p. 6).

This persecution in concert with the colonized education (e.g., Western-based curricula and residential schools) imposed on many Indigenous peoples contributed to the stigmatization and colonization of Indigenous knowledge and medicine (Martin-Hill, 2003).

These historical impacts continue to mystify IH/TM for Indigenous and non-Indigenous alike. However, there are contemporary issues which further complicate the understanding of IH/TM and obscure the potential benefits for Indigenous peoples’ health and well-being. One fundamental problem lies in how terminology surrounding “medicine” including, efficacy, curing, healing, illness and disease are understood and applied. In his work on efficacy of traditional medicine, Waldram (2000) noted common definitions of these terms in the medical anthropology literature. Curing was often defined as “a primarily biological process that emphasizes the removal of pathology or the repairing of physiological malfunctions, that is, disease” (p. 604). Healing was defined as “a broader psychosocial process of repairing the affective, social, and spiritual dimensions of ill health or illness” and sickness described the two concepts, disease and

illness, together (Waldram, 2000, p. 604). Waldram cautioned against an assumption that Western medicine only “cures disease” or that traditional medicine only “heals illness.” Furthermore, he warned that it should never be implied that healing of illness and curing of disease are unrelated. With this understanding of the relationships between types of medicine, in concert with the fact that IH/TM and Western medicine have common goals, one can argue that bringing the two healing traditions together to treat sickness may be beneficial.

However, the potential for braiding IH/TM with Western medicine is mired in perceptions of efficacy of IH/TM in its own right. Waldram (2000) examined several issues which confound the understanding of efficacy for traditional medicine, namely: how efficacy has been defined; who holds the authority to determine efficacy; who is in receipt of the healing; and whether there is a timeframe for determining efficacy. In all, he argued that it is pointless, erroneous, and inherently biased, to discuss, measure or determine the efficacy of IH/TM with Western concepts, tools or ideologies. Instead, Waldram held that efficacy must be viewed as “fluid and shifting, the product of a negotiated, but not necessarily shared, understanding by those involved in the sickness episode, including physicians, healers, patients, and members of the [family and] community.” The complexity of these understandings concerning IH/TM has created barriers for Indigenous peoples attempting to braid³ IH/TM with Western medicine in the treatment of cancer.

³ Following a recommendation by the Community Advisory Committee, the terms braid or braiding have replaced the terms integrate or integration. Braiding reflects how the two types of healing, IH/TM and Western, can be brought together to strengthen the healing journey for individuals wishing to use both, where one type of healing is not subsumed by the other.

Calls for improved communication and understanding

Before any braiding of the two types of healing can be considered, the need for improved understanding of Indigenous healing/Traditional medicine by physicians (Shelley, Sussman, Williams, Segal & Crabtree, 2009) must be addressed. To add another perspective, there is ample evidence that improved communication is needed across cultures and between physicians and Indigenous peoples with cancer (Butow, Tattersal, & Goldstein, 1997; Mitchell, 1998; Shahid, Finn, Bessarab, & Thompson, 2011; Shahid, Finn, & Thompson, 2009). Overall, studies have demonstrated that improved communication between Indigenous peoples and health care providers is required (Browne & Fiske, 2001; Durey, Thompson, & Wood, 2012; Gracey & King, 2009; Kalbfleisch, 2009; Kelly & Brown, 2002; Simonds, Christopher, Sequist, Colditz, & Rudd, 2011). Literature about patient-clinician communication suggests that there is a lack of communication about patients' use of traditional, complementary and alternative medicine (Shelley et al., 2009). This lack of communication is, in part, due to physicians' insufficient understanding of, and skepticism about, such practices and their unwillingness to provide medical advice based on their limited understanding (Martin-Hill, 2003; Shelley et al., 2009; Zubek, 1994).

Furthermore, the literature suggests that physician-patient communication, in general, can be improved if physicians or health care practitioners invest time and work to establish trust and increase satisfaction in these relationships (Guadagnolo, Cina, Helbig, Molloy, Reiner, Cook, & Petereit, 2009; Kalbfleisch, 2009; Simonds et al., 2011). Without an effort to improve communication and commitment to make progress within the spectrum of cultural safety (i.e., from cultural awareness to cultural congruence/integration) (St.

Pierre-Hansen et al., 2010), braiding IH/TM with Western medicine will be difficult. Recently, researchers have even referred to such barriers in communication and understanding between Indigenous patients and their physicians as a form of ongoing structural violence in health care (Farmer, Nizeye, Stulac & Keshavjee, 2006; Kirmayer, Gone & Moses, 2014; Maar, Manitowabi, Gzik, McGregor & Corbiere, 2011).

Addressing structural violence through cultural safety

Researchers have made a critical link between the social determinants of health to what has been termed “structural violence” (Farmer et al., 2006; Kirmayer et al., 2014; Maar et al., 2011). Structural violence is defined as those “social structures – economic, political, legal, religious, and cultural – that stop individuals, groups and societies from reaching their full potential” or “put them in harm’s way” (Farmer et al., 2006, p. 1686). Farmer et al. argued that a biosocial context and understanding of social determinants, such as poverty and racism, are necessary in examining health issues, especially for practitioners working with marginalized populations. While most practitioners have not been trained in addressing the social determinants of structural violence, these understandings are viewed as essential to improving accessibility and treatment outcomes. It has been documented that structural violence and social determinants influence the diagnosis, staging and treatment of disease, outside of pathophysiology (Farmer et al., 2006). For instance, American Indian/Alaskan Native patients were less likely to receive “guideline concordant” (i.e., optimal cancer treatments) than their white counterparts and thus had worse cancer-specific survival rates likely due to “systems-based, provider-based, and patient-based factors” (Javid, Varghese, Morris, Porter, He, Buchwald, & Flum, 2014, p. 7). In a pragmatic fashion, researchers concentrating on other areas of health were able to

propose concrete, structural applications designed to address barriers, reduce health disparities and improve outcomes for chronic diseases including AIDS and diabetes (Farmer et al., 2006; Maar et al., 2011). One such application that featured prominently in Indigenous healthcare literature is cultural safety.

To reiterate, the apparent disconnect in communication between patients and physicians concerning IH/TM can be framed as a form of structural violence. There are barriers to physicians' uptake of cross-cultural understandings which, in turn, affect the physician-patient relationship. There is a need for physicians to develop an understanding of the social structure, cultural behaviours within and values of Indigenous communities (Gracey & King, 2009; Zubek, 1994). One structural intervention that has been widely documented to address this knowledge gap is cultural safety. A myriad of studies (Aboriginal Nurses Association of Canada, 2009; Smye & Browne, 2002; Smye, Josewski and Kendall, 2010; St. Pierre- Hansen et al., 2010) exist concerning the provision of culturally safe, culturally competent, culturally appropriate or culturally sensitive health care for Indigenous peoples, and other marginalized groups. Without a frame of reference, one can become bogged down in the literature when trying to determine exactly what these terms mean or whether they are interchangeable. In a Canadian study by St. Pierre-Hansen et al. (2010), a conceptual model of a cross-cultural client safety continuum was provided which served to bring meaningful perspective to this literature base.

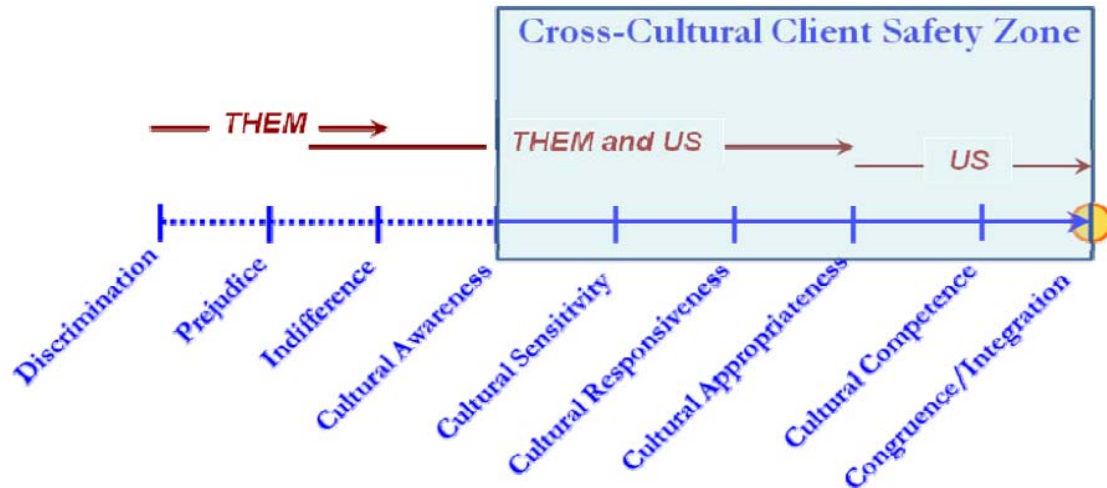


Figure 1: The Continuum of Cross-Cultural Client Safety

Cultural safety, a concept developed for nursing education by Ramsden in the 1990s, was a response to the colonialism and structural inequities experienced by the Maori in New Zealand (Smye & Browne, 2002). Cultural safety goes beyond an awareness, sensitivity and competency of health care practitioners working with Indigenous cultures. Instead, the concept reflects the power differentials in health care systems and more broadly, the political, social, cultural and economic structures in which those systems operate (Aboriginal Nurses Association of Canada, 2009; Smye & Browne, 2002). Moreover, the concept is also a lens through which “unequal power relations are exposed and managed” to influence change and action for health equity (Aboriginal Nurses Association of Canada, 2009, p. 25).

In their overview of cultural safety, Smye, Josewski and Kendall (2010) outlined four core competencies assumed by cultural safety which are relevant to health care practitioners’ work with Indigenous peoples. First, is the understanding of colonialization, Indigenous determinants of health, as well as government policies and

how they perpetuate health inequity. Second, is a focus on respect for the unique cultures, languages and lives of Indigenous peoples, as well as relationship-building, reciprocity and collaboration with Indigenous peoples including those in their support systems (i.e., Elders, family, and traditional knowledge keepers). Third, is a focus on culturally safe communication and language. Finally, there is recognition of Indigenous knowledge and practices as legitimate options for health and well-being of Indigenous peoples, in addition to what Western medicine has to offer.

Braiding IH/TM with Western medicine

The collaborative delivery of traditional and Western medicine cannot be integrated without building a two way relationship of trust and respect (NAHO, 2012).

Research has been conducted that examines the integration of Indigenous healing with conventional Western approaches and the implications for healing, taking into account the issues of domestic violence (Puchala et al., 2010), developments in addictions programs (Brady, 1995), mental health (Maar & Shawande, 2010), palliative care (Clarke & Holtslander, 2010; St. Pierre-Hansen et al., 2010) and the treatment of chronic illness (Mehl-Madrona, 1999). In general, the research about the integration of traditional healing and Western medicine demonstrates effectiveness (Coulehan, 1980; Hunter, Logan, Goulet & Barton, 2006; Mehl-Madrona, 1999; Puchala et al., 2010; Walker, Cromarty, Linkewich, Semple, St. Pierre-Hansen & Kelly, 2010) and positive outcomes for patients (Maar & Shawande, 2010; Mehl-Madrona, 1999). More importantly, the research emphasizes that a range of approaches should be made available to Aboriginal patients (Brady, 1995; Clarke & Holtslander, 2010; Lucero, 2011; St. Pierre-Hansen et al., 2010).

Despite the success of integrated approaches in other areas of health, research has been limited about cancer experience. Struthers and Eschiti (2004) described the experiences of Indigenous people diagnosed with various types of cancer who have incorporated Indigenous traditional healing with Western medicine. The authors state that understanding the experiences of individuals using traditional healing will assist health care professionals to deal with patients incorporating traditional methods.

Martin-Hill's (2003) report provided examples of how Indigenous healing/Traditional medicine has evolved and attempted to meet the expectations of current Western methods of disease management. Some changes cited in this document include the use of surgical gloves and sterilized equipment for the Sundance ceremony and access to the necessary medication and dietary needs of diabetics participating in sacred ceremonies and fasts. It should be noted that the agency responsible for spearheading these changes was the Indian Health Service in the United States. To further support the progress of Indigenous healing/traditional medicine, consultations with Elders suggested that learning opportunities be provided for healers to learn from one another to enhance their skill sets (Martin-Hill, 2003). The findings from this report beg the question as to who will initiate, facilitate and ultimately be responsible for braiding Indigenous healing/Traditional medicine with Western medicine, if this is indeed possible.

It has been recommended in several studies concerning Indigenous healing that health care providers develop a willingness to take part in a discourse regarding Indigenous medicine and holistic healing (Broome & Broome, 2007; Marbella et al., 1998; Martin-Hill, 2003; Struthers, 2003; Struthers et al., 2004; Struthers et al., 2008), promote

partnership with Western medicine (Martin-Hill, 2003; Struthers, 2000; Zubek, 1994) and encourage Indigenous peoples to incorporate Indigenous healing practices for optimal well-being (Struthers et al., 2005). The Elders consulted in Martin-Hill's (2003) report recommended that those working from Indigenous and Western perspectives of health should be afforded the space and opportunities for learning from one another in an interdisciplinary fashion, which can foster learning about both domains of health care. Such an endeavour in holistic care will undoubtedly require the cooperation and discussion amongst Indigenous knowledge keepers, healers, Elders and Western health care practitioners.

Zubek (1994) reported methods for encouraging Western practitioner and Indigenous healer cooperation and mutual understanding which include: "dialogue groups, joint workshops on primary health care issues, multidisciplinary panel consensus reports, referral systems and joint clinics" (p. 1930). Any joint efforts must first begin with both cultures gaining an appreciation for the value of IH/TM and, more broadly, Indigenous knowledge in the lives of Anishinaabek, that is, developing cultural competence. Since IH/TM is still widely practiced (though not always openly) by Indigenous peoples, it has been clearly stated that it is critical for health care professionals to have at least a basic understanding of holistic well-being inherent in Indigenous health. Health professionals working with Indigenous populations are encouraged to continue to progress towards the eventual goal of cultural congruence/integration on the continuum of cross-cultural client safety (Figure 1).

Indigenous knowledge in relation to holistic well-being

One essential understanding inherent in Indigenous knowledge is the concept of Minobimaadiziwin and its place within the Anishinaabek understanding of “living a good, holistic way of life” (Manitowabi & Shawande, 2011, p. 443). This research attempts to establish awareness of Anishinaabe people's experiences with cancer and their choice of treatment options in the quest for Minobimaadiziwin, the balance of mental, physical, emotional and spiritual health. It represents the teachings for living a long, healthy life and is dependent upon individual choice (Hallowell as cited in Manitowabi & Shawande, 2011; Rheault, 1999). In order to live in Minobimaadiziwin, one must work to prevent illnesses by living well mentally, physically, emotionally and spiritually (Manitowabi & Shawande, 2011; Rheault, 1999). Life is often beset with difficulties, and the Anishinaabe teachings of Minobimaadiziwin acknowledge this, particularly in the teaching used to frame this dissertation, the *Miikaans*/Seven Stages/Path of Life teaching (Appendix 12) described later in this dissertation.

Many Indigenous cultures uphold the concept of Minobimaadiziwin, though it may be called something else. For instance, Cree scholar Naomi Adelson (2000) refers to *miyupimaatisiun*, a Cree equivalent of Minobimaadiziwin in not only linguistic form but also conceptual meaning. As in the Anishinaabe language, the Cree language does not contain a word for the English word, health. Instead, Adelson (2000) translates and summarizes *miyupimaatisiun* to mean ‘being alive well’ and, like Minobimaadiziwin, has a broader meaning than solely physical health. In Adelson’s (2000) analysis of the stories collected for her work, she stated that the term encompasses living life on the land, health, and the identity and politics of being Cree with all that this implies.

Michael Anthony Hart, another Cree scholar, penned *Seeking Mino-Pimatisiwin* as an example of another understanding of well-being for the discipline of social work. Hart's (2002) conception of *mino-pimatisiwin* goes beyond the individual's holistic experience of living well to include sharing and respect for fellow community members. It can be inferred that the term *mino-pimatisiwin* also conceptualizes the individual's experience as part of the greater social environment, where colonization has left its imprint on the individual, community and nation (Hart, 2002). Similar to both Adelson's *miyupimaatisiun*, and Hart's *mino-pimatisiwin* the conception of Minobimaadiziwin encompasses a multitude of understandings, and the acknowledgment of these concepts is central to healing for the Indigenous peoples for whom they have meaning. Minobimaadiziwin, for the purposes of the present research, is an Anishinaabe understanding of health and is appropriate for the proposed research sites (Manitowabi & Shawande, 2011). It is central to the paradigmatic and theoretical approach described below.

An Indigenous research paradigm⁴

It is imperative in any academic research to articulate the ontological and epistemological position of the researcher. Wilson (2001 and 2008) postulates further that a researcher working from an *Indigenous Research Paradigm* will also require a declaration of their axiology and methodology. The four aspects of this Indigenous research paradigm which guided the research were considered to be interdependent and circular where a change in one affected change in the others (Wilson, 2008).

⁴ The following sections within *An Indigenous Research Paradigm*, including An Anishinaabe Worldview, Ontology, Epistemology and Axiology were previously published in the *Anishinaabewin Niswi Deep Roots, New Growth* 2012 conference proceedings (Peltier, 2013).

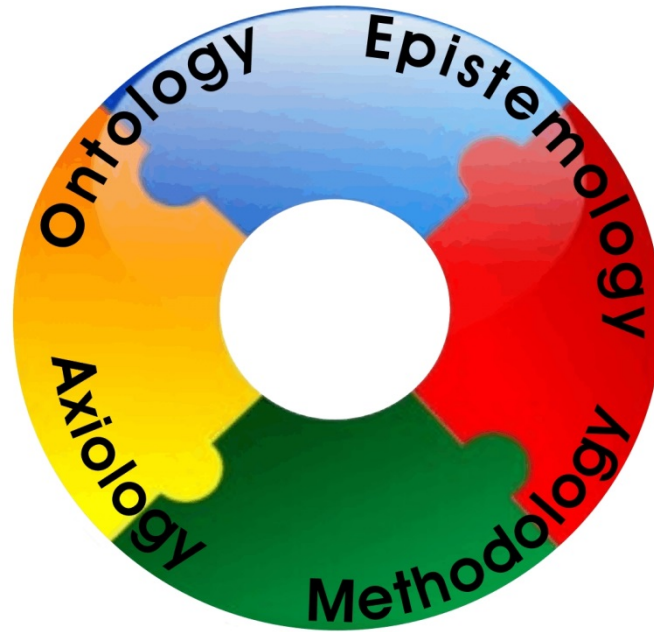


Figure 2: An Indigenous Research Paradigm

This declaration serves as an introduction to Indigenous knowledge and how it encapsulates *one* Anishinaabe worldview.

One Anishinaabe worldview

This worldview is based on Indigenous oral teachings which both inform my work and provide the philosophical foundation for it. I have italicized the word “*one*” (above) for a specific reason. I hope that it will be understood as an effort not to make judgments or to “paint all Anishinaabe people with the same brush.” I stress that the following teachings or understandings are not representative of all Anishinaabe people, nor are they meant to be representative of all Anishinaabe people of Manitoulin Island. Our ontology or the nature of our reality is based upon relationships in the past, in the present and in the future. These relationships shape who we are as individuals, as a collective, and determine our worldview. The following teachings and understandings are common to

many Anishinaabe cultures. Moreover, it is important to note that the teachings illustrated within this work are presented in an abbreviated form intended to provide reference for the reader. These teachings are sacred and their complete form and meaning is meant to be conveyed orally, in the language of the Anishinaabe and in ceremony in order to capture the “magnitude and depth of the spiritual history and heritage of the Anishinaabe people” (Benton-Banai, 1988, p. ii; Rheault, 1999).

The Anishinaabe worldview centers on a belief in *G’Zhe Manido* [Translation: The Creator]. In addition to the physical dimension, this worldview includes a spiritual dimension. There is an inherent belief in the seen and unseen. The existence of the Anishinaabe people is based on the Creation Story which sets out the purpose of physical reality. It is believed that the Anishinaabe people received Original Instructions that are intended to guide people through life and provide strong prescriptions for the way of a good life (Minobimaadiziwin). The Anishinaabe worldview is relational in that all life is related and interconnected, whether it takes the form of mineral, plant, animal or spirit. An oral tradition with the Elders being central to learning, Anishinaabe ideology is often conveyed in narratives using symbolism and metaphor (Cote-Meek, 2011; Rheault, 1999; Wilson, 2008).

I see the worldview articulated here, albeit summarized, as the origin of my ontology, epistemology, axiology and methodology for my research. These four aspects of the *Indigenous Research Paradigm* are difficult to explain in isolation; however, the theme that connects these concepts is the notion of relationships. Wilson (2008) describes a vision of interconnectedness in which he postulates that ontology and epistemology are

based on the relationships in the past, present and future. These connections of relationships tie us to everything and everyone we know so that we could not *be* without *being in a relationship*. The source of our reality, our ontology, is these many connections or relationships.

Ontology

Ontology is concerned with the nature of reality, being or existence (Dyson & Brown, 2006). Anishinaabe culture is based on two forms of reality: the physical and the spiritual. These are two different expressions of a single reality which are interconnected. To illustrate, the Anishinaabe people live in a world which encompasses both human beings and spiritual beings, where spiritual beings are encountered in dreams and visions obtained through fasting (Rheault, 1999). The nature of being is expressed in the Anishinaabe Creation story, which is re-counted elsewhere in Benton-Banai's (1988) *The Mishomis Book*.

Although these concepts have been articulated by different Indigenous scholars, the theme of interconnectedness or relationships remains. If our ontology is the relationships, then our epistemology is the systems of knowledge that make up the context of those relationships (Wilson, 2008). In this view, one's ontology is tied closely to his or her epistemology.

Epistemology

Epistemology is concerned with defining knowledge as well as the process of acquiring knowledge (Dyson & Brown, 2006). More simply, how we come to know what we know.

Rheault (1999) describes seven aspects of knowledge within Anishinaabe culture. They are referred to as the Seven Directions of *Kendaaswin* (knowledge), and they include: *Bzindamowin* (learning from listening to cultural stories); Anishinaabe-*Kendaaswin* (attaining traditional knowledge through ceremony); *Manidoo-waabiwin* (seeing in a spirit way or knowledge gained through spiritual events such as, dreams, visions or intuition); *Gnawaaminjigewin* (empirical or scientific knowledge that comes from observing the world); *Eshkakimikwe-Kendaaswin* (land-based knowledge); *Kiimiingona manda Kendaaswin* (Original Instructions); and *Manidoo-minjimendamowin* (spirit memory). In terms of their relevance to the present research, all forms of knowledge may encompass the process of collecting and preparing natural medicines (Rheault, 1999), the uses of Indigenous medicines and how this information may be passed on to future generations.

Wilson (2008) contends that epistemology includes systems of knowledge and relationships which also include:

... interpersonal, intrapersonal, environmental and spiritual relationships, and relationships with ideas. Indigenous epistemology is our cultures, our worldviews, our times, our languages, our histories, our spiritualities and our places in the cosmos. Indigenous epistemology is our systems of knowledge in their context, or in relationship (p.74).

In the context of research, one's epistemological stance is inextricably tied to his or her axiology or moral stance. How the research gets done is a reflection of how we relate to others, and the aim with Indigenous research is to be responsible for your actions and accountable to your relations. Indigenous people refer to "all my relations,"

acknowledging those relationships we have had with those that came before us, those who are still in this realm and those generations to come.

Axiology

Axiology refers to the study of values and ethics. Its significance for the present discussion is the centrality of the Seven Grandfathers teaching of Respect in the ethical principles and what Indigenous scholars refer to as “The Three Rs of Indigenous Research”: respect, reciprocity and responsibility (Weber-Pillwax, 2001; Wilson, 2001; Wilson, 2008). Ideally, all research methodology should be respectful and ethical for the participants and communities involved. However, such research methodology should be underscored for Indigenous peoples because of their past experiences with poorly conducted research and the misrepresentations of Indigenous peoples in historical texts and past research literature. As an Indigenous researcher I feel that I have a special responsibility to the Anishinaabe people to change this negative view of research. In an effort to conduct research with the Anishinaabe community which is respectful, responsible and reciprocal, I have chosen to couple Participatory Action Research (PAR) and Indigenous Methodology (IM) as my methodological approach. This methodological approach will be defined in Chapter 3.

Spiritual elements of the paradigm, theory and approach

Throughout my PhD journey I have often been reminded by scholars that I would be expected to explain and account for the sources of philosophy or knowledge which may have influenced my thinking. Marsden (2004) argued that relational validity concerns all domains of knowledge: the personal, the community and the academic, and that each of

these must be acknowledged as a valid source of knowledge. Personal knowledge can originate in the spiritual realm of the self, for example, through dreaming, prayer, ceremony and seeking the advice of Elders (Kovach, 2009; Marsden, 2004; Walker, 2001). Walker (2001) noted that this aspect of personal learning through our spiritual selves is often ignored within Western academia. As other Indigenous scholars have done, I will share how this knowledge from my spiritual self is the root of this academic endeavour (Kovach, 2009; Lavallee, 2009; Struthers, 2001; Walker, 2001; Weber-Pillwax, 2004). To remain authentic and true to my Indigenous paradigm and to give credit to an integral source of knowledge in this work, I acknowledge, and therefore validate, the spiritual experiences which provided the Indigenous philosophical foundations of this research.

Notwithstanding potential criticism from non-Indigenous scholars or those schooled primarily in Western thought, I have chosen to share where, and how, I received the teachings and the direction to complete this work because I feel that this is a form of validation for the spiritual source of my knowledge. As the Anishinaabe-kwe I have become, I have learned through many life experiences that prayer can serve as a way of demonstrating gratitude for my life and all that is received, but prayer can also facilitate guidance from the Creator. One of my teachers continued to remind me that praying for guidance and direction would help in the completion of my work. The offering of *Semaa* [Translation: tobacco] with prayer continued throughout the research process. I was also encouraged by my teachers to go through the sweat lodge in an effort not only to seek direction, but to have my work sanctioned by the Spirits, which I did early on in my learning journey. This process of asking for guidance served me well when I was having

difficulty in the formulation of a data analysis framework and again in writing the thesis. The structure of the thesis is the result of many mental, physical, spiritual and emotional tasks; that is, it is a true reflection of balance in the teaching of Minobimaadiziwin.

The process was mental in that I was constantly thinking of ways to frame what was shared with me in a good and meaningful way. It was physical because I am a visual learner and needed to physically manipulate the printed stories (i.e., the data) into a visual model. It was spiritual because the “image” for this model came to me while dreaming after seeking spiritual guidance through prayer and ceremony. The process was emotional in recalling a period of my life that was steeped in the source of many of my teachings. I have learned that those teachings, or life lessons, are derived from even the most adverse of human experiences. The source of the Minobimaadiziwin teachings I have presented here originate from traditional teachers I met during a difficult period for my family and whom I later sought to assist me with this work. Unbeknownst to me, those teachings I gathered during this period of time would later serve to form the foundation of my PhD work and would facilitate much of the healing which assisted my dad through his cancer experience. I am truly grateful for my teachers and the window of understanding which continues to grow throughout my life and work.

Theoretical model for two-eyed seeing

The theoretical model informing this dissertation (Figure 3) included a Western theory, Critical Medical Anthropology (CMA), since it cannot be denied that the Western world has had an influence on how Anishinaabek live. However, central to my theoretical model is where I have placed and honoured Anishinaabe *Gikendaasowin*. This lens of

this Indigenous research project can most accurately be described as “two-eyed seeing,” a phrase coined by Mi’kmaq Elder, Albert Marshall. In Elder Marshall’s view, two-eyed seeing refers to learning from the strengths of both Indigenous and Western ways of knowing for the betterment of all (Hatcher, Bartlett, Marshall & Marshall, 2009). My theoretical model was in development early in my doctoral thesis journey and probably even prior to that, since some of these teachings were received earlier in my life. The knowledge gathered to create this theoretical model was cultivated through my personal experiences with family members, and by speaking with Elders, Indigenous knowledge keepers, academics and, of course, through reading literature on Indigenous health. This preparatory work culminated in a theoretical model that is not entirely new since the theory and teachings have been shared and understood in differing contexts; however, I believe this model of two-eyed seeing to be an original and purposeful way of looking at the health of Anishinaabe people.

I found it difficult to frame my thinking and work within existing models or theoretical frameworks, since they were based predominantly on Western academic theory. Due to the subject matter, I was determined to ground this work in Anishinaabe teachings, and to ensure every aspect of this work remained congruent with Anishinaabe worldview, ontology and epistemology, that is, within the Indigenous research paradigm outlined above. Kovach (2009) speaks about the use of Indigenous inquiry in cooperation with a Western approach and how this may be possible, but that one must be transparent about the chosen approach and not contribute to subsuming Indigenous thought and ways of knowing under the Western qualitative banner. In keeping with the 3 R’s of Indigenous research, I did not take my responsibility to honour and respect the Anishinaabe

Gikendassowin I received throughout my doctoral thesis journey lightly. I aimed to honour, preserve and share the stories and teachings “in a good way.” This enabled me to use them in the development of a teaching tool for Anishinaabe people with cancer; thereby, the knowledge had a reciprocal quality. Moreover, the model holds Anishinaabe *Gikendaasowin* at its centre.



Figure 3: Theoretical Model for Two-eyed Seeing

The three rings surrounding the diagram in the theoretical model illustrate Critical Medical Anthropology (CMA), a framework that was developed by medical anthropologists Merrill Singer and Hans Baer in 1995. The CMA framework “emphasizes the importance of political and economic forces, including the exercise of power, in shaping health, disease, illness experience, and health care” (Singer & Baer, 1995, p. 5). The framework was born out of the principles of critical theory and action-oriented research and views social inequality and power as primary determinants of

health and health care (Singer & Baer, 1995). Central to CMA is the praxis approach, whereby CMA seeks to both study and change “culturally inappropriate, oppressive and exploitive patterns in the health arena and beyond” (Singer & Baer, 1995, p. 60). CMA provides a framework to analyze and understand health care and health-related behaviour from a political-economic point of view. It has been employed by other researchers in Indigenous health (Browne & Fiske, 2001; Jacklin & Kinoshameg, 2008; Pace, 2013; Warry, 1998). The four levels of analysis are: macro-social, intermediate social, micro-social and the individual.

The macro-level can be described as locating health in the capitalist world-system, within government policy and as the hegemony or dominance of Western medicine (Singer & Baer, 1995). The intermediate level is concerned with the health institutions and their policies, in addition to relationships among health care providers and administrators (Singer & Baer, 1995). The micro-social level is concerned with the doctor-patient and healer-patient interactions, as well as interactions among health personnel. Finally, the individual level includes the patient’s support network, as well as what Singer and Baer (1995) referred to as the “sufferer or illness experience.”

The three rings also illustrate the work of Indigenous scholar Loppie-Reading and Wien (2009) who examined factors which are known to impact the health of Aboriginal peoples. They created an Integrated Life Course and Social Determinants Model of Aboriginal Health. These factors surrounding the individual’s cancer experience are known as the social determinants of Aboriginal peoples’ health. There are three groupings of determinants of health which include: distal, intermediate and proximal.

The proximal determinants of health are those influences which originate within, or are closest to, the individual. They include health behaviours (e.g., smoking, alcohol consumption, diet), as well as the physical (e.g., housing and food security) and social (e.g., family support) environments. The intermediate determinants of health influence these proximal factors and include the influence of the community in terms of its infrastructure, resources, and capacity to provide educational or health support to the individual (Loppie-Reading & Wien, 2009). The level of distal determinants represents those theoretical constructs which are all-encompassing for the community and individual. This level included the political, social, economic, cultural and historical influences which impact and shape overall health and well-being of Aboriginal peoples (Loppie-Reading & Wien, 2009).

Singer and Baer's CMA framework for analysis (1995) dovetailed with the work of Loppie-Reading and Wien (2009) on health inequities and social determinants of Aboriginal peoples' health. I have inferred connections between these models and incorporated these in the development of my *Theoretical Model for Two-eyed Seeing* (Figure 3). In my theoretical model, the three outer circles in the model surround the person and have certain influences on how Anishinaabe people see and experience the world around them. In my model, Singer and Baer's (1995) four levels of analysis have been collapsed into three where the individual's experience is located at the centre of the model.

In the new model, the Distal-Macro-Social level concerns the historical, political, social and economic contexts of the individual's experience. They may include the broader

concepts of colonialism, racism, social exclusion, self-determination (Loppie-Reading & Wien, 2009) and the hegemony of Western medicine (Singer & Baer, 1995). For the purposes of this research, the participants' reflections on the residential school system and their current connections with their own culture, language, family and community were considered. Cultural continuity (Loppie-Reading & Wein, 2009) was inferred in the context of participants' use of Indigenous healing and their connection with family and with those who pass on traditional knowledge and language. Participants reflected on why their own cultural continuity may have been dislocated. The Intermediate-Intermediate-Social level, focused on the health care systems and access. The Proximal – Micro-Social level concerns the relationships the individual had with the Indigenous and Western health care practitioners (Singer & Baer, 1995), as well as with their families and communities (Loppie-Reading & Wein, 2009). While Singer & Baer (1995) would have placed the “sufferer or illness experience” at the Micro Social & Individual level, my theoretical model places the individual’s cancer experience, including relationships with family and community members, at the centre of the model and it is couched in Anishinaabe *Gikendaasowin*.

Research setting

My dissertation research was set on Manitoulin Island, Ontario, Canada. Manitoulin is located on the north shore of Lake Huron in northeastern Ontario. Manitoulin Island is approximately 100 km to 225 km in driving distance to the nearest urban center of Greater Sudbury, Ontario, where a tertiary care, referred hospital, Health Sciences North and the Northeast Cancer Centre are located. It is approximately 700 km in driving distance to Toronto, Ontario where some residents access specialist services.

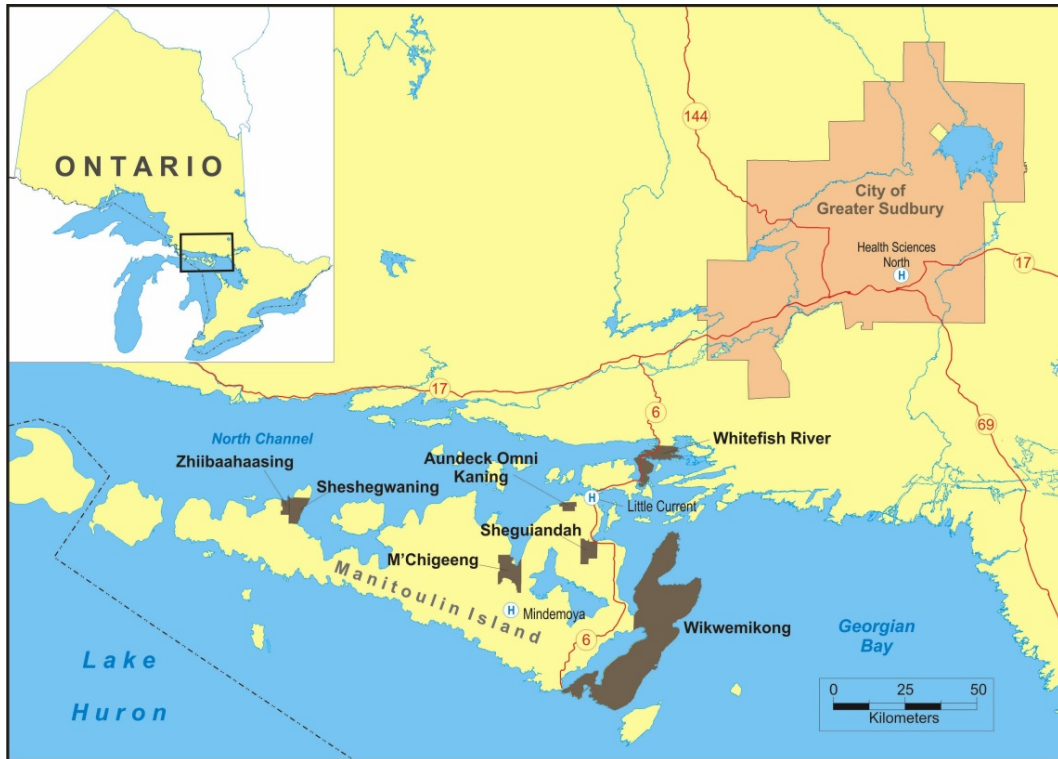


Figure 4: Map of First Nations in the Manitoulin Area

With a population of 13,048 Manitoulin (Statistics Canada, 2013a) is home to Anishinaabe (i.e., of Ojibwa, Odawa and Pottawatomi descent) and non-Anishinaabe people. It is estimated that approximately 41 percent (i.e., 5,315) of the population is of Aboriginal descent (Statistics Canada, 2013a). The Manitoulin area is home to seven First Nation communities which include: Aundeck Omni Kaning, M'Chigeeng, Sheguiandah, Sheshegwaning, Whitefish River, Wikwemikong Unceded Indian Reserve and Zhiibaahaasing.

The population of each First Nation community is indicated in Table 1.⁵

First Nation	Population (Statistics Canada)	First Nation Statistics
Aundeck Omni Kaning	365 (Statistics Canada, 2013b)	374
M'Chigeeng	897 (Statistics Canada, 2013c)	886
Sheguiandah	154 (Statistics Canada, 2013d)	182
Sheshegwaning	118 (Statistics Canada, 2013e)	104
Whitefish River	487 (Statistics Canada, 2013f)	--
Wikwemikong Unceded Indian Reserve	2,592 (Statistics Canada, 2013g)	3196
Zhiibaahaasing	55 (Statistics Canada, 2013h)	55

Table 1: First Nation Community Population for Manitoulin Island District

There were three research sites selected for this research: Wikwemikong Unceded Indian Reserve (via Nahndahweh Tchigehgamig Health Centre), M'Chigeeng First Nation (via M'Chigeeng Health Centre) and Mnaamodzawin Health Services. Both Wikwemikong and M'Chigeeng health centres independently provide access to primary care through the North Eastern and Manitoulin Central Family Health Teams, medical transportation and home care services for their community members. Mnaamodzawin Health Services offers a range services including home community care (e.g., liaison for physician care, home visits, personal support, PICC and IV line maintenance, discharge planning from hospitals, provision of health equipment and palliative care) to the remaining five First Nations on Manitoulin Island and in the surrounding area, including: Aundeck Omni Kaning, Sheguiandah, Sheshegwaning, Whitefish River and Zhiibaahaasing. The Manitoulin Health Centre organization has two hospital sites (i.e., Little Current and Mindemoya) servicing the Manitoulin area population. The Mindemoya site also houses

⁵ It is acknowledged that population data from Statistics Canada may be under reported. This under reporting may be attributed to incomplete enumeration or discrepancies in on- and off-reserve residence status (Waldram et al., 2006). Available First Nation, on-reserve population statistics are also reported.

the Community Oncology Clinic Network Satellite providing systemic (chemo) therapy services locally for Manitoulin residents.

Outline to the thesis

In Chapter Two, I explain how the theoretical framework informed the methodological approach for this dissertation. The chapter will outline the rationale for this Indigenous inquiry. The term researcher-in-relation is described with respect to my involvement as an “insider researcher.” The pairing of Indigenous methodology and participatory action research is related to Marshall’s (as cited in Hatcher et al., 2009) concept of two-eyed seeing. The chapter then follows the steps in Jacklin and Kinoshameg’s (2008) Aboriginal Specific Participatory Action Research Model as the research strategy for this work. The steps outlined in this model are described in Chapter 2 as they relate to my methodological strategy: research planning; research implementation; production and dissemination; and action and self-determination. The research planning section includes processes of community engagement, as well as the recruitment procedures and description of the sample. The research implementation section addresses the use of mainstream- and Indigenous-based ethical protocols for consent, reciprocity, the gathering and sharing of stories, as well as the process of making meaning. In keeping with Jacklin & Kinoshameg’s model, this chapter addresses the process for production and dissemination of knowledge for academe and the Anishinaabe community, in addition to the acknowledgement of moving this research into practice.

This dissertation presents the findings in four separate chapters. These findings are presented within an Indigenous framework for analysis and to honour and privilege the

participants' voices. The synthesis and my own interpretations and connections to the literature and prevailing theory are presented in the final chapter.

The first chapter concerning findings is Chapter Three. In this chapter, the term Minobimaadiziwin is defined. Minobimaadiziwin is an Anishinaabe concept that is central to this research. Participants were asked what Minobimaadiziwin meant to them personally. Therefore, this chapter concerns the participants' definitions of Minobimaadiziwin.

In Chapter Four the collective story of the participants is presented with a specific concentration on six stages of the cancer journey. This chapter discusses the collective story from the time of cancer diagnosis to the palliative stage or end of physical life, privileging the voices of the participants. The cancer journey usually began with the Cancer Diagnosis stage marking the beginning. The Gathering Information stage involved the participants' personal conceptions of what cancer is, how they believe they got cancer and how they learned about cancer from a variety of sources. The Making a Choice stage concerned the participants' choice in the type of cancer treatment they would receive. For the purposes of this study, the two choices were: to receive conventional cancer treatment based on the Western medical model only or to braid Indigenous healing/Traditional medicine with Western medicine. The stage entitled Experiencing Cancer described participant experiences with cancer treatment reflecting on their personal choices and how this affected Minobimaadiziwin. Acceptance may have occurred at differing times within the cancer journey and was unique to each person. For some participants, the end of the cancer journey was marked by the receipt of Palliative

and Western Doorway Care. However, all Anishinaabe participants involved in this study reflected on this stage at some point along the journey.

The next two results chapters concern the influences on the participants' cancer experience. Although not to be considered apart from the cancer experience, these influences weave in and out of the experience at several places along the cancer journey. It was for ease of reading and interpretation that the influences have been presented in two separate chapters. Chapter Five describes the influence of relationships on their cancer experience, since Anishinaabe participants' cancer experiences were affected by relationships with other people, the land and the Creator. There were five main types of relationships shared, including relationships with: Western practitioners; creation; Indigenous practitioners; community; and family. Participants shared how these relationships changed throughout the cancer experience.

Chapter Six concerns a second major influence on the cancer experience, that is, types of healing chosen for the cancer treatment. The two types discussed in this chapter were Indigenous healing/Traditional medicine and Western medicine, which were not mutually exclusive. Similar to the influence of relationships, the influence of the type of healing filters in and out of the cancer experience and concerns accessibility and how each type of healing was perceived by the participants.

Finally, in Chapter Seven I present the synthesis and discussion of the overall findings in this thesis. This chapter also contains the concluding statements as well as the application of those statements in the form of suggested recommendations for continued cancer care for the Anishinaabe people of Manitoulin Island.

Chapter 2: Methodology

This chapter discusses the theoretical and methodological approach to gathering stories (i.e., collection of data) and understanding the elements of those stories (i.e., analysis of data). The theoretical approach to this thesis is grounded in Indigenous knowledge, more specifically, in Anishinaabe *gikendaasowin* [Translation: knowledge, information, and the synthesis of our personal teachings] (Geniusz, 2009); therefore, it stands to reason that the collection of stories and the methods used to understand those stories be rooted in this same knowledge. Throughout the process of this thesis, a conscious effort was made to achieve the best practices of community-based participatory action research design (Jacklin & Kinoshameg, 2008). It was of paramount importance to remain accountable to and meet the expectations of the participating Anishinaabe communities. This was accomplished with the formation of a community advisory committee that was consulted at various decision-making points prior to and within the research process. Through these consultations, coupled with teachings about Minobimaadiziwin that were gifted to me by my traditional teachers, an Indigenous Analysis Framework was constructed which framed the production of knowledge in the form of a collective story. With the assistance of the participants, the community advisory committee and a community-based research assistant, a *Collective Story of Cancer and Minobimaadiziwin* for Anishinaabe people has been created based on the Medicine Wheel and Minobimaadiziwin teachings. The following chapter provides descriptions of: the rationale for an Indigenous inquiry; the Aboriginal-specific participatory action research strategy; Indigenous and mainstream ethical protocols; the study participants; and the Indigenous analysis framework and process.

Rationale for this Indigenous inquiry

This study focuses on the lived experience of Anishinaabe people with cancer and how it affects Minobimaadiziwin. The study examines the use of both Western medicine and Indigenous healing/Traditional medicine (IH/TM) in the treatment of cancer for Anishinaabe people. It is clear that IH/TM remains an important element in the lives of those who participated in this study, whether or not they included it in their cancer treatment plan, and thus it is a critical component of this thesis. Anishinaabe *Gikendaasowin* is central to the subject matter of IH/TM and Anishinaabe people's understanding of wellness or their Minobimaadiziwin. While it can be argued that not all Indigenous research requires an Indigenous methodological approach, the subject matter in this case strongly warrants grounding from tribal epistemology (Kovach, 2009). For this reason, it would be inappropriate to study this subject matter in a way that did not honour an Indigenous system of knowledge and worldview. Other scholars (Kovach, 2009; Martin-Hill, 2009; Tuhiwai Smith, 1999) agree that Indigenous health and wellness issues should be understood through an Indigenous lens to make the research relevant to the people for and by whom it is being conducted. Moreover, Johnson and Ruttan (as cited in Saini, 2012) have argued that previous attempts made to force Indigenous systems of knowledge into Western frameworks have been difficult, and key concepts are lost in translation. Through Martin-Hill's (2009) overview of traditional medicine and Indigenous knowledge literature, she posits that Aboriginal health and wellness issues are best understood using Indigenous knowledge frameworks. These speak to balance among the four elements of spiritual, emotional, physical and mental life, defined in this work as Minobimaadiziwin.

It is recognized that other forms of narrative inquiry deriving from Western epistemologies, for example, the interpretive approaches influenced by Hermeneutic phenomenology and Heideggerian philosophy have been considered in other Aboriginal health research (Barton, 2004; Pace, 2013; Struthers and Peden-McAlpine, 2005) because of their compatibility with aspects of Aboriginal culture such as storytelling, the sacred circle and holism. For this research, however, an Indigenous method of inquiry was employed in order for the study to remain grounded within Indigenous knowledge, or more specifically, Anishinaabe *Gikendaasowin*. The research questions and methodology were aligned with an Indigenous Research Paradigm, consisting of an Anishinaabe worldview, ontology, epistemology and axiology.

Indigenous scholars have proposed that a research approach, in this case, the Indigenous methodology, must flow from a congruent Indigenous paradigm (Kovach, 2010; Wilson, 2001). The methodological approach to data collection which I chose is the conversational method as outlined in Kovach (2010) mainly *because* it aligns with my Indigenous research paradigm and was informed by it. This method has been referred to in various ways by Indigenous researchers: Aare (as cited in Saini, 2012) refers to storytelling as re-membering (Tuhiwai Smith, 1999) and as collaborative storying by Bishop (as cited in Kovach, 2010), to name just two. The conversational method for this Indigenous research is appropriate since it honours the oral tradition of the Anishinaabe (Kovach, 2009) and is concerned with co-creating knowledge within a relational context (Graveline, 1998). Within this relational context, there is an awareness of the interplay of relationships between myself as both a researcher and an Anishinaabe community member and those Anishinaabek participants who share my reality. The conversational

method also allows for collectivism, common to Indigenous societies (Deloria, 2004). This method involves a flexible, informal, two-way dialogue with the purpose of sharing stories in an attempt to assist others (Kovach, 2010) and therefore has an emancipatory component. In summary, the conversational method facilitated the creation of a collective teaching story (Kovach, 2009) for Anishinaabe people concerning cancer and Minobimaadiziwin.

Researcher-in-relation: An Indigenous “*insider*” researcher

What is good research? I considered this as I contemplated how I was going to discuss being an Indigenous “insider researcher.” It became a daunting task to determine whether the insider/outsider debate had bearing on what is meant by good research. There are competing notions on who is best positioned to conduct research with Aboriginal communities. Stevens (as cited in Saini, 2012) asserts that Aboriginal people are the authorities on their own way of life and are therefore in the best position to conduct this research. Others hold that success in research with Aboriginal peoples depends on the involvement of community members in research (Jacklin & Kinoshameg, 2008). On the other end of the spectrum, there are those who declare that insider research can be problematic. Sibthorpe et al. (as cited in Saini, 2012) argued that participants may be unwilling to share their stories and issues with fellow community members who are researchers. Conversely, younger community researchers may be reluctant to approach older participants, out of respect, or those with whom they are socially connected.

It seemed that if it was my intention to have my research taken seriously in Western academia, and thus, be considered good research, then I must declare that my work was

objective, neutral and valid. Indigenous scholars like Absolon and Willett (2005) claim that neutrality and objectivity cannot exist in research because all research is conducted through some human epistemological lens. Instead, these Indigenous researchers emphasize the importance of authenticity and self-location in Aboriginal research. It has also been acknowledged that one way to maintain trust with fellow community members is to locate oneself as an Indigenous researcher (Absolon & Willett, 2005; Linklater, 2011). As such, I have declared my position at the outset of this dissertation.

The concept of relationality is entrenched in Indigenous research (Wilson, 2008). Relationality and its significance to me as an Indigenous researcher were apparent at almost every interview. I was inevitably asked to name my parents or grandparents, if this was not already known. Very often the participants would speak about relationships cultivated with my family members in an effort to make a connection based on this relationality. Kovach (2009) stated that “Indigenous inquiry and story are grounded in a relationship-based approach to research” (p. 98). Because of the relationships the researcher has forged with community members, and their shared collective history, Indigenous researchers have responsibilities to the community beyond those of an outsider researcher. Linklater (2011) argues that Indigenous researchers have a responsibility to conduct “a respectful and culturally grounded research inquiry that honours community participation while recognizing their relationship as an insider” (p. 72). Being an insider researcher, I acknowledge that I have lived on Manitoulin Island for most of my life and I have family, work or ancestral connections in the participating Anishinaabe communities. It was not unusual that I knew virtually all of the study participants, or that they knew me, or that they had connections with members of my

family. Within a Western research paradigm having these types of relationships may be viewed as problematic and a potential source of bias. However, every researcher will agree that participant recruitment can be difficult, especially in small communities. The level of difficulty increases when you receive interest from potential participants with whom you have this degree of relationality, which is a reality for the Indigenous insider.

Kovach (2010) outlined how the story gathering method of choice, that of the conversational method within an Indigenous paradigm, has implications for the “researcher-in-relation.” Since the research participants and I had this degree of relationality, I had some credibility and trustworthiness in their eyes. This type of rapport was not something that had to be cultivated over time. Kovach (2010) asserts that with this level of trust, deeper conversations and more profound insights into the research questions may be possible. As a researcher-in-relation, I acknowledge that this facilitated the sharing of experiences. Kovach (2010) and Maina (2003) assert that research between the insider and participants should allow the conversation to be dialogic where the researcher-in-relation is also a co-participant. This reciprocal sharing of experiences and story allowed for authentic conversations that might not have been possible with a one-sided, extractive (Kovach, 2010) process.

When the “researched become the researchers” (Tuhiwai Smith, 1999, p. 183), Indigenous scholars are calling for Indigenous methodologies and Indigenous knowledge to be the foundation for the research agenda (Kovach, 2009; Tuhiwai Smith, 1999; Wilson, 2008), especially for research that is for and by Indigenous peoples. However, there has been recognition of the fact that Western approaches to research can be

effectively paired with Indigenous approaches to bridge the “ethical space” that exists between them (Ermine, Sinclair & Jeffery, 2004; Kovach, 2009). It is my intention that this thesis also sit in that ethical space between Western and Indigenous thought.

Two-eyed seeing: PAR with IM research strategy

All research should be respectful to and ethical for the participants and communities involved. However, respectful and ethical research should be underscored for Indigenous peoples because of their past experiences with poorly conducted research in which they had minimal input or consultation, misrepresentations of Indigenous peoples in historical texts which contribute to our contemporary education systems, as well as an ongoing struggle to place Indigenous knowledge at the centre of Indigenous research and scholarship as a legitimate means of communicating our perspective (Battiste, 2000; Battiste & Henderson, 2000; Tuhiwai Smith, 1999). As a researcher-in-relation, I feel that I have a special responsibility to those Anishinaabek involved. Through this work, I endeavoured to change the prevailing negative view of research by conducting research that was respectful, responsible and reciprocal, referred to as the three Rs of Indigenous research (Weber-Pillwax, 2001; Wilson, 2001; Wilson, 2008).

Current Aboriginal research focuses on ethical research that benefits the participating communities (Ermine et al., 2004; Jacklin & Kinoshameg, 2008) and abides by the Tri-Council Policy Statement (TCPS2) on Ethical Conduct for Research Involving the First Nations, Inuit and Métis Peoples of Canada (TCPS2, 2010). Such research aims to address social inequity while aiming to be culturally relevant, empowering, respectful and congruent with Indigenous epistemology (Ermine et al., 2004; Jacklin &

Kinoshameg, 2008; TCPS2, 2010). Termed an “emergent approach,” Indigenous Methodologies (IMs) are recent additions to the qualitative research landscape (Kovach, 2009). Inherent in IMs are Indigenous values and a respect for Indigenous ways of knowing, but for the purposes of this research, IM's most salient feature is that the research is conducted by, and for, Indigenous peoples using methods that reflect Indigenous knowledge and worldviews (Denzin, Lincoln & Smith, 2008). IM and PAR have been used together successfully in other Aboriginal health research projects (Evans et al., 2009) and are consistent with my convictions and the aims of the research.

PAR, as a research strategy, is representative of a Western approach to research that is compatible with IMs which honour and respect Indigenous peoples, but further qualitative research with an emancipatory component (Evans et al., 2009). One of the most salient features is PAR's aim of community involvement in the design and delivery of research, as well as with the importance of usefulness and benefits for Aboriginal communities (Jacklin & Kinoshameg, 2008). The guiding principles of PAR and IM applied in this research are that: an Anishinaabe researcher-in-relation carried out the research; there was on-going involvement with Anishinaabe communities; Anishinaabe *gikendaasowin* was central to its theoretical and analytical frameworks; it was reflective of the community; it transferred skills to community members; and it contributed to goals of community involving empowerment and self-determination as means of change (Ermine et al., 2004; Jacklin & Kinoshameg, 2008; Macaulay et al., 1999; Singer, 1993; Singer, 1994).

Through her doctoral work with the community of Wikwemikong, Jacklin formulated a research model for others who engage in research with Aboriginal communities.

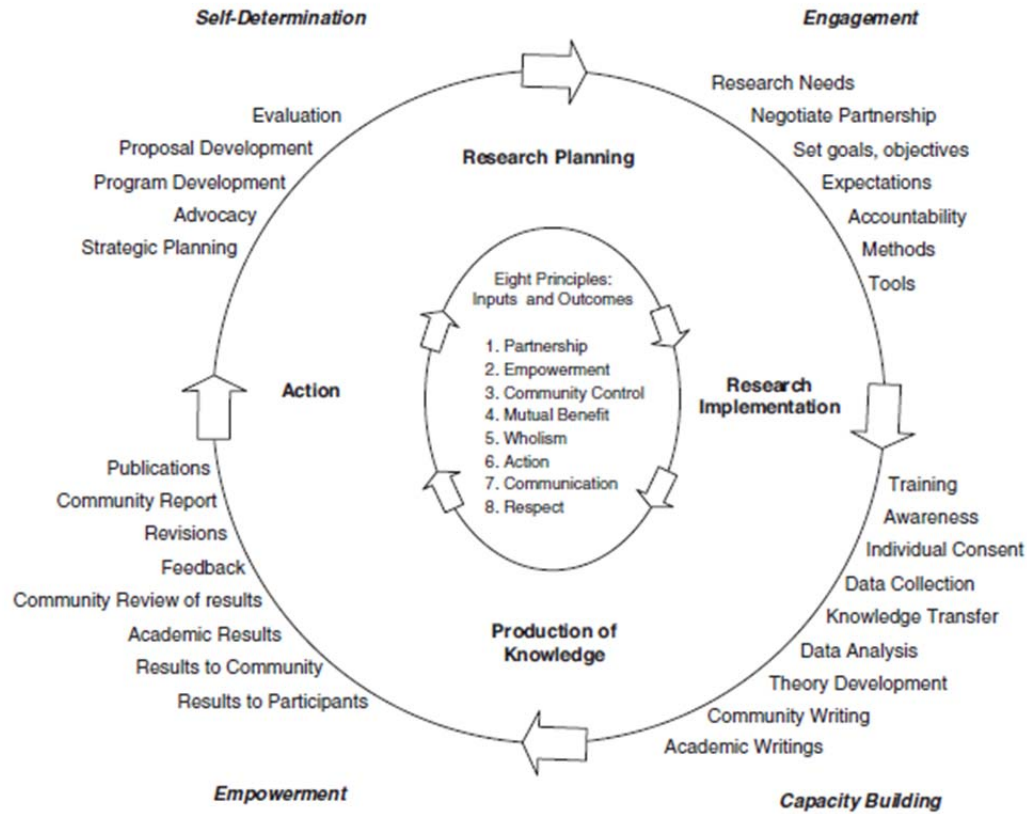


Figure 5: An Aboriginal Model of PAR

Methodologically speaking, this model provided a road-map for this work. The following sections address each step in the Jacklin and Kinoshameg (2008) model of PAR with respect to the present study.

Community engagement: Community consent process

Prior to beginning this research, I visited with three Elders in my home community to determine whether they believed the work which I proposed to undertake was necessary for our community. Their response provided me with the conviction to apply to the PhD

program in the School of Rural and Northern Health at Laurentian University. Their words echo when I have doubts about my work or question my focus. One of the Elders I consulted reminded me that putting down my *Semaa* [Translation: tobacco] would serve to guide me and my proposed work “in a good way.”

I had prior knowledge of the communities I approached to gauge interest in my research, and my rationale for selecting the research sites was embedded in the concept of relationality (Wilson, 2008). Wilson (2008) explains this aspect of how Indigenous communities work: “a key to being included is not only the work that you have done in the past but how well you have connected with others in the community during the course of your work” (p. 81). I chose to approach the leadership in Wikwemikong for several reasons. Aside from being raised and educated in Wikwemikong, it is home. It is also a place where I have developed working relationships with community members through my work in the education and health sectors. Similarly, the United Chiefs and Councils of Mnidoo Mnising (UCCMM) communities have afforded me both teaching and consulting opportunities in the past. These have, in turn, provided me with ample time to develop working relationships with many of the staff and community members in other Aboriginal communities across northeastern Ontario, including Manitoulin Island.

Research in the academic setting involves obtaining ethical approval for any proposed research within institutions. Therefore, ethical approvals were sought and obtained from the Laurentian University Research Ethics Board (Appendix 1) and the Research Ethics Board of Health Sciences North (Appendix 2). Wilson’s (2008) relational idea of axiology and accountability extends to maintaining those relationships with Indigenous

communities. Ethics and community approvals were also sought and obtained with the Manitoulin Anishinaabek Research Review Committee (Appendix 3). A Band Council Resolution (BCR) was obtained from the Wikwemikong Unceded Indian Reserve (BCR 3713), and formal presentations were made to the M'Chigeeng Health Services Board, UCCM Mnaamodzawin Board of Directors and the Wikwemikong Health Services Board.

Prior to the commencement of data collection, I met with the health directors in each participating site (i.e., M'Chigeeng Health Centre, Nahndahweh Tchigehgamig Wikwemikong Health Centre and UCCM Mnaamodzawin Health Services) by way of personal introduction and to gauge interest in the project. This process initiated formal engagement with the communities in a partnership that would be safe and ethical for each individual community. This process was reflective of PAR, as the health directors determined whether the study had meaning for their respective communities.

Presentations of my research proposal were provided to the respective Health Board or Health Committee for each research site, and a partnership was formalized (Appendix 4).

Recruitment and the research participants

This study employed a purposive sample of participants who fit the following criteria. Each participant was: an adult over the age of eighteen; an Anishinaabe person who resided in Wikwemikong Unceded Indian Reserve, Aundeck Omni Kaning, M'Chigeeng, Sheguiandah, Sheshegwaning, Whitefish River or Zhiibaahaasing First Nation (UCCMM communities); and a person clinically diagnosed with cancer at least three months prior to their participation in the study who was able and willing to communicate his/her story

(Struthers, 2000). It was recognized that the diagnosis phase can be especially difficult, so the inclusion criterion of having a clinical diagnosis at least three months prior to participation gave potential participants time to process their diagnosis and ensure that they had begun a treatment regimen. The study aimed to have participants who incorporated Indigenous healing/Traditional medicine and Western medicine, as well as those who used only Western medicine in their cancer treatment. The key informants included health professionals working from both the Western and Indigenous healing perspectives. A total of 30 interviews were conducted. Of the total participants, 13 were Anishinaabe people with cancer (n=13); 9 were key informants working from an Indigenous perspective (n=9); and 8 were key informants working from a Western perspective (n=8).

The 13 participants diagnosed with cancer were women between the ages of 48 to 72 ($M = 59.15$, $SD = 9.49$). Although the recruitment of participants was open to both men and women, only women responded to the call. The Anishinaabe women were diagnosed with a variety of cancers: breast cancer (n=5), lung cancer (n=2), renal cancer (n=2), colon cancer (n=1), brain cancer (n=1), multi-myeloma cancer (n=1) and *leiomyosarcoma* cancer (n=1). With the exception of one woman who lived in Sudbury, but was originally from M'Chigeeng First Nation, the rest of the women resided in four of the Manitoulin Island First Nations. At the time of the interviews, two of the women were in the palliative stage of cancer, one was in active treatment and the others had concluded their cancer treatment or did not require treatment after having surgery.

Interviews were also conducted with male and female key informants working from the Indigenous (n=9) and Western (n=8) health perspectives. From the Indigenous perspective, these included traditional healers (n=3), traditional helpers (n=1), knowledge keepers (n=2), a traditional coordinator (n=1), Anishinaabe language and cultural advisor (n=1) and an Anishinaabe author with cancer (n=1). From the Western perspective, key informants included physicians (n=3), nurses (n=2), a chemotherapy nurse (n=1), a Manager of Supportive Care (n=1) and a Manager of Inpatient Services (n=1).

The following recruitment posters were created by a local Anishinaabe entrepreneur (i.e., *Abordigital Websites and Graphic Design*, (www.abordigital.ca) and were employed in the recruitment process.



Figure 6: Recruitment Posters

The poster recruitment strategy resulted in calls of interest from six respondents with cancer. The other seven Anishinaabe participants with cancer were identified with the assistance of UCCM Mnaamodzawin Health Service's Home Care Nurse Manager, Debbie Selent. As a nurse manager, she was the initial contact who spoke directly with potential participants diagnosed with cancer and inquired if they would be interested in participating in this research to share their stories. The potential participants gave their consent that the nurse manager could provide their contact information to this researcher.

Three key informants working from a Western perspective were recruited through this researcher's colleague connections. The poster recruitment strategy resulted in one call of interest from one key informant working in Western medicine. One key informant from the Northeast Cancer Centre was directly approached, as recommended by my academic committee, due to the nature of her experience in supportive care. An additional three Western key informants were obtained through active recruitment at the Manitoulin Health Centre sites. After the Manitoulin Health Centre Ethics Committee approved my request for a letter to be sent to the appropriate hospital staff, Executive Director Derek Graham sent an email, attaching my letter requesting their participation.

All key informants working from the Indigenous perspective were recruited via word-of-mouth and the snowball effect. Three Indigenous key informants were recommended to me by participants diagnosed with cancer. One key informant from Minnesota read about this research project in a 2012 online news article (<http://www.manitoulin.ca/doctoral-candidate-seeks-anishinaabe-cancer-patients/>) posted on the Manitoulin Expositor website. He, in turn, put me in touch with a second key informant from Minnesota. The

remaining four key informants were contacted by the principal researcher through recommendations from community members and participants. The data were supplemented by family members participating in two of the Indigenous key informant interviews where both original respondents had a cancer experience of their own.

Research implementation

The research implementation steps in the Aboriginal Model of PAR (Figure 5) proposed by Jacklin and Kinoshameg (2008) are: individual consent, capacity building, data collection, data analysis and accountability. Each stage with respect to the present study is discussed below.

Reciprocal sharing and individual consent

The standard informed consent process outlined in university research ethics boards (REBs) reviews the potential harm to participants while assessing the potential benefit (Fletcher et al., 2011; TCPS2, 2010). The TCPS2 has made recommendations for ethical research in Aboriginal communities. Moreover, some Aboriginal communities have developed their own guidelines for ethical research. A case in point is the *Guidelines for Ethical Aboriginal Research in the Manitoulin Area* (GEAR), which is based on Anishinaabe values and addresses concerns with how past research has been conducted (Noojmowin Teg Health Centre, 2003). These guidelines frame the informed consent process of this research. Regardless of these great efforts to make research ethical and do it in a “good way,” the process is not exempt from challenges.

Early in the research process, I faced the challenge of participant recruitment. My experience with one woman, who has since passed on, has stayed with me. This woman initially agreed to participate; however, at the time of the interview, she chose not to, and I later understood why. Initially, I saw this as a setback since I had driven more than two hours round trip to her home for the interview. When I arrived she pointedly asked me, “Can you tell me how this will help us? I’ve seen so many researchers coming into our communities, but nothing ever changes.” While we did not proceed with an interview, some valuable teachings were shared. As was common with many Anishinaabek I visited, she invited me in for tea. When I stepped into her home, I immediately saw how overwhelmed she was that day. She was visibly tired and she explained that she was just home from a cycle of systemic treatment. She was in the middle of doing laundry for her grandchildren, who were staying with her, and she was working on a community project for All Souls Day. She explained that in her community All Souls Day was celebrated with a community feast and the placement of wreaths in remembrance of family members who had passed on. She was instrumental in this annual tradition, and she and the children made these wreaths. While we visited, I helped her with some of the unpacking and sorting of the dried flowers and craft supplies. She thanked me for the help and the visit. Her words have come back when I have had doubts about being able to complete this project, and I have come to view this visit as an important turning point for my research. The point is not to “get the interview” but to try to make a difference for our communities with those shared stories. I could simply have attributed this to the research fatigue common in Anishinaabe communities in the Manitoulin area (Noojmowin Teg Health Centre, 2003). However, there was more underlying this experience for me as an

Indigenous researcher, as it spoke directly to relational accountability and how Indigenous researchers-in-relation have a greater responsibility and role in undoing and decolonizing the “standard” research process. As Pidgeon and Hardy Cox succinctly stated, “Research is not a word that is taken lightly by Aboriginal peoples” (as cited in Fletcher et al., 2011, p. 326).

The majority of the initial face-to-face meetings with participants took place in a location of their choosing, and most preferred their homes. I met with one participant in the Elders’ Centre in her community, where she felt most comfortable. Following the “standard research protocol” in these first meetings, a discussion of the contents of the consent form and an explanation of the study was provided. Informed consent was obtained only after each participant was provided with: the purpose of the research; a copy of the interview guide; how the information would be shared; the right to refuse to participate or to withdraw if desired (TCPS2, 2010). As an Indigenous researcher, I will admit that although the informed consent and signatures were requirements of the Laurentian REB, this aspect of the research felt somewhat antithetical to the relationship-building that happens when we, as Anishinaabek, visit. Furthermore, I thought that my intent in doing this research “in a good way” might be lost in these Western formalities, which I saw as another challenge. These first meetings involved visiting, which is an acknowledgement of each other’s spirit, as I would later learn. These visits were conducted in *Anishinaabemowin* [Translation: Anishinaabe language], if preferred by the participants and if Karen (community-based research assistant) was present to translate. Each participant also received a monetary gift of \$75 for their time and participation. In light of the current financial state of affairs in many of our Anishinaabe communities, I

saw this value as appropriate for the time and effort required for this particular research. The gift, I reasoned, could be applied to the cost of travel for treatments, though no expectation was placed on how the gift could be spent. In addition to these protocols, commonly found in Western research, the Indigenous protocol for the sharing of story was also observed.

Conducting Indigenous research “in a good way” means conducting research that is respectful of and deferential to the protocols in a given Indigenous community (Gone, 2006). In Anishinaabe territories, the passing of *Semaa* [Translation: tobacco] as a gift signifies that a request is forthcoming (Gone, 2006). This practice was adopted as the “traditional consent process” for each participant when they were offered the sacred medicines, including *Semaa* [Translation: tobacco], in a medicine bundle.



Figure 7: Medicine Bundle Gift

Passing the sacred medicine bundle signifies to both the recipient and the giver that they have formally agreed to participate in the sharing of story. One participant explained that she did not “believe in this stuff” (referring to the medicine pouch). However, she accepted the gift with an explanation of why she did not share in these spiritual beliefs and then agreed to participate. She is an example of the diversity in spirituality, beliefs

and values of Anishinaabek. The remaining participants accepted the traditional consent process which supplemented the formalized, informed consent process (Appendix 5 and Appendix 6).

A former Wikwemikong Chief was interviewed for the *Three Fires Confederacy Historical Research Project* (Wikwemikong Board of Education & Kenjgewin Teg Educational Institute, 1995), and he shared what I believe is at the core of being an Anishinaabe researcher-in-relation and the shared roles of those involved in the ethical sharing of story. His words speak to the trust, responsibility and mutual understanding that exist between Anishinaabek when they share in a conversation.

When two people are sitting together and engaging in a conversation, they must know each other and have respect for each other as human beings put on this earth by the Creator. With the mutual respect, they are able to communicate with each other freely because of their culture and their upbringing. People can actually pass on to each other this respect and support for each other and educate each other in the process. We can always learn from one another (p. 99).

Capacity building: Reciprocity

The hiring and training of a community-based research assistant, in addition to the development of a community advisory committee, were means to build capacity for this research process. The funding for the hiring of the community-based research assistant was secured through the Indigenous Health Research Development Program (IHRDP) in the form of a research allowance (www.ihrdp.ca). The hiring and training of the

community-based research assistant was done in collaboration with Nahndahweh Tchigehgamig Wikwemikong Health Centre. The formation of a community advisory committee was accomplished in collaboration with the health directors in the three research sites (i.e., M'Chigeeng Health Centre, Nahndahweh Tchigehgamig Wikwemikong Health Centre and UCCM Mnaamodzawin Health Services). The health directors invited key staff with relevant research and program expertise to participate within their respective organizations.

This community advisory committee provided guidance for the research, ensuring that the expectations of both the participating communities and the researcher were aligned (Noojmowin Teg Health Centre, 2003). This committee consisted of the health directors and other staff in the three participating research sites: Wikwemikong Unceded Indian Reserve (i.e., the health director, a community nurse/home care coordinator, the manager of Nadmadwin Mental Health program and an administrator from Nahndahweh Tchigehgamig Wikwemikong Health Centre); M'Chigeeng First Nation (i.e., the health director and a community nurse from the M'Chigeeng Health Centre); and the executive director and the home care nurse manager from UCCM Mnaamodzawin Health Services. UCCM Mnaamodzawin Health Services, while not a community but rather a research site, oversees the home-community care needs of Aundeck Omni Kaning, Sheguiandah, Sheshegwaning, Whitefish River and Zhiibaahaasing First Nations. The community advisory committee provided guidance for the project in all areas of the research process: planning, engagement, implementation and dissemination. More specifically, they assisted in: hiring the community-based research assistant, recruiting participants,

refining and approving the interview guides, reviewing the presentation of the analysis and results and providing input on the community dissemination component.

The story-gathering or data collection process involved a joint effort between the principal researcher as the primary story gatherer and the community-based research assistant, Karen Pitawanakwat, who is a fluent speaker of *Anishinaabemowin* [Translation: Anishinaabe language]. It is my assertion that bringing community perspective is much more than just permitting someone to speak their language and then to translate that into English for others to learn from. It is about a process of attempting to get back to the original meaning of those carefully chosen words in *Anishinaabemowin* [Translation: Anishinaabe language] and bringing that understanding to recommendations using our Anishinaabe *gikendaasowin*. It is hoped that this work will assist those with cancer within Anishinaabe communities as well as those from the health care field who work with them. This is a reflection of *biskaabiyyang* or a “returning to ourselves” (Geniusz, 2009, p. 9). With this in mind, this project is fuelled by reciprocity and capacity building that is bi-directional. The primary researcher is learning from community members and the community-based research assistant while they, in turn, are learning from their involvement in this research.

Karen took on this project with the aims of further developing her skills with the research process and sharing her knowledge. She is an *Anishinaabe-kwe* [Translation: Anishinaabe woman] who resides in Wikwemikong with her husband of 25 years. She is the mother of two children and grandmother to one. Karen belongs to the Thunder Bird Clan and holds *Anishinaabemowin* [Translation: Anishinaabe language] in the highest regard. Karen has

been nursing in Manitoulin Anishinaabe communities for 20 years with a focus on home care for the elderly and is currently the Home Care Coordinator of Nahndahweh Tchigehgamig Wikwemikong Health Centre. In addition, Karen has extensive research experience in Indigenous communities including initiatives concerning diabetes and dementia. As a community member and nurse with a deep understanding of Anishinaabe culture and language, Karen brought an in-depth and valuable perspective to this research. She also participated in the community advisory committee.

Karen articulated that her first priority for involvement in this research was to learn and discover how she could assist her community members in making informed decisions and to provide a better understanding of what it means to live in Minobimaadiziwin. A second priority was to bring this information to her colleagues in her community's circle of care in order to improve practice. The purpose of having a community-based research assistant was two-fold. The principal researcher had an opportunity to learn and improve her *Anishinaabemowin* [Translation: Anishinaabe language] skills, indirectly bringing a deeper meaning to the interpretation of the results. Additionally, the research participants were given the chance to use their preferred language of communication (i.e., English or *Anishinaabemowin*). Ultimately, the participants decided whether or not they felt comfortable with the research assistant's presence at the interview(s).

Hired as the community-based research assistant in July of 2012, Karen began her two-day training on August 21, 2012, and signed a Statement Reflecting Confidentiality (Appendix 7) prior to participating in this research. Her role involved participation in and transcription of interviews, translating *Anishinaabemowin* when required and co-

constructing the collective story through data analysis. As it turned out, she was unable to participate in many of the interviews. Unfortunately, at the time of story-gathering, Karen's husband was diagnosed with cancer, and caring for him and her family became her priority. However, Karen wished to remain in her role as community-based research assistant for this project, and when time permitted, she listened to all of the interviews to develop her own perspective on the stories gathered and then participated in the analysis stage.

Gathering and sharing stories

Gathering stories, also known as the data collection process, involved the principal researcher and the community-based research assistant, whenever possible. This research employed semi-structured, in-depth interviews as the initial method of data collection. In keeping with the principles of participatory action research [PAR], culturally-appropriate, community-specific interview guides which attempted to capture a holistic cancer experience were developed in consultation with the community advisory and supervisory committees. The interview guides were based on a literature-guided approach where domains were designed to address the research questions. The questions for participant and key informant interviews can be perused in Appendices 5, 6 and 7.

From an Indigenous methodological perspective, these interview guides served as a starting point for the gathering and sharing of story. The open-ended nature of the questions prompted participants to share their stories in a non-threatening and conversational manner. Bishop (as cited in Kovach, 2010) refers to this conversational manner as "collaborative storytelling." This is very much a description of my way of

sharing and participating in the story gathering. As a researcher-in-relation with familial experiences with cancer, I actively listened and contributed, where appropriate, to the conversation with participants. At times, this involved a direct question about those familial experiences from the participants themselves. Other times, the participants referenced my relatives or fellow community members in their storytelling. Indigenous scholars, like Wilson (2001) and Bishop (as cited in Kovach, 2010), posit that through this kind of relationality the relationships are strengthened, deepened and both researcher and participant become engaged in co-creating knowledge (Kovach, 2010). Each conversational interview ranged from one to three hours in duration and was completed in a single session. With the participants' consent, each interview was recorded with a digital audio-recorder and a journal for reflective notes.

A task I found to be daunting in conducting good research was the consideration of the Western notion of data validity, that is, the assessment of whether the results of the study as presented actually reflect the phenomena being studied (Saini, 2012). In other words, was I presenting only what I wanted to see rather than what was actually there? The results in a qualitative study are arguably dependent upon the researcher's interpretation and meaning-making strategy. I found that the answer to this query lay in how I monitored potential sources of bias in this story-gathering stage. Nelson (as cited in Saini, 2012) claimed that one way to minimize bias has been through reflection by the researcher or the use of reflective journals or notes. I have maintained notes, but I have also used introspection, an aspect of *Minobimaadiziwin*, by remaining conscious of my thinking in relation to the emotional, spiritual and physical aspects of myself. Moreover, validity was solidified through data analysis in which each participant was permitted the

opportunity to actively collaborate with the researcher and research assistant to improve the validity of the accounts (i.e., that the participant's story was not misinterpreted). Therefore, validity was underscored with this participatory approach which is attributed to constantly going back to the people for clarification or verification and involving the community to participate in all aspects of the research process.

Making meaning from stories

Kovach (2009) posits that Indigenous researchers can choose to use a mixed-method approach whereby Indigenous methodology may be used along with a Western approach to data organization which will involve presenting the research in two ways; that is, it may be presented in the academic literature and as a tool to assist communities with cancer care, as with a two-eyed seeing approach to research. By employing a mixed-method approach to data organization, the researcher meets the requirements of the academy, so that the research may be presented in the academic literature. Such a method also ensures that the research is done “in a good way” and is useful to Indigenous peoples. PAR studies produce action-oriented findings which are intended to improve the situation for community members but may not be of interest to the academy whose interests lie in theory and generalizability (Bourgeault, Dingwall & de Vries, 2010).

The first step in meaning-making involved the verbatim transcription of the digitally recorded in-depth interviews, or more accurately, conversations. Some of the transcription was completed by the community-based research assistant (i.e., three interviews). The remaining twenty-seven interviews were outsourced to TranscriptDivas (transcriptdivas.ca), a company based in Toronto, Ontario that offers fast and reliable

academic data transcription services and came highly recommended. Specific instructions were provided to TranscriptDivas. First, the “strict verbatim” form of transcription was preferred, where I would later edit the “spoken language” of the transcripts to create more readable documents. Second, concerning the use of the *Anishinaabemowin* language in the conversations, it was requested that time coding be used to facilitate the translation process. When the completed transcription files were received, each transcript was anonymized to protect the identity of the participants and to ensure confidentiality.

This Indigenous inquiry prompted the creation of an analysis protocol to complement the conversational method of my Indigenous Research Paradigm. I have outlined the strategy I followed for analyzing many stories to create a collective, teaching story (Kovach, 2009). Similar to Indigenous researchers Kovach (2009) and Linklater (2011), I returned to the teachings to create my analysis framework. I deliberately avoided use of Western methodological terms like phenomenology, ethnography or narrative inquiry in the description of my meaning-making process. However, one can see that until I fully trusted my assertions, my heart and my Indigenous methodology, I floundered. Outlined below are the steps I followed (including my struggles) in the creation of this collective story.

- 1) I read through the entire transcript to get the sense of the whole.
- 2) I read and categorized each completed interview transcript by reading through each statement made and assigning a code to it. I was constantly comparing these codes with those in other interviews. At the end of this reading and comparing stage, I had a total of 45 possible codes drawn from the interviews.

- 3) I created 30 member-checking interview summaries which would be shared with the participants. Each summary contained a code followed by the corresponding participants' quotes. These summaries also included my interpretation or comments about their statements. The participants were provided with a copy of the coded and interpreted interview. I thanked them for participating and provided them with some time to respond. I heard from five participants and assumed the others were fine with what I had shared. Any comments or suggestions were incorporated into revised interview summaries (Appendix 11).
- 4) At this point, all of the revised member-checking interviews, summaries and corresponding sound files were shared with the community-based research assistant, Karen Pitawanakwat. Ten language translation files were created which outlined any *Anishinaabemowin* words that required translation. The *Anishinaabemowin* words had previously been time-coded to simplify translation.
- 5) The completed interview summaries used for member checking were subsequently collapsed across the participants. All of the statements listed under the 45 codes were combined to create new files which I called integrated code files. For example, an integrated code file would contain all of the statements made about a single code (e.g., the Minobimaadiziwin integrated code file would contain all statements made about this concept by every participant).
- 6) Originally, I used my *Theoretical Model for Two-eyed Seeing* (Figure 3) to group my codes into larger analytic categories. These categories were assigned according to where I thought each code would sit on the outer circles of Figure 3 (i.e., distal, intermediate, proximal determinants). I took all of the codes which related to

Anishinaabe *Gikendaasowin* and made a separate analytic category. I had them grouped as: 1. contextual factors for illness; 2. systems, braiding and access; 3. relationships, communication and decision-making; 4. cancer understandings and education; 5. Anishinaabe *Gikendaasowin* (which involved all codes concerning the teachings or items specific to *Anishinaabe* culture).

- 7) I was disappointed with this first attempt at structured meaning-making. It was at this point that I began to re-visit and trust the process of Indigenous methods. I reviewed my readings and worked on developing a better understanding and fit for my data and congruence with my Indigenous paradigm. I also went back to my research questions and realized that this first attempt at meaning-making was not suited to my question, or the dissemination project that I had envisioned. I needed to create a story!
- 8) Probably the most important step in this meaning-making process was to re-visit the teachings that were gifted to me. Ultimately, it was the teachings that I used to frame the collective story of cancer and *Minobimaadiziwin*.
- 9) I looked at the stories and began to create and sequence the ten new themes, each representing a separate part of the cancer journey. For each new theme, I created new theme files by engaging with the original codes again and comparing each with the ten themes. Essentially, I re-read the original code files to find out what the participants were actually telling me about their stories and the sequencing of the collective story. I only omitted those code files which were not directly associated with the research questions (i.e., the use of other alternative methods of healing and co-morbidity or additional health conditions).

10) From this new meaning-making strategy, I created an Anishinaabe data analysis framework I will refer to as the *Collective Story of Cancer and Minobimaadiziwin* (Figure 8). It was based on the experiences of all of the participants in this study. The newly created themes would later form the structure of my Results section.

Anishinaabe data analysis framework to understand the story

Indigenous people have the right to revitalize, use, develop and transmit to future generations their histories, languages, oral traditions, philosophies, writing systems and literatures, and to designate and retain their own names for communities, places and persons. – Article 13, Declaration on the Rights of Indigenous Peoples (UN, 2008, p. 7)

The meaning-making framework that was created was based on Anishinaabe *gikendaasowin* – Minobimaadiziwin teachings. These teachings have many names and involve multi-dimensional layers of Indigenous knowledge (i.e., Little Roads, Life Path or Seven Stages) and can have a variety of interpretations. This data analysis framework is unique in that it uses Anishinaabe teachings to interpret participants' stories in order to create a collective teaching story. I have been gifted with Minobimaadiziwin teachings which have been shared in their entirety in Appendix 12, and these teachings form the basis for this collective story. I have decided to share the teachings below, as they were told to me in an effort to honour and preserve their integrity. These teachings are a sacred gift which I feel should not be dissected for further analysis and will not be considered to be the Results of this thesis. The collective story of cancer and healing is illustrated (Figure 8) and described in Chapter 4.

Production and dissemination of knowledge

There have been claims made by those in Aboriginal communities that past research studies have not been shared, or that the information produced has not been useful to communities on Manitoulin Island (Jacklin & Kinoshameg, 2008; Noojmowin Teg Health Centre, 2003). This remains crucial for ethical research with all Aboriginal communities. The present study aimed to share the results and deliverables in a meaningful manner with community stakeholders and with the community in general. To address this in my work, the dissemination of results takes three forms: the first is the creation of a collective teaching story for Anishinaabe people concerning cancer and Minobimaadiziwin; the second is the production of “knowledge for use” by reporting the data that will allow Health Directors to use the results in future funding proposals or program development (Jacklin & Kinoshameg, 2008). The final form of this dissertation will be submitted to academic publications. These reports and publications will be shared with participating communities and health centres as indicated in the Community Research Agreement Form (Appendix 4).

In order to share the results in a meaningful manner and reach as many different audiences and community members as possible, I have incorporated an artistic element into this research. With a research allowance from the Indigenous Health Research Development Program (www.ihrdp.ca), I was able to enlist the help of the local Indigenous theatre company, Debajehmujig Storytellers, to create a video to share with community members. Manitoulin First Nation communities are accustomed to Debajehmujig Storytellers productions, as they are a community-based theatre company and often work in collaboration with the participating communities. Using the Results

chapters, Debajehmujig Storytellers will create a video based on the collective story of cancer and Minobimaadiziwin. The video project will be shared via YouTube in an effort to share widely with Indigenous and non-Indigenous peoples alike. Community members will be invited to a screening of the video held at the Debajehmujig Creation Centre on Manitoulin Island.

This step of the research model is a work-in-progress since it is my intention to produce publications to share with academia. The results of this work were also presented formally to each participating community as outlined in the Community Research Agreement Form (Appendix 4). Participating communities may also decide to use the results or recommendations of this work to assist them with their own strategic initiatives as outlined in the final step of the PAR model below.

Action and self-determination

The final step in Jacklin and Kinoshameg's (2008) research model is the action stage of the research process. This will involve knowledge transfer and moving research into practice. As mentioned in the previous section, communities may use the results for proposal development or to further strategic planning (Jacklin & Kinoshameg, 2008).

This stage of the process will be dependent upon whether the community wishes to involve the researcher (Jacklin & Kinoshameg, 2008). Control over this stage of the research process remains with the participating communities.

Chapter 3: Interpretations of Minobimaadiziwin

A gifted interpretation of Minobimaadiziwin

The “Path of Life” or Minobimaadiziwin teaching has been utilized as an instructional aid in ceremony and originates from pictographs found in Ojibwa sacred scrolls (Angel, 2002). The interpretation of Minobimaadiziwin used to create a meaning-making framework for this study is based on the *Miikaans* [Translation: little roads]/Seven Stages/Path of Life teaching (Appendix 12), which was gifted to me by John Rice of Wasauksing First Nation for this research. John is a second-degree member of the Three Fires Midewiwin Society who has dedicated his life to learning the *Miikaans* teaching and is also the author of *Understanding Cancer, a Ningwakwe’s Healthy Life Series* publication. To summarize what was shared with me, the *Miikaans* teaching speaks about the spirit journey, which begins at the Creator’s side. A spirit will come through the Eastern Doorway at the time of birth and throughout life will continue westward toward the Western Doorway. At the time of death, or the end of physical life, the spirit will travel out the Western Doorway and back to the Creator’s side. Throughout life we will reach, and hopefully, pass through seven stages of life. At each stage of life, we are faced with a temptation or challenge to be overcome if we are to live to old age or Elder-hood. At each of the seven stages, there are seven corresponding “little roads.” Each little road represents an instance or situation that can mean an early exit from the path of life or Minobimaadiziwin. Those who hold this teaching have not identified what each road represents, and therefore there is room for interpretation, which I have made use of within this framework. I have been told that one “little road” can be representative of an illness like cancer.

Minobimaadiziwin teachings provide Anishinaabek with the teachings for living a long, healthy life which is ultimately dependent upon individual choice (Rheault, 1999). The path one chooses at each of these little roads is also a matter of choice. As the adage states, “to each his own,” I have taken the liberty of interpreting that participants’ choices within the cancer experience are a reflection of their own personal Minobimaadiziwin.

Participants’ interpretations of Minobimaadiziwin

Minobimaadiziwin is representative of many things that are intertwined throughout the lived experience being examined in this thesis. The participants’ definitions frame the entire thesis, and the concept of Minobimaadiziwin is reflected throughout the cancer experience just as it is throughout life for Anishinaabe people. The participants in this study were asked to define what Minobimaadiziwin meant to them. Their interpretations speak to how one can achieve balance and how this is affected throughout the cancer journey. These interpretations are reflected throughout the body of the Results chapters in this thesis.

When asked, most of the participants provided a literal translation of Minobimaadiziwin in four ways. The concept was described as involving “balance” and being able to live well physically, mentally, emotionally and spiritually. Participants shared that the concept also involves “respecting and treating others well.” The concept of Minobimaadiziwin was also understood by some participants as “a life path” reminiscent of the *Miikaans* teaching. For them, this life path can change and can have obstacles which represent those things in life that one needs to overcome if one is to continue living well. It is notable that participants mentioned change, where one’s direction for change is

based on a choice – a central tenet of Minobimaadiziwin (Rheault, 1999). In this chapter, it is evident through the participants' definitions that Minobimaadiziwin is a collection of teachings that provide a prescription for living well.

Balance

Participants shared that when trying to understand the Minobimaadiziwin, one should remember that balance is about, and within, the four elements of a person's being, the physical, mental, emotional and spiritual. It was stated that it is difficult to separate or discuss those elements separately. Within the present study, the four elements have been examined separately for ease of analysis and explanation. In reality, the elements cannot be separated. Similarly, while I have tried to separate the definitions and stories about Minobimaadiziwin into four areas of focus, one can see that the interpretations often overlap.

As Nishnawbek we always kind of thought about four of them – your physical and then your spiritual, emotional and the mental all kind of goes in one, Minobimaadiziwin and trying to tear it apart and see how it works, you can't, because it's your way of life, it's your thinking about how you're living, but also it's how you eat, how you speak to the Creator, how you thank the Creator, how you look upon your fellow man or your fellow person. It's all just that one way of life and it's hard to break it apart.

(APDC05)⁶

⁶ APDC is the acronym for Anishinaabe Person Diagnosed with Cancer.

Indigenous teachings, all of those are holistically based. They address all parts of your being; they don't divide it up and only address your mental or your emotional or your spiritual, or physical. It looks at how those are out of balance individually but also together because they all affect each other. (IHP06A)⁷

One participant spoke about her process of healing and the turning point in her health. She acknowledged that *Minobimaadiziwin* involves all four elements of a person working together to produce wellness. She recalls her experience in working with her healers and how they encouraged *Minobimaadiziwin* or balance for her wellness.

They said, "Not only will you continue to take the medicine, you will continue in prayer, continue in a good thought process, a good thinking place" that *Bimaadiziwin*, and spiritually being in constant prayer, giving thanks. And so they also talked about that, about those elements of who we are and that not only do they take care of the physical aspects in regards to my physical sickness through the medicines, I had to look at what else was going on in my life to bring that to a place of acceptance and love." They said, "You need to look at these things in order that you will continue to physically be in a good place, to physically be well. We forget to have that balance with the physical, the mental, the spiritual and the emotional parts. So now with any bouts of illness, I look at those anytime I am off-balance. I have to seek that within myself to bring myself back to balance. It's a daily process. (APDC11)

⁷ IHP is the acronym for a participant from the Indigenous Health Perspective.

In response to staying in balance, some participants added that they believe Minobimaadiziwin is achieved and maintained by working through the four elements of a person's being.

It's taking care of your mind. Physically, taking care of your physical needs; sleep, eating right, exercise. Emotionally, looking after your emotional health; not carrying a lot of grief, anger, hatred, those kind of negative emotions and keeping a good outlook in a positive way. And then spiritually; we use the sweat lodge, we pray, we fast, we offer tobacco, those kind of things. That to me, that's Minobimaadiziwin. You're looking after your life that way. We also say is that the spirits only want one thing for us and that's Minobimaadiziwin. That's a good life and to be happy. Spirits love it when we're happy. (IHP05)

I think Minobimaadiziwin is a good life – literally translated that's what it means, a good life – our wellness. We always say we're well physically, mentally, spiritually, emotionally, if we look at those four areas and balancing all those areas. We're told that if you're not in balance, even in one of the areas, then you're not Mnaamodzawin, you're not well. Physical would be how you look after your body, so how you eat, your exercise, your sleep, your rest that recharging and that healing takes place. The mental, they say we have to keep our minds healthy too and that's by learning, to think positive, not to think negative. Then your emotional self, one of the healers said that that comes from the spirit – your emotion, how

you feel. Then of course our spirit we have to try and make our spirit healthy too. I think this is where we miss out. You have to get to the spirit if you're going to heal your whole body because that's where the key is. There're lots of things that we can do to look after the spirit, to feel good about ourselves and about who we are. You come from a certain family; you come from a certain place – Wikwemikong – so we may be Ojibway, Odawa, or Pottawatomi. People should know who they are; know your clan; know your name. When you're given an Anishinaabe name, [know] what it stands for and live that name. (WHP05)⁸

Other participants incorporated the idea of maintaining this balance in your life regardless of change or obstacles that we face. Acknowledging that there is room for change in one's life implies that one also has to make choices for Minobimaadiziwin.

It's about that good life that we all seek. We all want to have a good life free of too much negativity but it's about balance. Walking in balance and everyone has their own balance so it's up to you to find your balance in your life and giving things in your life “in a good way” and you'll receive those things as well. Accepting the challenges that life presents to you and we have some ability through our life choices. The good life talks about that journey of balance and when we talk about balance it's not just physical, it's spiritually, mentally, emotionally and physically. Making those choices and acknowledging the balance and we need in all of those parts. (IHP06A)

⁸ WHP is the acronym for a participant from the Western Health Perspective.

Respecting and taking care of one another

Participants in this study also referred to Minobimaadiziwin as being able to “live from the heart” where one strives to live well by using the heart to guide one’s actions. One participant acknowledged that achieving Minobimaadiziwin is not easy and definitely requires work. “Life is not easy, that *Bimaadiziwin*, *Minobimaadiziwin* to be able to live from the heart.” A healer explained that a return to the Anishinaabe way of life would mean to live from the heart. He sees this as the answer to helping Anishinaabe people move to a place of healing or Minobimaadiziwin. He shared this story to illustrate what this means.

We have to go back to our Anishinaabe way of life. It’s a way of life, it’s a way of thinking, it’s a way of doing things, it’s a whole different train of thought. A young Anishinaabe travelled all around the world and he was sitting there telling his grandfather, boasting to his grandfather about all the places he’d been. [The grandfather] said, “Grandson, the longest journey anybody can take is between the head and the heart.” When people go back to the culture, truly go back to the spirit of it, it moves us out of our head and back into our heart and that language of the heart is truth. (IHP08)

Living from the heart also entails treating others with respect, love and kindness. It involves taking care of one another. Many participants recalled the importance of the first gift that the Creator bestowed upon all Anishinaabe people: *Zaagidwin* or love. The Elder who shared the *Miikaans* teaching with me shared, “If you go through this life using love as your guiding principle things will manifest for you in a good way; that’s where you get

that kindness and everything from that” (IHP09). One participant’s interpretation of Minobimaadiziwin was reminiscent of other religious teachings, that is, to treat others as you want to be treated. She saw this as a form of taking care of her life and those around her, ensuring that her family will reap the good things she has done for others in the past. She also warned that “what goes around comes around” and that your actions can have repercussions which can “splash back” on your family’s well-being.

To me it means to try and take care of my life and a way of life. They say what goes around comes around. If you’re good to people, good things will happen to you. And when I say good things, it’s not just physical or tangible stuff but spiritual. Like in my case, my health I think has come back because I believe very strongly in being positive. That also extends to my family and those around me, I think anyway [laughing]. My children are getting the help I gave the students or the people I worked with. They’re getting emotional assistance, spiritual assistance that I might have given to somebody a few years ago. So to me, that’s Minobimaadiziwin, to look upon your fellow man as you want to be looked at or helped. In the Lord’s Prayer it says – “Forgive us our trespasses and we forgive those who trespass against us.” Well, if I don’t forgive anybody, I don’t expect the Creator to forgive me. If I’m not nice to you, I don’t expect anybody else to be nice to me, or my family. Because what you do – *Shkweseh* [Translation: a word describing balance. It is used here to describe the balance of life and how it was meant to be lived. Be good to all living spirits, and only good will come to you and all

those you love], when hot water splashes back, or splashes ahead. You do something bad; it splashes onto your family. (APDC05)

We have to keep feeding the spirit, and we feed that spirit by taking care of our body, mind and spirit. The way that we think about ourselves, that's feeling good about who we are as individuals and as a people. The way we are with one another. We treat one another with respect, with kindness and help each other. We're supportive, we're affirming, we're loving, and that's how we feed each other, that's how we feed ourselves. (IHP07)

One participant shared a part of his daily morning prayer that reflects this component of Minobimaadiziwin: "Help me help my Anishinaabe people." He believes that he leads a good life and acknowledges that it won't be the perfect life until he gets to the other side, and so he acknowledges the spirit journey.

Wii doo kawishin n'ji wii doo kawagwani n'ji Nishinaabe, Help me help my Anishinaabe people. Wii doo kawishin boonendimaan, Help me forgive. We have a pretty good life, it's not perfect, it won't get perfect until we get to the other side. Bimaadiziwin is living the good life, to live a good life and to help others. (IHP01)

In this participant's prayer, he acknowledges the spirit journey. The teachings of Minobimaadiziwin reflect a journey where Anishinaabe peoples' spirits leave the Creator's side and journey through physical life toward the Western Doorway where we

will return to the Creator's side. Other participants have shared their views of Minobimaadiziwin using the metaphor of the life path.

Path of life and choice

Participants referred to Minobimaadiziwin as a path that Anishinaabe people follow throughout their lifetime.

Mnaamodzawin – that's the life I'm going through, the path I'm going through. The path, that's the way I see it. My *Bimaadiziwin* is changing now. (APDC01)

The Good Life is just about how you want to walk on this earth path, wanting to do good for people around you and putting the Grandfather Teachings into what you do and how you choose to live your life. (IHP06B)

Changes are understood by some participants as obstacles that one must overcome. For some, cancer was seen as one of those obstacles. One participant's experience illustrates what influenced her choice in treatment for cancer. She was one participant who chose to forego Western cancer treatment and to work with Indigenous medicine people, but to be monitored by Western doctors.

I think that when it comes to dealing with our health we know that our [Western] doctors specialize in physical aspects of health and that's what their training is. For our people it is always about all four. And our medicine people will say, 'It is your choice if you choose to do both or one

or the other' because in their infinite wisdom our teachings were about choice. (APDC11)

Other participants described that living in a holistic way can be achieved in the daily choices that people make. This participant implies that there are different paths that we can choose.

Being holistic for someone can be totally different for someone else. We don't know if we're always doing the right things; we think we are and we're trying. But if I get there before you, well, then maybe it's because I took a different path. (APDC12)

It was stated by some participants that an illness like cancer can bring us closer to Minobimaadiziwin, making cancer a metaphorical "fork-in-the-road" where a deciding moment is presented and people are forced to make a choice. In this way, it is believed that the one who is ill has a choice to make in that they either choose Minobimaadiziwin by making changes for better health or they don't.

[Cancer] either forces a person to look at their lives and make those changes, to correct things in their life or better their lives. Or, it's simply the person just doesn't make those changes and heads down a road of uncertainty and maybe in the end that they will accept that this road has an end to their time here. It's really up to them. There's two roads presented to them and they have to choose. There's only one choice if you want that Minobimaadiziwin and that's to look at it and address it and make those

changes, be willing to do that ... even not making a choice is a choice. So it forces you to do that, to look at it and choose. (IHP06A)

When somebody has that feeling that a treatment's not good for them and your mind is telling you -- your gut is telling you, it doesn't feel right, then don't do it. It's your body telling you -- you're getting in tuned with your body and that's good health. That's good understanding, and when you have those little butterflies in your stomach, that's you getting in tune with your mind, body and spirit. It's whatever you choose. But I think the number one thing a person should not forget is that they have a choice, which is the greatest gift of all. (WHP08)

It seemed to be the consensus that living in Minobimaadiziwin is entirely up to the individual. This can apply to one's daily life choices or when they are faced with an obstacle in their life path, such as cancer. The choice is one that belongs to the individual and as one participant aptly stated, "*Kiingwa*" [Translation: it's up to you].

Chapter 3 discussed interpretations of Minobimaadiziwin, an Anishinaabe teaching employed as a meaning-making framework for this study and is situated at the centre of my *Theoretical Model for Two-eyed Seeing*. The participants' definitions of Minobimaadiziwin were representative of four meanings. The first concerned balance. Participants found it difficult to speak about the four aspects of their being, that is, the physical, mental, emotional and spiritual, as separate entities. They are seen as a whole and are interrelated, where a change in one affects change in the other areas of one's life.

Minobimaadiziwin, and consequently healing, are dependent on working to balance and “looking after” all four areas of one’s being, including when one is faced with challenges and difficult choices. This is an important consideration for the participants’ choices in healing method. In order to look after all four areas, one can assume that Western medicine’s focus on the physical is not sufficient to achieve Minobimaadiziwin.

The participants shared that Minobimaadiziwin entails “living from the heart.” This involves respecting others and treating them with kindness. Minobimaadiziwin is a path that can change and is dependent upon the choices made by the individual. There are choices involving treatments for cancer. It was expressed that even not making a choice is a choice. Minobimaadiziwin involves paying attention to signals from our body, mind, and spirit which help us to make life choices. Participants’ comments also reflected the importance of family and community for Minobimaadiziwin but that ultimately it is up to the individual to make their own choices for Minobimaadiziwin.

Chapter 4: The Collective Story

The structure of this Results chapter is based on Anishinaabe *gikendaasowin* (Indigenous knowledge) shared with me by Elders as a culmination of teachings (Appendix 12). The participants' collective story from thirteen Anishinaabe participants diagnosed with cancer (APDC) is illustrated in Figure 8. It focuses on six aspects of the cancer journey, each aspect being represented by a slice of the path of life that has been magnified. Figure 8 depicts the collective story from the time of cancer diagnosis to the palliative stage. In addition, influences which surround the cancer experience are represented as ovals surrounding the six "slices" of the four-coloured life path. These influences include relationships and the type of healing chosen by participants are discussed separately in Chapters 5 and 6.

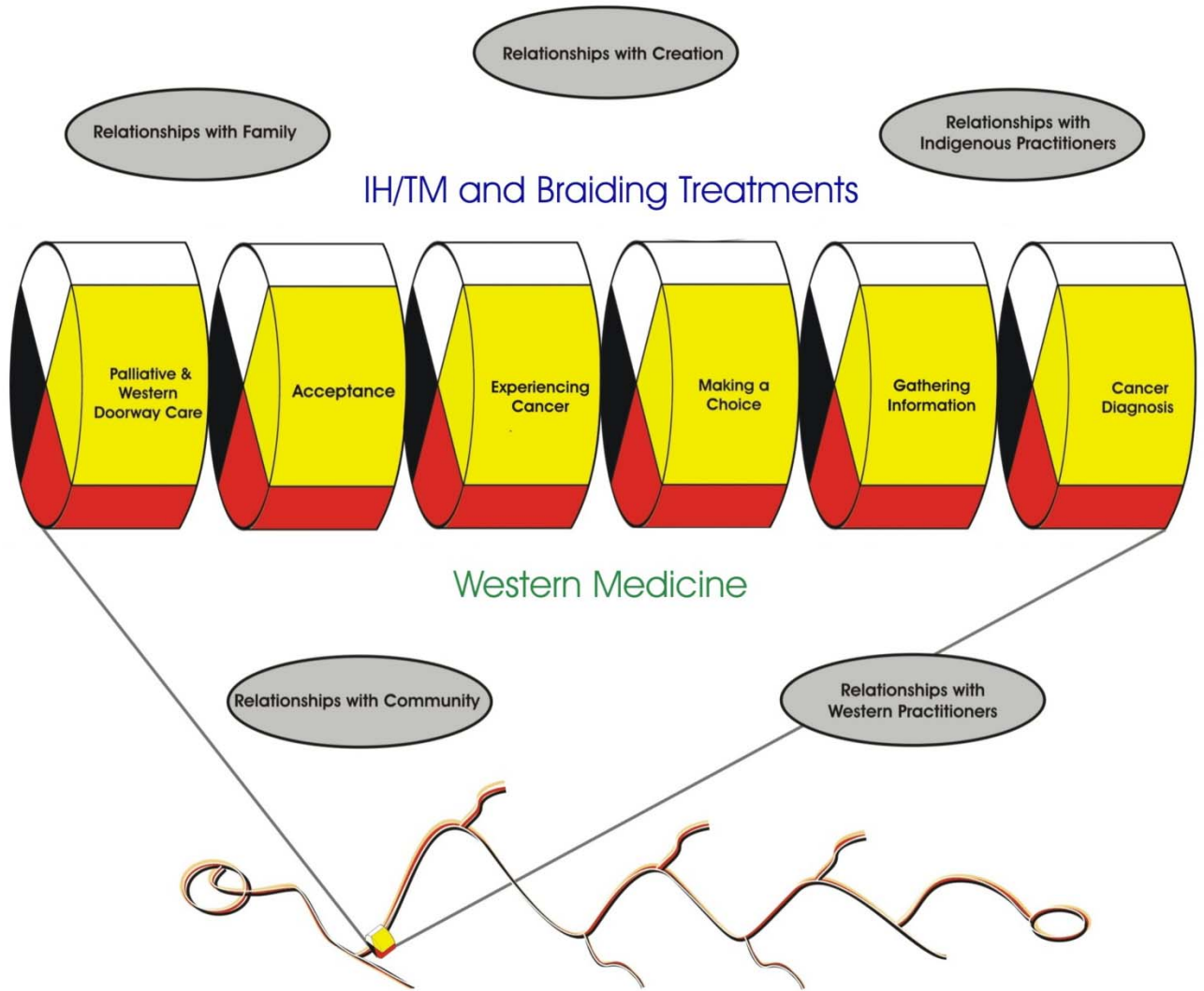


Figure 8: A Collective Story of Cancer and Minobimaadiziwin

Figure 8 is meant to be read from right to left or from east to west, and the collective story it depicts is the spirit journey from birth to the end of physical life. The women whose stories are gathered here are between the ages of forty-eight to seventy-two and can be described as entering, or being in, the stage known as the Elder, grandmother or pure stage of life. The women are reflecting on the knowledge they have gathered along their life paths and have the responsibility of sharing and reciprocating what was shared

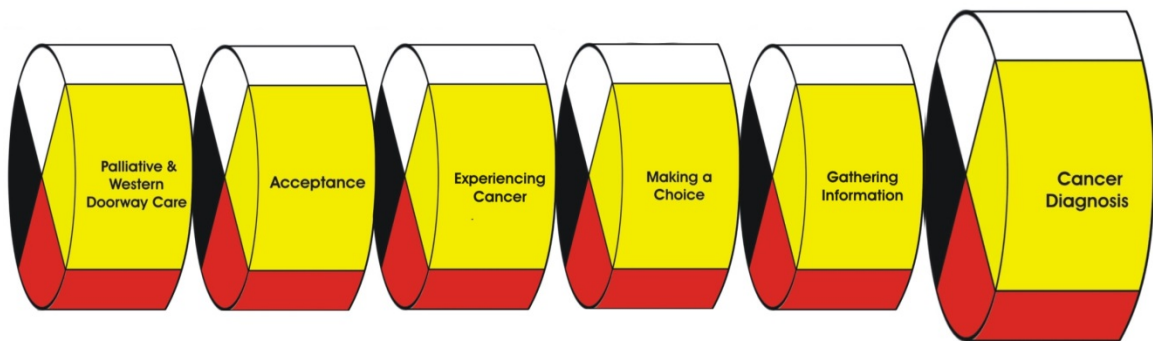
with each of them in their youth. The women have earned this responsibility by looking back, but also looking toward the Western Doorway and anticipating “going home.”

This chapter presents a collective story of cancer and Minobimaadiziwin, privileging the voices of the participants. Therefore, I have chosen to write this story in the first person plural form. The cancer journey usually begins with a diagnosis (Cancer Diagnosis); however, for some Anishinaabek, the cancer journey began prior to the receipt of this news. Many people had shared their personal conceptions of what cancer is and how one gets cancer. Anishinaabek in this study shared how they acquired knowledge about cancer; most sought cancer information from a variety of sources. Others received their education about cancer directly from a health professional (Gathering Information). Ideally, each person made a choice regarding the type of cancer treatment they would eventually receive (Making a Choice). For the purposes of this study, the two choices were: to receive conventional cancer treatment based on the Western medical model only or to braid Indigenous healing/Traditional medicine with Western medicine. The Anishinaabe participants described their experiences with cancer treatment reflecting on their personal choices and how this affected their Minobimaadiziwin (Experiencing Cancer).

At some point in the cancer journey, Anishinaabek in this study came to a point of acceptance (Acceptance). That point of acceptance may have occurred at differing times along the cancer journey. What acceptance meant was unique to each person. Acceptance could mean the acceptance of the cancer diagnosis, the acceptance of death, or the acceptance of a life beyond the cancer experience. Upon approaching the end of the

cancer journey, some Anishinaabek were deemed palliative and were approaching the acceptance of death. However, all Anishinaabe participants involved in this study reflected on their own end to physical life at some point in their journey (Palliative Care & Western Doorway Care).

Cancer diagnosis



I knew something was wrong

For many Anishinaabek, the cancer journey began well before the receipt of an official cancer diagnosis. Some never expected to receive a cancer diagnosis, and others knew something was physically wrong. We may have been experiencing problems, but were not able to explain our symptoms, especially if we had been in good health for most of our lives. Some Anishinaabe participants' first language is *Anishinaabemowin* [Translation: Anishinaabe language], but since English is the primary language in a health care setting, we may have trouble accurately expressing how we were feeling. It is possible that we may not be explaining symptoms in a way that facilitates an accurate or timely diagnosis. If our feelings are not understood or are ignored or dismissed, trust in the health care system is lost, and we may give up.

There was something going on with me but I didn't know what it was. It kind of scared me. I didn't feel sick or anything. I don't know how to explain it, but I went to emergency. I felt like I was going to be coming down with a cold or something. They must have thought I was odd when I got to the admission office and said, "I don't know why I'm here. But there's something wrong. I don't know what it is. I can't explain it."

(APDC06)

At other times, medical professionals may have been focused on some other aspect of illness, and Anishinaabek may have felt that our concerns were being ignored or dismissed, especially our initial concerns.

For the last few years, I just knew something was wrong. My doctor looked at me and he said, "How long have you known?" I said, "I was always in here for pain, but you wouldn't believe me. I was in pain for the last two years, so I probably had my cancer already." (APDC09)

When the medical community finally acknowledged the problem, these Anishinaabek felt at least somewhat validated in having noticed that something was wrong. For others, the diagnostic process tested our patience.

Arriving at a diagnosis can be a long and frustrating process

For some, the diagnostic process was a long, drawn out and very frustrating part of the cancer journey. The diagnostic process can involve several tests, and they can be painful.

They told me I had to have lots of tests because they had to find out what kind of cancer I had. They didn't know. I had to have a mammogram, a

colonoscopy, an MRI, CAT scans and I had a lot of blood tests. The final one really hurt. They stuck a big needle, right in my leg and took bone marrow. Oh, that frickin' hurt! That's when they found out that I had blood and bone cancer, multiple-myeloma cancer. (APDC09)

As the adage states, hindsight is 20/20. Study participants may have felt that cancer was easy to spot and may wonder why it was not treated sooner or more expeditiously. As noted by this physician, our knowledge about illnesses and how they are investigated is often misinformed.

People don't understand. If you're looking backwards in time, "Aha, that's what was happening" and wonder, "Why wasn't this done?" But in fact, if you look at the person's symptoms, it was all pointing into another direction for a long time and it was only when they got this other symptom that it kind of changed the perspective. It depends a lot on people's understanding of the illness and investigations. (WHP04)

The process for arriving at a diagnosis is multi-faceted and complex. This physician explained that it can be difficult to arrive at a definitive cancer diagnosis despite the fact that both the physician and the patient suspect cancer. It is difficult to get people into the specialist's path of investigation. A physician must be sure that the symptoms cannot be attributed to some other disease or infection. This process can be a frustrating experience for the person, the family and the physician.

You might be thinking it's a cancer, but unless you get a tissue diagnosis, you can't actually get them into that part of the system at all. There are

questions: Is it cancer? Or is it some strange infection? It makes it a lot harder for the family and for the person, even though you're trying to treat their symptoms at the same time. I think sometimes that leads to, “Well, if you haven't come up with a diagnosis yet, you're not trying hard enough.”

(WHP04)

The ability for some Anishinaabek to cope mentally or emotionally with cancer may be impacted by how a diagnosis is communicated. Whether their diagnosis was received in a timely fashion or not, most Anishinaabe participants agreed that the cancer treatment protocol began with little or no delay.

Everything happens quickly

Once a diagnosis of cancer was given, the participants noted that everything progressed relatively quickly. Some realized the need for the sense of urgency and accepted that treatment decisions needed to be made. Some believed that this was due to the possibility of our cancer spreading. We realize that this process, although intrusive, is meant to save lives.

It's just so fast, and it's a really aggressive cancer. It wasn't there and then it was there! (APDC03)

Some Anishinaabek expressed that there was a lack of time in which to ask questions or to consider any other options. This was disconcerting and ultimately impacted their decision-making concerning their own treatment. This participant, in hindsight, wished that she had opted for a double mastectomy.

My doctor said, “You have cancer and we need to take your breast. Would you like me to take both?” I looked at her as if she was nuts! I said, “No, one is bad enough.” I wish today she took both, but I had no time to even think. (APDC10)

When considering other types of healing, Anishinaabe participants revealed that Western medicine was usually the only option presented, so it was the only option considered. We had little time to consider further treatment options or decisions.

Everything happened so fast, and before I knew it, it was surgery. So I mainly had to rely on Western medicine. (APDC08)

The majority of the health professionals stated that people with cancer tend to have the most difficulty dealing with the diagnosis and early treatment phases of cancer, as they do not have a frame of reference for the cancer experience.

Time of diagnosis is probably one of the most poignant crisis periods in that cancer journey. There’s the shock of being diagnosed and there’s the whole introduction to a system that the person does not understand. They quickly have to familiarize themselves with this system and then make decisions about treatment to save their life. (WHP07)

A cancer diagnosis forces people to face the unknown and wonder about where this illness will lead. The learning curve is steep, and decision-making is felt to happen in haste. This life-changing experience is accompanied by a range of emotions including disbelief or denial.

I didn't expect this ... not me!

When Anishinaabek receive the news of cancer, we are often in a state of shock and disbelief. Younger people tend to believe that they are invincible, and therefore cancer is not usually on the radar. If we are older, have led healthy lives and have not encountered cancer in our families, we might also expect to remain cancer-free. Several participants mentioned that they never expected to receive a cancer diagnosis within their lifetime.

I initially thought that my diagnosis was some sort of mistake since I had been relatively healthy and was not experiencing any symptoms. When the doctor called me, I cried because I didn't think this was for me. This was for somebody else, not for me. I thought it can't be me. Maybe they made a mistake with somebody else's report. I seemed to bypass the symptoms.

The only thing that really affected me was tiredness but I didn't know it was a symptom. I thought I was just tired. (APDC08)

Upon receipt of a cancer diagnosis, people express a range of common emotions. Anishinaabe participants in this study shared those same emotions but also expressed a unique element which layered this experience for them.

Fear, hurt, anger and *zhagwenmowin*

The time of diagnosis is laden with emotions which include shock, sadness, anger and fear. For some Anishinaabe participants, there is also an element of *zhagwenmowin* [Translation: imposed shame]. Some Anishinaabek mentioned immediately thinking of and fearing death, as a result of cancer. Our thoughts turn to the worst-case scenario, and the idea that cancer is a death sentence is still very prominent with the Anishinaabek.

These emotions are echoed not only in this participant's words but how these words are expressed in a whisper.

Some people are really scared when they hear the word cancer. It's a scary word. They'll say, "I've got cancer" [whispering]. They are just full of fear. Cancer relates to death, that's how I see it. (APDC01)

One health professional put into perspective the fear that many people, Anishinaabek and non-Indigenous alike, will feel.

When you're facing a diagnosis of cancer, you don't know if you will be in the 15% that doesn't make it, and so you constantly live with that fear. Anybody who's faced with a cancer diagnosis understands that challenge of possibility, "If I get it, will I survive?" and it is frightening. (WHP07)

As Anishinaabek, we are not immune to fear, and some feel we fuel this fear by not acting on things in a timely manner. A health professional who has worked in a number of Anishinaabe communities for many years acknowledged the notion that cancer as a death sentence may very well be a truth.

I think people leave it until there's nothing left to be done. One lady waited three months before she went to the doctor. If she had gone right away, then something could have been done. She had a lump in her breast and she said, "The minute I found out. I didn't want to touch it anymore." They wait too long because they're afraid, they ignore it or they're not paying attention or listening to their bodies. (WHP05)

Fear was an emotion expressed, not only by those diagnosed with cancer, but by their friends and community members as well. Health practitioners acknowledge that there is still a stigma about cancer, and cancer myths can negatively affect those diagnosed with cancer. Anishinaabe participants have acknowledged a fear of cancer as a possible contagion and have observed it in friends and family. There is clearly a need to demystify cancer and to debunk the myths for Anishinaabek.

I have noticed the way they are around me. It was as if cancer was contagious, that's how some of my friends act ... I think you lose your friends, too. (APDC09)

Anger was an emotion evoked when some Anishinaabe participants faced cancer a second-time. A recurring cancer diagnosis is something that can be frustrating especially for those of us who have been cancer-free for some time. We are often angry when cancer returns.

I went for about 13 years of being in good health and then I got my second diagnosis. I felt shocked, very angry this was happening again. I didn't understand why this was back in my body again, but I was also afraid because I think I had a different knowledge of it. (APDC11)

Sometimes anger was directed at the medical professionals because we believed they were ignoring our symptoms, not finding the cancer sooner, or refusing to provide a satisfying treatment plan.

I had it in the breast, then it recurred in the brain. When I went for the one year check-up they told me it had metastasized into the brain and liver.

The radiation and chemo doctors were shocked because this was not what they expected. First thing was, “We need to take your license.” So they took it right there. “We need to call your son immediately,” they called him and he came over. They said, “You need to go upstairs so we can hook up an IV to relieve pressure from your brain” and then they put me on steroid pills. “Then we will set you up for radiation six treatments,” and basically then I could go home and make my plans to die. “Do you have any questions?” I said, “Yes! You mean to tell me you have had my life in your hands for one year now and you’re telling me this? Well, I am not accepting this. I will be staying in Sudbury for the week. I have a cellular phone for you to call me and get me into tests, but I am not going home to die. I want a plan and with all the money spent on cancer there has to be one there for me!” (APDC10)

Zhagwenmowin or imposed shame may not be considered a typical response to cancer, yet participants shared that some of their family and community members who had cancer expressed feelings of shame. This may stem from a belief that cancer is happening to them as a consequence of something *we* have done in the past. More often, *zhagwenmowin* is a manifestation of what has happened *to* us in the past and has become a deeply rooted part of Anishinaabe identity.

As *Nishnawbek*, we tend to hide cancer. It’s almost a disease where you’re at fault, you’ve done something. See, if I lived a good life, I’ll never have cancer. If I breastfeed my kids for six months, nine months, I’ll never have breast cancer. But if you get breast cancer then, “Ah, maybe you did

something that the rest of us haven't done." The majority of them hide the fact that they have cancer because they feel guilty for some reason. For *Nishnawbek* it's almost a stigma. (APDC05)

I think there's still a stigma of having cancer, especially if it deals with sexual organs. People will often not be comfortable. One woman disclosed she had had breast cancer for a long time and nobody really knew. She had kept it a secret all her life and it was not something she talked about because of fear and shame. (WHP07)

These emotions, though common in the initial stage of cancer diagnosis, did not cause the Anishinaabe-kweok [Translation: Anishinaabe women] in this study to remain in a brooding state of mind.

Seeing is believing, a time for action

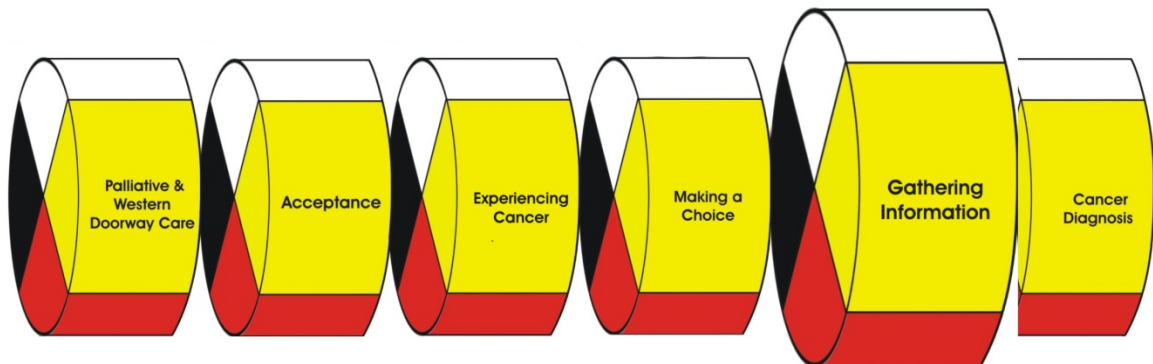
It was mentioned by some Anishinaabe participants that their diagnosis signalled a call to action. The receipt of the diagnosis was a time to learn about cancer and how we can begin to heal. One participant found that it helped to have a visual or see the cancer in order to have direct knowledge of her cancer. It has been said that our people are visual learners, and a visual cue can help us to understand what cancer is and to conceptualize the process of treatment. Providing this information may help in accepting a cancer diagnosis and understanding what will come next.

During colonoscopy the doctor shone the light on the tumour. He said, "That's cancer, you're lucky it's bleeding." That was it, I could see –

maybe that's why I was more accepting because I could see the cancer. I could see what it looked like and I came face to face with it. I guess they take pictures of them to show the Oncologist. I was so sorry I didn't ask for a picture. It wasn't a big thing, it wasn't a scary thing and it was going to come out. There it was and it was just a little ball that was going to come out. Things kind of moved along pretty fast. And I said *Nahow*, [Translation: okay] next step. I wanted the end product to be - it's gone. (APDC05)

Health professionals agree that everyone deals with cancer in their own way. Some will take cancer on as a challenge and will see their diagnosis as a call to action. Specifically, this may be a call to learn about cancer and how it can be treated.

Gathering information



What is cancer?

Education is essential to changing the prevailing negative views of cancer in Anishinaabe communities. In order to change our mindset, we need to be educated about what cancer is and how it can be treated. Like everyone else, Anishinaabek have conceptions about

what cancer is and how we get it. As study participants, we shared what we thought cancer is and provided our personal definitions for this disease. These definitions ranged from commonly held scientific beliefs to metaphorical understandings, to Anishinaabe cultural understandings of the disease. Although many have a basic understanding, many more are still misinformed about cancer. People's definitions indicate a lack of understanding of cancer's processes and etiology. It may be that many are learning about cancer from unreliable sources, and this has implications for how cancer education might be provided and improved.

Cancer to me is just bad cells in the body. I don't know what triggers them or anything. I'm thinking that they were there and something triggered them to develop into bad cells and wake them up. (APDC03)

Two medical professionals were able to provide a basic biomedical definition of the disease. Having worked in our communities for some time, one physician was able to explain this in the context of Minobimaadiziwin.

Cancer is cell development that has gone wrong, has changed and has some loss of control. It's a reflection of some risks that we put on ourselves and then some inherent risks that are beyond our control. That's a very simplified version of what cancer really is. (WHP02)

I would say it comes primarily from an imbalance within the system that isn't attended to. Gradually, it progresses from being just an imbalance in any of the four aspects of a person's being to a sort of an inflammation, a disease, and then eventually a lack of immune response because of the

disease or illness within the person. I think cancer cells are probably forming all the time within people, but if you're in a good state of health and balance, you can get rid of them. If you're not, they build up to the point where they become noticeable by either tests or symptoms or signs.

(WHP06)

Anishinaabek also have metaphorical understandings of cancer, which emerge from their everyday experiences. Cancer has been likened to insects or plant life. The dominant culture also has metaphorical understandings of cancer that include engaging in war or battle with cancer. These metaphorical understandings can be helpful, but at other times, they can conflict with our belief systems. If we are always focused on physically fighting cancer, we may ignore the maintenance of Minobimaadiziwin in other areas of our lives.

Cancer is just a growth, like a weed. Depending on how you treat it, it'll keep on growing. If you have a burdock growing under your stoop or outside your house and you ignore that, eventually it grows and you have to work hard to dig out the roots. Sometimes you can't kill the roots because the roots will keep coming back. But if you see that burdock and you stop it, you dig out the roots while it's still small, you can get rid of it. Well, that's the same thing with cancer. Cancer is something that does not belong in your body. It's like a weed that has found a spot to grow and you've got to get rid of it. Sometimes you can get rid of it early enough with the traditional medicines. Sometimes the root is so deep in there you need somebody to cut it out. (APDC05)

Some Anishinaabe understandings of cancer are grounded in Indigenous knowledge and are based on our ways of knowing and being. Our healers provided their own interpretations and teachings about cancer, and the participants advise that cancer is something we have to acknowledge in order to overcome it.

We talk to that sickness because it's alive in us. We don't look at it as an abstract thing, we acknowledge it. Through those teachings there is the acknowledgement of the spirit of that sickness because cancer's a living thing. It breathes and it wants to live. With anything happens in your body, you need to acknowledge the spiritual aspect. Our teachings tell us that we have to acknowledge that in order to overcome. (APDC11)

For Native healers, cancer is one of the most devastating sicknesses that we have. It's insidious in its actions and how it eats the person alive. We look at it as a spirit that's in the body, in the tissues, in the cells, and that's where it thrives. It's alive and we look at it as an entity, as something that needs to be dealt with and we need to come to terms with how we do that. The cancers today are different, they're stronger and faster. They're more resistant even to our stuff and more resistant to the chemotherapy and the radiation. They're so much more aggressive that we have to use double the medicine on them than we used before. They're one of the strongest life takers I've seen. (IHP05)

In an effort to come to terms with cancer, Anishinaabek have acknowledged that it is difficult to literally translate and define cancer using *Anishinaabemowin*, our language.

However, we have come up with some of our own terms to describe cancer or the feeling of cancer such as, *Mn'ji-ii-ish* [Translation: a description of something that can continue to manifest itself in your life as a negative experience]. A community member explained the meaning of the term *mn'ji-ii-ish* as a recurring feeling that is not easy to control, and one which we have to learn to work with. Using a term borrowed from mental health, it is akin to the experience of relapse. In order to maintain Minobimaadiziwin, we need to have awareness of *mn'ji-ii-ish* and learn how to work with the aspect of ourselves that is causing us to feel out of balance.

My dad had cancer and I asked him one time, what is it? And I don't think he knew how to explain it. What he said was "*Mn'ji-ii-ish*." *Mn'ji-ii-ish* is something that's no good. That's the only way that I know how to describe what the word is. (APDC06)

Chi-akoziwin is another common term we use to describe cancer. *Chi-akoziwin* is a great sickness that has the potential to take someone's life.

For us, we call cancer *chi-akoziwin* which is actually an illness.

Sometimes cancer or *chi-akoziwin* manifests itself in the later stages because people are not aware of it. (IHP04)

There are easy ways to describe it. The first one is *mnidons*, little bugs.

Then another way they say it is *mugwa*; it is something that's eating you up. (IHP08)

Anishinaabe participants have also put forth a cultural interpretation that cancer is a signal or a consequence of not living in Minobimaadiziwin. The source of imbalance can occur in any of the four aspects of the person and, if left unattended, can progress to a disease-state. In sharing Anishinaabe *gikendaasowin* (Indigenous knowledge) on Minobimaadiziwin teachings, many Anishinaabe participants referred to the fact that an illness can develop if our health is not attended to in a timely manner.

There's also a spiritual element to cancer, when you're not in tune with your spirit and your life purpose. Sometimes you can develop that illness and from an unbalanced mental state. One of the things that our people say is if you hold in anger, it can become cancer because you're not releasing that emotion and it creates disturbances within your physical self. (IHP09)

It is a common Anishinaabek belief that cancer cells exist within us and the cancer can develop and grow to unmanageable proportions, especially if we are not mindful of our Minobimaadiziwin. Anishinaabe participants shared beliefs on why we get cancer.

Why are we getting cancer?

The Anishinaabe holistic view holds true in all aspects of life. In our beliefs or thoughts on why we are getting cancer, we share a variety of reasons which can be attributed to the four elements of a person's being: physical, mental, emotional and spiritual.

It comes from what we are consuming

Many Anishinaabek believe that cancer stems from what we are eating and drinking. We discussed how our modern diets and food additives in this modern time may be a source

of cancer. Specifically, we have concerns about food additives such as monosodium glutamate (MSG); food colourings; toxins that have been linked to the modern canning process; growth hormones and steroids. We have concerns about the shift from eating natural foods to a reliance on convenience foods. Some participants recognized that this shift began in the 1950s. We mentioned the detriment to health due to a change in the way food is grown, harvested and prepared. As well, Anishinaabe women have a special role as the keepers of water. Therefore, we have special concerns about the quality of our drinking water, and we question the safety of chemicals that are being added. This Anishinaabe-kwe's comment provides a summary of many of our concerns.

I always think the way that we live has something to do with it. A long time ago, we didn't hear about cancer. It wasn't until maybe the 50s, when we started to change our lifestyles, our eating styles, our exercising, our mind and our thinking. A lot of factors came into play and we were gradually absorbed into these changes. As much as we wanted to stay the way it was a long time ago, change was brought in gradually and it affected us. I think our lifestyle has been through a change which has caused a lot more cancer among First Nation peoples. Non-First Nation people also have it. I think they went through changes too. Everything is fast nowadays. We're in a fast generation where we've got to get things done right away. Rather than walk, we drive; rather than boil potatoes, we microwave them. Our water has been deeply affected. Just what are we taking from those chemicals that are put into our water nowadays?

(APDC08)

We believe that the Anishinaabe have always been aware of how to eat properly and that these changes in our diet and lifestyle have contributed to this illness.

It comes from the environment and our lifestyles

Anishinaabe participants also believe that cancer has an environmental etiology or is due to unhealthy lifestyles. One of the gifts that the Creator gave each person is free-will. We have the ability to make our own choices and it was acknowledged that cancer can be the result of our own behaviours and choices. For example, many Anishinaabek have made a conscious choice to misuse alcohol or non-traditional tobacco. We have also opined that a source of cancer can be exposure to chemicals in the air, some of which come from industrial pollution. This Indigenous health practitioner shared her views on cancer and the environment.

I see that cancer comes from the environment. There are so many toxins that we breathe; it's in what we eat and what is around us. We need to be aware of what we're putting into our bodies to be more aware of what's out there in our surroundings. Substance abuse and smoking are things that people talk about, even second-hand smoke. People don't talk about cars, it's all about smoking, but it's also cars and the amount of pollution that come from the airplanes. There are also the industrial sites, the mining companies and the garbage that is dumped into the environment. As I see it, if we are weak, the environment wears us down and then we are more susceptible to these illnesses. (IHP04)

In addition to smoking as a well-known cause of cancer, Anishinaabe participants also attributed cancer to genetics.

It's in our genes; we all have the potential to develop cancer

Some participants wonder if there may be a hereditary component to cancer and if cancer can run in families. We have observed lately that cancer is becoming more common in our families.

There's a lot of cancer in my family. I've lost an aunt, an uncle, my grandmother, three or four right there with really primary, hard cancers of the esophagus. My mom had uterine cancer and my grandmother had blood cancer. When the cancer hit me, the worst part about it was that it's not staying in that age range and it's hitting a younger person. Maybe it's hitting me today and maybe my brother tomorrow. I'm trying to open their eyes and say, "I'm one generation younger, so be careful with your children." (APDC12)

Health professionals concur that cancer may be linked to genetics, but not necessarily to heredity. The American Cancer Society (2014) attributes only 5 to 10% of all cancers to inherited gene mutations. They are careful to say that it is the abnormal gene, and not the cancer itself, that is inherited.

It is basically now agreed that it is a genetic disease, not necessarily a hereditary disease. Our genes are supposed to protect us and work a certain way to correct all of the mistakes or check uncontrolled growth, but because of some malfunction they're not quite doing their job;

therefore, we develop a certain type of cancer. It's mostly just bad luck. Even smokers say, "Okay, I got cancer because I smoked." Yes, that contributed to it, but there are a lot of smokers who don't get it. It's your body, some switch gets turned off at the right time in a wrong way and here you are. It can basically happen to anyone. (WHP01)

Regardless of the etiology, many participants believed that the potential for cancer is within us. We believe that the cancer cells are in a dormant state and something triggers them or wakes them up.

I think we all have it in us. I think it's a cell that's dormant. We all have it in our body. If, and when, that cell decides to come alive is when we're in trouble. It's just that one little cancer cell that just decided to come alive and just grew and grew. (APDC12)

Health professionals agree that cancer may result from a combination of sources, and there are some that just appear without any apparent cause.

There are definitely risks for cancer that people do have control over, such as smoking and alcohol, but there's not necessarily a good explanation for why some people without those lifestyle risks get cancer and others don't. Sometimes it's genetic. There are some cancers, for example, HPV can lead to cervical cancer. If you're talking from a basic point of view, you can get it from a sexually transmitted disease. Cancer itself, I think, comes out of risk behaviours, but there is a subset of cancer that just appears. (WHP02)

Sometimes it's genetics, sometimes it's environmental. Even within the environmental factors there's the big schism of it being something that we have done as individuals that's increased our risk or something that our society has done that's increased our risks. There's the effect of aging. You can't give one unifying theory because it doesn't exist. (WHP04)

The participants also recognize the possible mental or emotional contributors to cancer.

There is connection between stress/trauma and cancer

There are Anishinaabe participants who declare a connection between stress, trauma and cancer. We discussed an unbalanced emotional state where some of us named stress as the cause of our cancer. We also acknowledge that our past traumas can have far reaching effects. We applied our knowledge Minobimaadiziwin and acknowledged that when we are not in a state of balance or if we have not resolved past traumas, cancer can be the devastating result.

I had a really hard time when my common-law husband left, and then I had a hard time with my son. He was always angry, breaking things in the house and stressing me out. I would hide in my bedroom and cry because he would scare me. I think that's why cancer happened. (APDC01)

Stress builds up in your system and it's got to go somewhere. They say it's like that fire that burns and burns. Stress is a killer and if it has no place to go, it could manifest in cancer. (APDC05)

Sometimes we mentioned unresolved grief, past trauma or what has been referred to as “soul pain” or a “soul wound” (Duran, 2006). One Anishinaabe-kwe thought about her experience at residential school and how she had not really “closed these wounds.” This is an example of how our collective histories affect us throughout life. She believed that the atrocities experienced by some at residential school caused dysfunction and resulted in *zhagwenmowin* [Translation: imposed shame] and an unwillingness or inability to talk about these experiences. Some Anishinaabek believe that unspoken, unresolved grief as a consequence of historical traumas, such as negative residential school experiences endured by the Anishinaabe, have resulted in a cumulative stress and illness later in life.

Unspoken, unresolved anger, rage, guilt and shame come up in a physical manifestation. Even that whole residential school thing, Holy! You never really get over that. Those pulled some triggers for me. As soon as I start to talk about other people’s experiences, their stories, it comes out. I realized then, you never forget. I’ve come to realize that I never really did close those wounds. It’s like an open wound and you have to find a way to mend it, to heal it or to cover it. (IHP07)

We alluded to these unspoken experiences as we recounted some personal experience with cancer and how it may be related to past suffering. It is believed that these traumas can affect people at different stages of life, depending on how and when they were hurt. The Three Fires Midewiwin Seven Stages teaching tells us that people usually move through life stages successfully. However, if some trauma has impacted their life, a person can become “stuck” at that stage. Recognizing this aspect of our teaching,

Anishinaabek encourage that when treating cancer we should be looking at the whole person, including our history, not merely the physical treatment of cancer.

What was going on in my brother's life? Why he couldn't breathe and what was choking him or what couldn't he digest? I was trying to look back on the history part. What might have created something where you don't feel good about yourself? I wonder was it something at residential school? What happened there? I'd listened to this one lady; she talked about soul pain. When I phoned the hospital to speak to my brother, I didn't recognize his voice and it was as if a little boy answered the phone. I was thinking about that soul pain and wondered if this had something to do with it. I think if something had happened to him when he was at the stage when he was a boy - he forgot that little boy and he left that little boy behind. When I talked to that lady about soul pain she said, "You need to work with him and bring that little boy back to the present because he left his little boyhood behind." I don't know if cancer would be the same way, if something happened at a certain stage and how that affects their life? I think that's why we need to work more with that person, bring out the history part. We're not just going to treat the cancer with the medication. We've got to include the whole person. (WHP05)

Our people who work from an Indigenous health perspective discussed the role of trauma and stress in illness. They see their role in healing as being able to help people manage or rid themselves of stress, unresolved anger or hatred. These Indigenous practitioners believe that IH/TM involves more than physical healing. It is the opinion of many

Indigenous practitioners that Anishinaabe people have been impacted by many forms of trauma, if not directly then indirectly.

I think a lot of it is helping people to get rid of stress. They have past issues or they have so much anger or hatred. I try to get people to come to terms with these things and to let them go. (IHP08)

In our culture, everything we do deals with trauma in people. The traumas of their experience are honoured and recognized and then if the person wants it relieved, we help to release the trauma. (IHP09)

Those working from a Western perspective of health also feel that mental health and stress may be an underlying source of cancer. They acknowledge that the connection between stress and well-being is not fully understood within the medical community. This acknowledgement of a stress-cancer connection is similar to our Anishinaabe *gikendaasowin*, which speaks to an unaddressed divergence from *Minobimaadiziwin* or imbalance in a domain of life that can result in physical manifestations like cancer.

I think it would be a critical thing to try and reduce some of the mental health stresses that have accumulated within the communities. These stressful, negative energies are underlying increased cancer rates in First Nations – that's more in the preventative aspect. (WHP06)

We don't understand the true connection between stress and wellbeing, but I certainly think that when people are under stress for a longer period of time, they're producing cortisol in the body, and it has ramifications

over time. If there's not that balance, you're putting yourself at risk.

(WHP07)

This holistic picture of why we are getting cancer is incomplete if we do not consider the spiritual aspect of life. Anishinaabe participants believed that there is also a spiritual component to why we are getting cancer.

It's meant to be, it's happening for a reason

The Anishinaabe people ascribe to a variety of belief systems, and this has impacted the variety of ways we think about cancer. We may attribute cancer to a more spiritually-based cause or, as some explained, as part of the Creator's plan.

It happens for a reason. I find myself thinking that all the time that this must be happening to me for a reason. (APDC01)

If I didn't have the heart attack they never would have found the cancer.

Thank God I had a heart attack! Isn't that a hell of a way of looking at it [laughing]? ... It was meant to be, *gii zhi seh waani zhowehbuk*

[Translation: the plan was set in motion. All of the circumstances connected and it was time for these events to take place]. What was going to happen, it was meant to be. I digress [laughing]. (APDC05)

It is common for Anishinaabek to view cancer as a teacher of an important life lesson. Our knowledge keepers attempt to teach us that illness should be accepted as a teacher. We are encouraged to think about what cancer is, and to consider, what it may be bringing. Another Anishinaabe teaching we are given is that we can learn to accept that

illness is a part of the path of life or Minobimaadiziwin. In the Three Fires Midewiwin Little Roads teaching, we can view cancer as the little road, and it is a teacher.

We say *kam na dap nan manda akoziwin* [Translation: taught to take illness in a good way]. You look at that illness and ask, “What is it?” You look at thoroughly and ask, “What is it bringing to me?” It has been a challenge in getting people to understand that there is something there that comes with that illness. (IHP04)

I try to tell people, maybe they're 65 years old, they have cancer and they say, “I should have changed my lifestyle.” No, you can't change teachings. You can't change those obstacles in your lifetime or else you don't grow. I think where they are and how long they've lived was just meant to be. (WHP08)

Indigenous healing practitioners believe that many of the illnesses that Anishinaabek face are spiritual illnesses. We believe that illness can bring awareness to the Anishinaabe that we have to pay attention to how we are taking care of ourselves. The illness experience forces us to connect with our spirit. We encourage maintaining these connections through prayer, sweats, fasting and even simply sitting with the land.

I think a lot of these sicknesses are spiritual sicknesses. They help that person become more aware of life, become more aware of what they eat, how they take care of themselves; everything. To me, that illness helps the relationship we have with our spirit. Connecting with that spirit whether it's in the sweat lodge or whether it's going out fasting, sitting by a lake

where it's nice and quiet and connecting with everything. Our people always had a relationship with the land. (IHP08)

We have outlined how we think we are getting cancer and that cancer can be a part of our life-long learning. Once we have cancer, we have to engage with cancer to learn.

Cancer education

Become an advocate for your health

As Anishinaabe participants, we shared what we learned about cancer as well as the sources for our knowledge about cancer. Some Anishinaabek have become advocates for their health and have been fortunate in learning how to use their voices. We shared how we were able to become advocates by reading, asking questions, maintaining our own health records and asking others about their experiences.

I went back to Hamilton and got to see the surgeon who did my first surgery. When he came into the room the first words out of his mouth were, "Start reading." In other words, he doesn't have all the answers and that I have to start understanding it. I started reading articles and testimonials on the Internet trying to get ahead of the ballgame. (APDC12)

Some Anishinaabe participants were diligent in keeping records of our health and inquired about cancer treatment. We emphasize the importance of asking questions and being informed about our own healing path. Western medicine is a maze that requires careful negotiation and preparedness. Therefore, we feel that documenting our own journey is important.

I just made sure that I copied everything down they told me, everything that happened; everything was written down. (APDC05)

I always bring my books if I go somewhere because I can't really explain everything. If I see a different doctor and they don't know what's wrong with me, it actually tells them what my doctors are doing or not doing. (APDC07)

We also shared that asking questions about treatment and inquiring about the doctors who are caring for us is important. We believe that each of us knows our own body best, and we have to be assertive in stating our needs and preferences.

I did my homework on the doctor. Apparently, he was the best so that made me feel really good. I got a hold of a gal from Wiky who I knew had that surgery. She told me he's very good. She gave me some names of other people who she had contacted who also had that surgery. (APDC06)

It was encouraging to hear that some participants have the strength to be advocates for health. However, it is a reality that many of our Anishinaabek are still at a loss in this process.

There is still a lack of cancer education

While being an advocate for our own health care may be second-nature to some, this is still a great challenge for others. Acquiring helpful information about cancer may be problematic for Anishinaabek with literacy problems. Therefore, we also shared that there is a need for further and more direct cancer education. Some Anishinaabe

participants revealed that we could not find information or that sometimes the information was provided, but that we had somehow missed it. This suggests that information needs to be presented in a variety of ways. We have also shared that *zhagwenmowin* [Translation: imposed shame] spills over into many areas of our lives, including our communication with health professionals. Sometimes the information that is provided to us is *misinformation*, or it may not be presented in a way that is conducive to our learning styles.

I don't think there's enough education. It's something that's new to Anishinaabek, it devastates them and they don't know how to deal with it. They need a lot of education on what's available to them in the Western and the traditional worlds – to have both sides of the coin, so to speak. When they hear the word cancer, right away they think of death. I think if they were educated about cancer and the many things that they can do, like surgery, chemo and radiation to help them along, things would look better for them. (APDC04)

One Anishinaabe-kwe recalled a negative experience which stemmed from a lack of information about her treatment process. While the information may have been provided, it may not have been appropriately disseminated. She talked about a time during her cancer treatment when she suffered with vomiting and a hospital admission that could have been prevented with an injection after chemotherapy. She stated that she had too much going on and she did not remember that she was supposed to have the medication. By the time she remembered the medication, it was not available at her local pharmacy.

I think there should be more information on this. Oh my God, I couldn't believe how mad I was when the needle wasn't there! I had a feeling they should have told me. I was so mad! Isn't there somebody who should have told me this? I don't know anything about cancer! Who is supposed to tell me these things? (APDC01)

It is widely recognized that Anishinaabek often have poorer health than the general population (Loppie Reading & Wien, 2009) and are likely to have co-morbidities like diabetes (Macaulay, 2009). We described that during our cancer journey we inquired about information on an appropriate diet and received little information. For others, the information may have been available, but it did not register, or essential details are missed because of a language barrier or a cognitive impairment.

I didn't even know what to eat. Every time I put something in my mouth it tasted awful. I didn't see it right away, but I wasn't supposed to eat oranges. I didn't know at the time, but it was on that paper. Oranges or juices bring out those sores. Someone told me about it [laughing] after I already had the sores. They should give a paper about what you should be eating. There's nothing out there. (APDC01)

There are implications for how information is being presented and how it is received by Anishinaabe patients. We will need to hear or receive the information in a variety of ways, not just in written form. We offered recommendations on how to improve the cancer education that is currently provided. One suggestion was to share the information

as a “to do list” for quick reference and to use simplified language and visuals to present complex information.

I think layman’s terms are really important. I don’t think that after giving the news, that that should be it. I think there should be follow-through with, not so much a doctor, but others who can further explain. I think the explanations need to be visual because we’re a visual people. I also think we need to start pushing the positive with the negative. (APDC11)

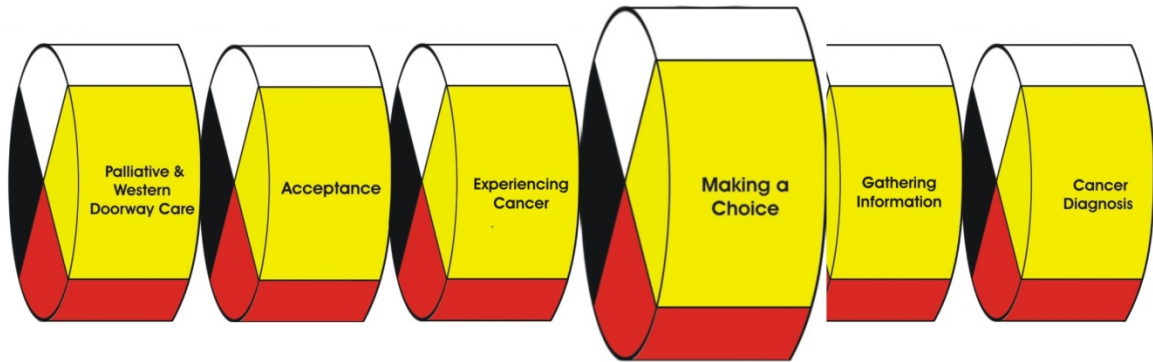
We stressed the importance of hearing the information from those who have “walked with cancer.” Health professionals agree that the message can be heard more effectively when it comes from our fellow Anishinaabek.

If they stay, they can give that teaching to others. They become the teachers of that illness, because they have walked that, it’s a part of them, so they are the best to talk about that experience. (IHP04)

The message that we need to get out there is that we don’t have a cure for cancer yet, but we have lots of ways of preventing it and we can stop it at early stages. I think that we need people that have gone through it to become spokesmen. We need people to speak up. More so within the Native communities that it has to not come from me. It has to come from the people themselves, the people within the community to step up and encourage people and to speak out for it. (WHP02)

With a new diagnosis and having engaged in learning about cancer, Anishinaabe participants faced the next challenge in the cancer journey, making a choice in their treatments.

Making a choice



When diagnosed with cancer, the Anishinaabek in this study made a choice between using Western medicine exclusively or using some combination of Western medicine and IH/TM. We shared the reasons for our choices.

A lack of choice

Some Anishinaabek feel that we are not given a choice regarding treatment for cancer. There are several reasons for this including the fact that everything happens so quickly after a cancer diagnosis that there is little time to explore other options.

You don't have a choice. They set up all these appointments. It's the hospital's choice and they just tell you this is what's going to happen. This is where you're going to go. Did I have a choice? No. It felt like if I don't do these things, I'm going to be sick. (APDC01)

The notion that there is no choice also originates from the fact that within a Western medical context, no other options are put forward to Anishinaabe patients. Choice assumes that one has knowledge of or is educated about choices that are available, if any.

This was the only option put forward to me, the only option that I knew about. No, there was no choice. I went to the doctor they said this is what we have to do: surgery, chemo and radiation and that was it. There was nobody who said, “Traditionally, you could go this way or do this to help you.” I’ve never been approached in that way at all. (APDC03)

Feeling that you do not have a choice often leaves the Anishinaabe feeling disempowered and no longer in control of the decisions being made. We felt that we must put our faith in the health system or face the possibility of death. Currently, there are no options within our health system for IH/TM or braiding it with Western medicine. Unless someone has the good fortune of being connected with a cultural resource person who can help, this option is non-existent. One health professional puts that experience in perspective.

I walk into a building that is foreign to me where the language is not mine, and I’m being hit with making treatment decisions and doing that on my own. I do not necessarily trust the system because there have been atrocious things that have happened in the past, but I have no choice but to trust it. Perhaps I must accept things that go against my own philosophical way of living or how I take care of myself. I’m painting a very extreme picture, but it can be a story that we see. (WHP07)

Other Anishinaabe participants feel that we always have a choice. Moreover, it is up to us to voice our preferences.

We have a choice, and we need to use our voices

Whether or not a choice is clearly spelled out, some Anishinaabek believe that there is always a choice. However, others feel that not making these decisions may be easier. As one Anishinaabe-kwe stated, “I think we all have a choice, but we tend to take the easy way.” Our choices are based on our ability to articulate what we want. It may be very difficult for some Anishinaabe people to articulate our needs; therefore, some may need encouragement to voice our needs regarding decisions so that we can feel comfortable.

Our lack of voice may relate to *zhagwenmowin*, the imposed shame that some Anishinaabek internalized with past trauma which, over time, has become a deeply rooted part of our identity. However, when Anishinaabe people are empowered, we have shown that we can make decisions in managing our own care. These Anishinaabe participants have demonstrated a lived example of the Seven Grandfathers teaching of bravery. This Indigenous practitioner explains how she enabled her clients to make choices.

We always give choices, and it’s whether they want to access traditional healing or they want to access both. When they see the doctor we always tell them, “You have a choice. What do you want? Tell your doctor then.” Again, that goes back to the historical issues of our people where we don’t have that voice to articulate our needs. They’re reluctant to speak up. Now, we are seeing some people who say, “*Ka*, no, I don’t need this. I don’t want chemo. I don’t want radiation. I just want to do this and I’m ready to go.” They say, “If I take this, it’s just going to drag it on. I don’t

want to take something that's going to make me sick. I would rather just die with whatever I have." They take it "in a good way" and so that's a choice. (IHP04)

Anishinaabe participants in this study also emphasized that we should not depend exclusively on doctors or medication to maintain our health, but that we have a choice to do something for ourselves. As one health professional pertinently stated, "*Kiingwa* ... it's up to you." The concept of personal responsibility in making a choice relates to the Path of Life teaching, where the life journey is full of choices and *Minobimaadiziwin*, in part, is a reflection of our personal choices.

I used to teach people with diabetes that it's about choice and that they have control. I'd tell them, "I could stand up here and I could tell you all about diabetes. I could tell you how to eat and how to prepare foods, but if you don't do anything yourself, nothing will happen. You have to decide what you want for your health, *Kiingwa* [Translation: it's up to you, you decide, it's your choice] it's up to you." (WHP05)

It seems that when given a choice, we may not trust our initial instincts or our own judgement. Despite feeling uneasy about health care decisions, we may agree to treatments because we do not know how to advocate for ourselves and our own health care. *Zhagwenmowin* appears to have a strong hold on some Anishinaabek. This health professional spoke of the importance of the teaching about choice and learning to listen to ourselves.

I was told the greatest gift is choice. You're given the choice to say yes or no. All of our teachings say that your gift in life is choice, whatever you want your life to be. You are the only person who knows your body, not the doctor. (WHP08)

The following illustrate how or why we made our choices in cancer treatment. Some Anishinaabek chose treatment based on a combination of our ancestral knowledge and a physician's "permission." Others chose based on what was offered through the Western medical model of care.

I chose to use IH/TM and Western medicine

Although we may not feel we had much choice regarding the course of Western treatments, some Anishinaabe participants knew of, or were already using, IH/TM in our daily lives. IH/TM has been a part of our lives and has been used within our families for generations.

Whatever it was that was bothering us or whatever we were sick with, we were given traditional medicines. We've been brought up to use traditional medicines. I have no question as to their effect on me, like what you would call blind trust because I've seen them work. (APDC05)

The use of IH/TM with Western treatments for cancer can also involve consultation with Western health practitioners. We find that some health care practitioners are supportive of IH/TM. For some Anishinaabe participants, the doctor's acceptance of our use of IH/TM was very important. Acceptance of, or at least, a willingness to discuss the use of IH/TM are examples of how medical professionals can empower the Anishinaabe patient

to make informed health care decisions. In turn, we will become advocates for our own health.

My doctor knows I've seen an Indigenous healer. He's very supportive of that, he's very proud of me and he's happy I did that. I had a choice. I felt that having both would be good for me. (APDC10)

I had shared with my doctor that I went through and followed through with my people. I can still remember the look on his face, there was that sense of respect. He never asked what it was that I was taking. He was very respectful in that way. Having that affirmation from the Western medical side was like having a sense of mutual respect. The first time he said it to me was like permission, like permission to go and seek out my people. I think because the doctor gave permission, I made my choice freely without resistance. I think that made a big impact. (APDC11)

Those who practice IH/TM state that this method of healing always involves the person's choice. One Anishinaabe-kwe illustrated how her choice in cancer treatment was facilitated by the ability to choose without *zhagwenmowin* [Translation: imposed shame]. She chose to forego chemotherapy and to work with the medicine people, but did opt to be monitored by her Western doctor.

I didn't want to go through the chemo. At that time, I was beginning to understand how our Native medicines and ceremonies worked and that it was hard for them to treat me after I had gone through that. Our people would never say not to because one of our teachings is choice. Our people

have struggled with the European value system for so long. We've done so many things underground and there's so much trauma and shame in our people. We need to be able choose without shame so it's about choice and having respect for our choices. (APDC11)

Those who work from the perspective of IH/TM hold that it is not about trying to influence people's decisions either way. A key tenet of IH/TM is recognition of the fact that our healing comes from within and through our relationship with the Creator. This tenet fosters the notion that we have a responsibility in our own healing and that the choice of who we involve in that circle of healing is an empowering aspect of that process. We are reminded that our healers and doctors are the facilitators of the healing process.

We remind them that they are Anishinaabe and there are healing methods from Anishinaabe teachings and knowledge that can help. According to what I understand, the healing is within them and their relationship with the Creator. The healer or the doctor is not the one who heals them but they help facilitate. It's really up to them, they drive this car. Our ways are there for them if they choose. Part of our perspective is balance so not to take anything off the table of choice. If you want to use Western and traditional you have that choice, you know what's best for you. (IHP06A)

He said it's up to you, or I could just stick with him all that time. But he made that choice mine. (APDC09)

Indigenous knowledge keepers remind Anishinaabe people that IH/TM can be a part of our choice, but our healing path can also include what Western medicine has to offer. We believe Anishinaabek were given “free will” and the freedom to choose what we believe will work for our situations.

I chose to use Western medicine only

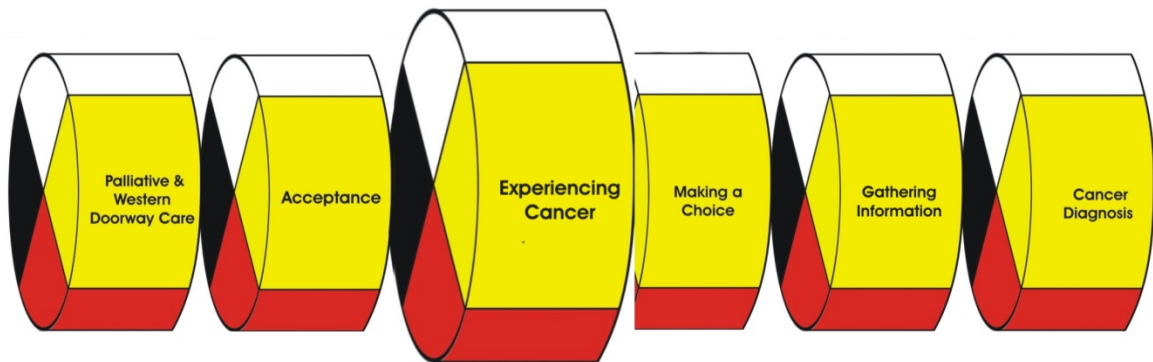
At times, we felt that we were well served with Western treatments. Our decisions may have been influenced by our own health care research, such as discussions with family members, or other community members with cancer, and reading or learning about cancer from health professionals. Most commonly, our treatment decisions were informed by doctors and family members. It was generally felt by Anishinaabek who chose Western medicine that to use Western medicine was a good decision. It helped to rid us of our cancer and it was advised by our health care teams.

When I had [cancer], all the Western medicine that I had to take, it was a fix for me. And right up to this day, I don't have any setbacks as a result of it, so it led to my Mnaamodzawin. (APDC08)

It was going to get rid of my cancer. I felt it was the best advice that my health team could give me. (APDC13)

Following the decision-making process, we shared what experiencing cancer meant for us in terms of Minobimaadiziwin: the physical, mental, emotional and spiritual domains of life.

Experiencing cancer



Impacts on the physical aspect of life

Anishinaabe participants spoke about the realities of how cancer and its treatment have affected us physically. We shared that physical symptoms like fatigue, pain and impaired physical mobility compounded some of the more socially isolating impacts of cancer treatment.

Before the surgery there was this extreme tiredness that I experienced. I was going to work and by the Bidwell Road, I would be so exhausted. I would just feel like pulling off the road and having a little sleep, that's how tired I was. I forced myself to stay alert, and I'd lie down as soon as I got home. (APDC08)

The physical side of it, having the PICC [peripherally inserted central catheter] line was difficult for me and the loss of strength that I had. I couldn't really go out when I had that PICC line because I couldn't fight off the infection as much, so I really didn't want to go anywhere. (APDC13)

One Anishinaabe participant observed that constantly thinking about cancer and treatments affected other areas of her life and consequently, her Minobimaadiziwin.

It physically it hurts. I don't sleep at night. My husband gets kind of angry at me because I go to bed at 2:00, then I'd be up at 4:00 or 5:00 and then just up. I can't sleep because I'm always thinking of this cancer. It's not letting me sleep so I'm not resting well. (APDC09)

On the positive side of things, Anishinaabek shared that since having cancer, we are taking better care of ourselves physically to support Minobimaadiziwin. Despite some very difficult times with the cancer journey, we were pulling through with positivity, a fighting spirit and recognition of physical activity as a key to Minobimaadiziwin.

I am able to take care of my lawn to a point. My brother tries to help, but I said I need the exercise. I'm just trying to live normally, as best as I can and trying not think about having cancer and what I can't do. I try and do everything to help myself. (APDC01)

You don't think about those things before you're sick, but now that I am, I'm trying to keep a healthy lifestyle like with my food. I'm trying to quit smoking and drinking. (APDC09)

The desire to maintain physical independence and to lead our lives as normally as possible also needs to be balanced with the need for rest. This thinking is in line with the teachings of Minobimaadiziwin – everything in balance. Rest was referred to as a natural doctor by Jan Kahehti:io Longboat, a Haudenosaunee Elder and healer from Six Nations,

in her talk given at *Shkagamik-Kwe Health Centre on January 5, 2012*. Learning to take that rest time is something that does not always come naturally to independent, busy, strong Anishinaabe-kweok [Translation: Anishinaabe women].

Taking time to sleep is sometimes hard if you like being busy. Give yourself the time you need to heal. (APDC10)

Why rest or take care of myself? I'll be tough, I'll be strong. I'll go back to work sooner. Your body has been crying that it needs attention. To me, it's such a mixed up message. It's the time to really honour, rest and care for ourselves. (IHP03A)

Most types of Western treatment, whether it was surgery, radiation or systemic (chemo) therapy, were described as harsh. Many patients did not feel ill until we received treatment and then we may have suffered with debilitating side effects.

I was very swollen when I was on this medication. I was 245 pounds! My feet wouldn't fit in my shoes and I was in wicked pain. They gave me a new pill to try and help with the swelling and to shrink the tumour in my head. Every day, I have Lovenox needles for blood clots and I take chemo pills. I also get chemo once a week at Mindemoya hospital for three weeks and then I get a one week break. (APDC10)

Some Anishinaabe patients underestimated the pain associated with cancer and its treatment, while others accept pain as part of the treatment. Some also expressed fearful anticipation of future cancer pain.

I don't have any physical pain but I fear pain because I know it's eventually going to come, maybe not today or tomorrow but it's going to be there sometime and I'm afraid of that. I'm not afraid of dying. I'm afraid of the process of pain you have to go through. I think to myself, which one do I want me to take me, this pulmonary hypertension or cancer? I actually prefer my PH to take me rather than my cancer. I think cancer is a painful thing. (APDC07)

Pain is an area of medicine that is still being explored and continues to pose significant challenges to Western health professionals (Campbell, 2011; Barkwell, 2005). The health professionals in this study agree that cancer and its treatment can be challenging, especially the area of pain management. One physician addressed some of the more difficult or challenging aspects of treating people with cancer.

I've had a few cases where people have had severe symptoms such as intractable pain. We've had to use enormous amounts of pain medication to keep them comfortable and that has been a trade-off because they wanted to be pain-free but they didn't want to be drugged to the point where they couldn't participate in life. So I have had some really difficult challenges that way with very painful cancers that were hard to control with pain medication. (WHP06)

The participants' interpretations of Minobimaadiziwin remind us that many of these physical trials have an impact on and overlap with the mental/emotional experience.

Impacts on the mental/emotional aspects of life

Cancer effects range from cognitive impairments as side effects of chemotherapy treatment to the emotional impact on daily life created by the life-altering experience of cancer. Anishinaabe participants shared that cancer and its treatment made it difficult to remember things.

I love to knit and I love to sew. I used to get right into it and just do it and finish it but cancer plays with your mind. Then you just lose your memory. Sometimes I'm ripping more than I'm knitting. I never used to do this. Cancer is on your mind every day – from the moment you wake up to the moment you go to sleep. (APDC09)

I have a hard time talking because I did so much chemo that my memory and my words don't come out right. I'll say things backwards sometimes or sometimes it'll take me a long time to express myself. I did chemotherapy for two years straight and it hits you hard. (APDC12)

Regardless of the stage of cancer, we were unsure of the future and this posed further emotional difficulties. We often fear cancer's return or the prognosis itself, if we were awaiting test results.

The difficulty is the not knowing if it's going to come back and if it does come back how it will affect me. My mom's been newly diagnosed. She's had cancer before too and she lived cancer free for 30 years and it came back and wham! (APDC03)

We have to work at maintaining a positive outlook about cancer and its prognosis, and in so doing, we constantly worked at achieving *Minobimaadiziwin*. We worked to change our thinking and this, in turn, helped to us better handle our emotions. We saw the mental, emotional and spiritual parts of our lives as being connected, so it was difficult to separate them in our discussions. As one Anishinaabe-kwe stated, “emotions, mental, physical and spiritual, they’re kind of all one.” Maintaining a positive attitude, sharing with others and being able to reframe our experience were helpful in coping with cancer.

Right now I’m very emotional. When I first found out I had cancer I was very emotional also, but I soon learned to deal with it because I have a young son and an older son. I didn’t want to be breaking down in front of them. I wanted to stay positive. I still have those feelings in me but I have to be strong. (APDC03)

My old way of thinking was that it was a death sentence, that whole attitude seemed to come back and prey on my mind. I really had to work on a better attitude and to rely on the knowledge of the doctors to be able to bring me back to recovery, which happened. (APDC08)

Many Anishinaabe participants disclosed personal difficulty with the issue of sympathy. We felt disempowered by having people look at us with sympathy. We believed that it ultimately had a negative effect on our ability to heal because those sympathetic feelings could become internalized, much like *zhagwenmowin*. A community member I spoke to while visiting the Northeast Cancer Centre shared his feelings about people embarrassing him by showing excessive concern. We did not ways appreciate the feelings of sympathy

others expressed and were careful not to treat others in ways that could impede their healing.

Going out of my house to see people was difficult. I could see how sorry they felt for me. I just wanted to bawl my eyes out. I did go to a concert when I had my PICC line and I could see the look on their faces. They're feeling sorry for you and you automatically like take that in. (APDC13)

Friends, family and community members should make every attempt to change how they approach anyone facing cancer. We noticed that when others ask, "How are you?" we felt disempowered and felt that cancer had taken over our lives.

"How do you feel? Oh don't get up, I'll do it." Wait! Share my experience, don't be afraid of it. I'll be fine. I want to put up a sign that says no pity here, no pity allowed [laughing]. If you have pity, leave it outside. You just bring people down if you start doing that. (APDC05)

Health professionals shared what they have observed about how cancer affects a person's mental or emotional well-being. They felt that most people eventually come to realize that cancer and its treatment are just a small part of a very full life. If one thinks about Minobimaadiziwin and the path of life, it is apparent that illness is a time when people reflect on their paths.

They say that it really is annoying when everybody always asks, "How are you, how are you?" It is basically, one part of the person, it's not their entirety. They are not just a cancer patient. They are who they were before

and having cancer is just a small part ... Cancer is not something that is going to make life really bad and overall it's just a small part. (WHP01)

Cancer or other illnesses may be one of those times where a divergence from the path may occur. It was explained that some people can become fixated on the cancer experience or cancer journey and fail to see that in the grand scheme of life, this time of illness is only a small part. By fixating on cancer or by considering it to be a death sentence, Anishinaabek are missing out on what the illness can teach about life.

I think for one thing it affects our outlook and sometimes when people have cancer they fall into the mindset that it's going to be terminal rather than seeing it as a journey. They become fixated on the process of being ill. (IHP09)

Health professionals acknowledge that psychosocial stress can not only contribute to cancer but can be a product of cancer as well. A cancer diagnosis is only the first period of distress that a person may face. These professionals explain that there are several points of distress along the cancer journey. It was observed by one health professional that if periods of distress are not managed and the person is not coping well, it can result in a physical manifestation and subsequent hospital visits. If we are not making efforts to live in Minobimaadiziwin and attempting to deal with underlying mental or emotional issues in our lives, they are bound to resurface in another way.

There are transitions in the cancer journey where there will be crisis. Time of diagnosis is probably one of the most poignant. All of a sudden you're in the flux of all this and it impacts you emotionally, mentally and

spiritually. There's the whole gamut of practical issues, on top of the emotional and physical issues, so it's a highly stressful time. The prevalence of distress that is quoted in the literature is that 35 to 45 percent of the cancer patient population will experience a level of distress. We also understand from the literature that if you do not attend to these issues, these patients will resurface in emergency departments, in clinics and in their primary care physician's offices because they're not coping. Over time, if you don't deal with these issues, the person will not have good quality of life and it becomes taxing on the system. (WHP07)

Other health professionals saw the importance of hope as a mental/emotional buoy in the cancer journey. It was felt that undergoing treatment for cancer can provide a sense of hope for physical recovery which supports spiritual, mental and emotional health. However, it was acknowledged again, that the mind-body connection is not fully understood by Western medicine.

It's amazing how some people have this hope despite a specialist telling them they have three months to live. Some people will come back to me and say, "He said I have three months but I told him that's not true." Then five years later we're into the palliative stage. I'm a firm believer that hope affects our physical being. I don't think we have any grasp in Western medicine and perhaps the Indigenous healers have a better understanding than we do. I don't think we fully understand the connection between our mind and our body. We see so many cases where a disruption in our mental well-being presents itself in physical ailments. (WHP02)

We spoke about how we coped with cancer, sharing lessons or advice about how others can cope with this disease. A common, over-arching message was shared: we should not let cancer take over our lives; nor should we be giving in to cancer or giving up on life.

Don't give it power. By power, I mean that it's going to take over your life. Your family's going to be super-solicitous or your family won't want to talk about it and they'll ignore you. Don't give it that power to do all these things. You have the power. It's there, accept it and talk about it. Don't hide it, because you're not giving your family a share in helping or supporting you. (APDC05)

We encouraged others to talk about their cancer experience and managed to maintain positivity despite some very difficult and painful experiences with cancer.

When I felt terrible, I would think to myself, "OK, today is bad, tomorrow is going to be better for me, if I make it through today." You do think that you are dying at a certain point. My pain was so bad that I was wondering, "I hope this is not the end of me" but that only happened for couple minutes, then I regained strength. (APDC10)

It really is a very tough battle and so many times I think to myself, "It's time to give up now. You can't do this anymore" but you end up turning another page and you just keep charging along. The next day is a better day and you just keep going. (APDC12)

However, having a positive attitude is not to be confused with ignoring or denying authentic emotions around the experience. Being present in the moment and allowing for the emotions helps to maintain Minobimaadiziwin. Some health professionals believe that denial of one's emotions can block acceptance of what needs to be faced in the cancer experience. Healthy coping depends on being allowed to feel all of your emotions and to accept your diagnosis or prognosis.

There are a lot of psychologies about maintaining a positive attitude and if you're not positive then you're contributing. That's not the positive attitude that I believe in. I think that to go through an experience like this, you have to feel the emotional pain. You can't put on the happy face and just pretend that everything is fine. There has to be the acknowledgement that this is hard but that you're working through it and that you can get through it. (WHP07)

Maintaining a positive outlook is synonymous with developing and nurturing a mindset that healing can be possible in whatever form it may take and, ultimately, the acceptance of that outcome. As in the Minobimaadiziwin teaching, we make the decision to move on in the most positive way to make the best of the life the Creator gave. We can still have a life after a cancer diagnosis.

In some ways there are more positive things to be said that happen to people with cancer than negative things. It's true that it's sometimes a fatal illness, but it's equally true that it sometimes gives a lot of life as well. I think that's a traditional way of looking at because First Nations people, the Elders in particular, have something to teach us all about how to see

the positive in situations that look pretty bleak overall, at first glance.

(WHP06)

Living through adversity has been a part of how Anishinaabek continue to survive. One of the tools that allowed this is humour, which is another healer that we often take for granted, but it is one of those gifts that empowers us to survive.

Keep your humour, it's the best medicine. If you can laugh, you let all that out of you. I know it's hard because I hadn't laughed for a while either.

Somebody told a joke one day and oh boy did it ever come out! It's really good to laugh. (APDC09)

I like the use of laughter and humor that First Nations people often bring to all kinds of different adverse situations. I've come to use a little bit of that as well and I certainly enjoy it when my patients come up with funny ways of looking at something that's actually pretty difficult. (WHP06)

Indigenous practitioners encourage those with cancer to have faith and not to give up fighting for Minobimaadiziwin. One healer shared that most people who are terminally ill with cancer are usually given a prognosis. His message to those with terminal cancer is not to let the prognosis become a self-fulfilling prophecy and that with determination and faith, healing is possible. Belief, faith or trust in healing is a critical part of any treatment.

Impacts on the spiritual aspect of life

Anishinaabe people rely on spirituality or their faith, in a variety of forms, to persevere through difficult times. We discussed how cancer and its treatment had affected the spiritual aspect of our lives.

Our people have different aspects of prayer and I think that we need to remember that we are a spiritual people. People who do not understand that Anishinaabe culture may not want to participate because they have become assimilated. They are still Anishinaabe and a spiritual people.

Through the process being imposed by this sickness, we can gain much knowledge and wisdom through prayer and spiritual aspects. (APDC11)

Among the Anishinaabe people, spirituality and its traditions are very diverse and highly individualistic. Some people choose to follow Anishinaabe traditional or spiritual ways, some choose to maintain our spiritual connection through other faiths or organized religions, while others choose some combination of the two. Choice in spirituality often mirrors or guides the healing methods chosen, that is, braiding IH/TM and Western medicine or relying exclusively on Western medicine. We reflected on how healing aspects of the two cultures are braided together in support of our spiritual well-being.

We were brought up to go to church on Sunday and then maybe go and pick cedar or medicines that afternoon. It's something that happens, side by side like *Abzeechigun* [Translation: a medicine that corrects illness/brings you back to health/immune boosting] and Synthroid for your thyroid, side by side. I've heard people speaking English to the Creator, but I also speak *Nishnaawbe* to God or Brother/Saint Andre. I don't know

if he understands, but I've spoken *Nishnaawbe* to him a couple of times.
So it's side by side or very close together. (APDC05)

I asked everybody to pray for me so that I would have a good outcome when I went down to Toronto. That's what I attribute my wellness to is the power of prayer, the power of people. I didn't just stay Christian, I also took our traditional healings. Some people would say, "Oh, how could you go over there, you're Catholic?" Yes, I'm a Catholic too, but we all pray to the Creator. He's just got different names. (APDC07)

Some Anishinaabe participants leaned heavily on forms of organized religion and Western medicine, exclusively, through the cancer journey. It was explained that prayer and a belief in God have been sources of strength during the cancer experience.

The cancer experience made me trust God more. We really prayed for God to guide the surgeon's hands and prayed for healing. I believe I'm healed. I think if I dwelled on it, then I wouldn't believe in God and what I asked of him. (APDC02)

Other Anishinaabek may not have relied on spiritual traditions in the past and have acknowledged a change and greater awareness of our spiritual lives, as a result of having faced cancer. It has been mentioned that many existential issues and questions surface in a time of crisis or distress. We have acknowledged a greater pull to spirituality and we may now rely on prayer more often as a source of strength.

All of a sudden I pray. I'd go to church may be three or four times a year before I had cancer. Now, I pray every day, even more. The thing is I didn't pray for myself, I prayed for my kids and I prayed for my husband. If I did pray for myself, I'd always ask, "Give me the strength today just to get through this day," because it's hard. I go outside, get some fresh air, and I say thank you, *Miigwech*. What am I going to do today? (APDC09)

The time of illness may prompt the Anishinaabe to seek out cultural medicines as a form of spiritual strength. Minobimaadiziwin involves gathering Anishinaabe *gikendaasowin*, or the knowledge about our teachings, throughout our lives. Sometimes we take our teachings for granted. When we are unwell or unbalanced, it is time to look at those things we've learned and to remind ourselves of how to live the good life. This may lead to a focus on our spirituality and gaining a greater awareness of who we are as Anishinaabe people.

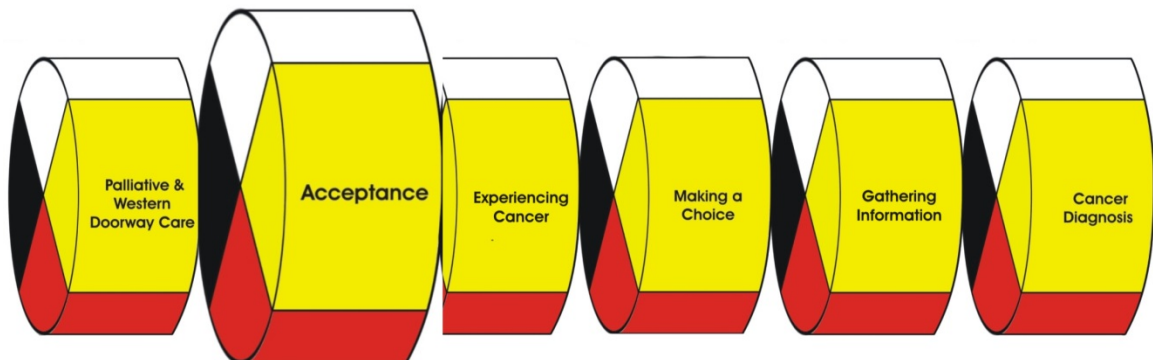
I started to take that medicine. I remember taking that and just trying to get a really good understanding of the spiritual component of who I was. I was learning more about the culture and traditions at that time and I really started to pick up our way, the *Nishnawbe* way. I was trying to live in a good way and embracing the four elements of who we are as a people the mental, the emotional, the physical, the spiritual. I was trying to encompass those and to understand and live those Grandfather and Grandmother Teachings. (APDC11)

One health practitioner acknowledged a difference she observed between First Nation and non-First Nation people when diagnosed with cancer. This difference highlights the fact that we as Anishinaabe have an inherent understanding about what cancer is bringing to us. Cancer brings spiritual awareness as a by-product of its process or journey, but it also is a signal for all Anishinaabe people to seek Minobimaadiziwin.

I've never seen First Nations people when they've been sick with cancer, near the end or just received a terminal diagnosis, question the Seven Grandfathers, their culture or spirituality. I'd say they embrace it more when they've gotten sick. In a non-First Nations person, I've seen people who've had a belief in God all of a sudden question that because they have this diagnosis. (WHP03)

Sometimes this recognition of our spiritual selves helps with the phase of acceptance.

Acceptance



At some point in the cancer journey, all of the participants arrived at a level of acceptance. For some, acceptance came early, at the time of diagnosis. For others, coming to terms with cancer happened much later, just before the end of physical life.

Kam na dap nan akoziwin [taking illness in a good way]

For Anishinaabek, acceptance can mean learning from the illness experience. It means taking the illness that we have been given in a good way, being able to learn from that and moving onto the next part of the spirit journey. The point of acceptance can be reflected in the analogy of a fork-in-the-road. In the *Miikaans* teaching, the “little road” can be seen as cancer, as a teacher, signalling that some change in life is required. It can also mean a divergence from the path of life or the end of physical life. At this point in the journey, we shared that illness can bring an awareness and can create change for the person with cancer but also for those who support us. *Minobimaadiziwin* is reflected in learning from the cancer experience and accepting what has been put in our path, even if it means death. We view the Western Doorway not as an end, but as a transition. It is a part of our journey back to the Creator.

When we get sick we *kam na dap nan akoziwin* means we take our illness in a good way and see what it brings us. What are the teachings that come with that illness? Cancer brings the person to a whole different awareness. Family comes together and having that love extends the wellbeing of that individual and *mina dap nan nii na wi akoziwin* [Translation: the person is taking the illness in a good way]. If it’s their time to go, then the person usually leaves in a good way and it’s not a drawn out process. The Western Doorway is seen as part of their life process. (IHP04)

In the beginning, they can realize and accept the fact that they’re on a journey with cancer. They’re not sure where that’s going and once they

work through that and they can get to the point of acceptance. Everyone's different, some remain in denial for a while before they look at it and realize "okay now I have to accept this and what do I do with this?" That awakening comes, "okay now what do I do with this now? What is the purpose of this?" (IHP06A)

This Anishinaabe-kwe commented on how cancer became a teacher for her. Although it was sometimes difficult, she was finding purpose in the cancer that had been put in her path.

I was so mad one day, I said, "Thank you for the shittiest day ever!" I just thought about it after. "Okay, I take that back. You've taught me a lesson" because you're learning. If you think about it, you do find your lesson in there. That's what I've learned. (APDC09)

Indigenous practitioners acknowledge that although we have this teaching of acceptance, the acceptance of death can still be very difficult.

They have to accept what they have, *n'dop niga dek minido ga nak ni get* [Translation: to take what the Great Spirit planned/past tense], accept the Creator's plan and that's tough! The Creator will take care of you. We're only down here for a period of time but there's a longer life somewhere else, much better than this. While we're down here, we have an assignment. Use your *Semaa*, use your tobacco. That's the hardest part to swallow, accepting what the Creator planned for you. (IHP02)

A particular challenge for Indigenous practitioners has been to bring people to the understanding that illness can be accepted as a teacher. For some Anishinaabek, cancer is a life-changer or a waking up. It was noted that the process of acceptance could be difficult, especially if we were constantly engaged in a “battle with cancer,” an incongruent cultural understanding of illness.

It’s a challenge to accept that illness, *kam na dap nan akoziwin* [Translation: taught to take illness in a good way]. It’s a different term compared to the mainstream saying, fight cancer. For us it’s totally opposite of that because we say *kam na dap nan manda akoziwin*. It’s so exhausting when you are fighting something. At least when you look at it and embrace it and say *kam na dap nan* take it in a good way, then you can start learning from that. We have bought into that mainstream concept *kaa mii god don* [Translation: taught to fight it], fight cancer! Fight this! Fight that! [Laughing] Everything is about fighting and that’s not our way. That’s foreign to us. When you look at the Elders a long time ago, there was always kindness. When there was illness they took it in a good way and when somebody would pass away, it was their time to go, it was just part of life. (IHP04)

In the teachings of Minobimaadiziwin, cancer can also represent a curve or an obstacle in the path of life. This Anishinaabe-kwe shares how perseverance is a key to Minobimaadiziwin. We can try everything to overcome that obstacle to no avail. Regardless, we must persevere, and this is also acceptance. If we are unable to overcome the obstacle, we accept that this was the length of our life path.

Minobimaadiziwin is like a road or a path that you follow. When cancer gets in there it's like a curve on the road or a big rock on the road. Sometimes you can climb over that rock or something will help you climb over that rock or you can't, but you still have to keep going. *Nishnawbek* talk about the path ahead. When somebody dies they say that was how long their path was. There was nothing anybody could do about it, that's what the Creator set out, that was the length of their life *mi bid'nik Bimaadziwin ... ekwabiising Bimaadziwin* [Translation: That is how long their life was meant to be. It is inclusive of all life. Everything has a living end]. Regardless, if you put them on life support, you do everything you can, but if your life is this long, that's how far you're going to go.

(APDC05)

The following are reflections on acceptance from those with cancer. For some Anishinaabe participants, acceptance was possible with IH/TM, which also brought them to readiness for the journey to the Spirit World. Therefore, a person can come to accept the end of their physical life and the teaching of *kam na dap nan akoziwin* [Translation: taught to take illness in a good way],

I was asking that that sickness I carried would be gone but at the same time finding peace in whatever it was that was going to happen. It was an unbelievable peace that if the sickness should take me I was okay.

(APDC11)

I believe when we went for the ceremony, for me, it was kind of a relief that he could go or he would stay. It was kind of like letting go and accepting whatever the Creator had in store for us. (IHP01A)

For other Anishinaabek, it was another form of spirituality which brought them to acceptance. The notion of acceptance appears to be expressed in the same manner regardless of the chosen spiritual tradition to which the Anishinaabe people ascribe.

I thought about my whole life and I just want to live from day to day, but I can also accept whatever comes. If that doctor told me that cancer was back in my body, somewhere else – maybe it's time. The Lord wants to take me now, [pause] I would accept it. (APDC02)

When I learned I had cancer, I was talking with Jesus. At that time, I told him that my work is done and I'm ready to come home. I guess he listened to me, so I can't very well go back on my word. (APDC04)

Many have observed that acceptance and the ability to move on with life relatively soon after diagnoses of cancer are Anishinaabe strengths. As the individual and the family accept death as a part of life, and everyone bears witness to this, it becomes a strength we can continue to rely on.

I think our people are able to adapt to things. Initially, there might be a feeling of shock, maybe even despair at first, but it's very short. Our people who have cancer have gone about their business pretty quickly.

They don't let it hold them down and they don't start dying, they definitely start living. (APDC07)

I think, overall, Anishinaabe are more accepting of what happens to them.

I think Anishinaabe accept that it's okay, this is part of my life and I am just going to go on living as before. I think acceptance comes sooner.

(WHP01)

Acceptance encompasses many meanings for those with cancer. It can also mean the acceptance of change in the direction of our lives.

Acceptance of change for Minobimaadiziwin

Cancer changed the participants' lives in numerous ways. Some noticed a change in the way we relate to others. We found we had more courage and gained insight into the Grandfather teaching of bravery.

I think it's made me realize that we are only here for a short time so try to make the best of things, try to take advantage of your day because you're not promised another. I'm going to speak my mind from now on because I was always quiet. (APDC03)

Anishinaabe participants also had a different view of cancer and of life in general, after having been through the cancer journey. We appreciate every day we have, and this prompted many to look at how we were going to continue living the remainder of our lives.

Cancer made me realize that life is short. It made me realize that you shouldn't worry about the little things. If at all possible, be good to yourself and other people. You shouldn't be angry at people. (APDC13)

Change can also involve acceptance of a new role as a teacher of the cancer experience to help others. This role, in particular, relates to the teaching of Minobimaadiziwin in treating others well and becoming a helper to others with cancer. As mentioned by health care professionals and Indigenous practitioners, when we are diagnosed with cancer and we stay in this physical realm, we can be the best teachers for those with cancer because we have walked that path.

I wanted to do this to give hope to other people whoever gets this and hopefully it will help them. (APDC01)

Minobimaadiziwin, or your path, is also shaped by how you look after yourself. Cancer can prompt a change in our lifestyles. These participants reflected on the change that cancer has brought to their lifestyles.

I have changed my lifestyle. I'm not out partying as much as before and I'm trying to get rid of the smoking. The cancer gave me an awakening of my life. I only have five or 10 more years, so now I have to turn my life around. (APDC09)

Cancer certainly made me appreciate life. Before, I was always on the fly. Cancer makes you take time to heal, rest and you really begin to say it's

about me. I have to look after me to get better. I have learned to accept the days as they come, to slow down and enjoy life. (APDC10)

One health professional spoke about a “loss of innocence” that people experience with their cancer journey. This is profound since many Anishinaabe participants spoke about the fact that cancer was a life-changer because it “woke us up” to change our lives and get back on that road to Minobimaadiziwin.

I think the loss of innocence symbolizes that we always take life for granted, that there is always a tomorrow. I know that I’m not exercising today and I know that I’m not eating properly. Maybe I’ll get to that tomorrow. We always assume that there’s time, but when you’re faced a diagnosis that’s potentially life threatening, you realize that time is not forever. (WHP07)

Indigenous and Western practitioners remarked that it often takes a crisis in someone’s life to create and accept the positive change required to continue on the path of Minobimaadiziwin. These reflections are reminiscent of the Minobimaadiziwin, or Little Roads teachings, where a person reflects back on their life when they are at the “fork-in-the-road.” An alternative to conceptualizing the fork-in-the-road as leaving the path of life, it can instead be thought of as leaving an unhealthy lifestyle or situation.

Cancer makes them look at life differently. Maybe it’s a blessing in disguise for some people because the only time people’s lives really change is when they have a crisis in their lives such as cancer. (IHP08)

Cancer permits you to make decisions about how you want to lead your life. People will make difficult choices about relationships say, choosing their health over a certain person, where this person will bring me down a path back to my old habits and I don't want to go back. Some people choose to leave marriages; some people choose to leave their communities; some make choices about work or friends. (WHP07)

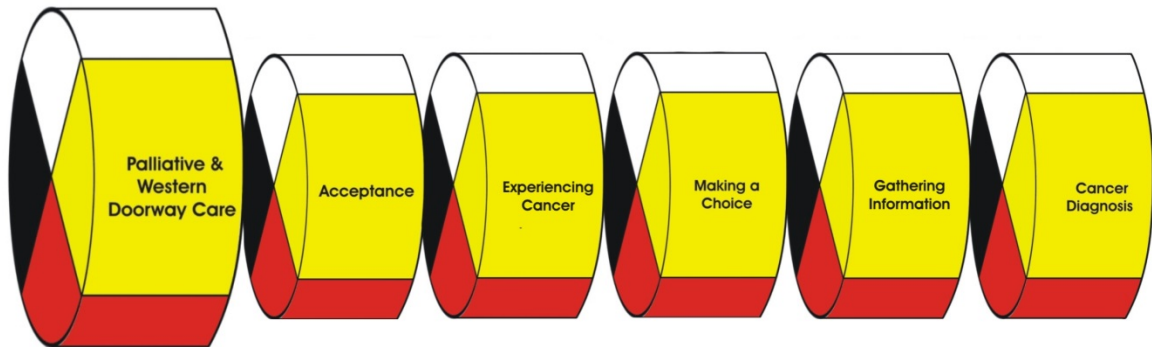
Indigenous practitioners shared that you can see a physical change in someone who has accepted cancer or their death. This acceptance is demonstrated in the way we carry ourselves and in our physical expressions.

You see that light in them, it starts to shine and they're ready to go out that Western Doorway. I find the spiritual aspect of their life becomes stronger. (IHP04)

It's interesting to watch someone's spirit grow while their body weakens. It's a candle burning even brighter. It's an amazing thing to witness, that spirit. (IHP06A)

The reflection of a stronger spirit is perhaps preparation for their return to the Creator.

Palliative and Western doorway care



Death is a Part of Life

*Someone said we begin to die the minute we are born. Death is a part of life.
Who knows why the Creator thins his herd.
Another saying says we must all be prepared to give up those we love, or die first.
Take time to mourn, take time to remember, everything happens in cycles.
The pain you feel is once balanced by someone's joy when that baby was born.
The loss you feel today will be replaced by good long lasting memories.
Is there a message here, yeah, treat others like this is your last day above ground.
(Jim Northrup, 2013)*

The Anishinaabe recognize that death is a part of life. This teaching has been shared with me in a variety of ways, but was most beautifully articulated in this poem by Jim Northrup, an Anishinaabe writer and cancer survivor who granted me permission to publish it as a component of my dissertation. This poem encompasses what everyone has taught me about life and death, and it reveals an important aspect of our concept of Minobimaadiziwin.

The use of Western medicine in palliative care

Anishinaabe participants and health care practitioners agreed that Western medicine assists in achieving Minobimaadiziwin in the physical domain at the palliative stage. The primary focus of Western medicine at this stage of cancer is pain relief or comfort.

Minimizing pain, we don't want to see those that are going suffering and the Western medicine will let them do that, to go peacefully. It gives the family comfort to see that their loved one is resting peacefully. (APDC05)

It was recognized that Western medicine and the use of narcotics in pain management was purely a physical solution. This is recognition of the importance of IH/TM in addressing the other aspects of a person's well-being at this stage.

Western medicine makes it a more peaceful, pain free transition, in combination with the traditional. I think the traditional meets more the spiritual, emotional, mental. Western is purely the physical. (WHP03)

For some individuals and families, the use of pain medication can pose a dilemma where providing the pain medication impedes the person's ability to communicate with others. There is a fine line between relieving pain and maintaining the patient's awareness of their surroundings and ability to communicate.

There is a tendency to hang onto that life and we struggle with that, to let someone go. Western tends to be more focused on the physical presence of the person and the little beeps on the screen. The physical pain and the drugs impact who they are and we lose them. They're just a body, a vessel breathing there. (IHP06A)

Anything that is going to relieve the severe pain also has a sedative effect. For some people that is not desirable but for some it is. They are quite

happy not to know what is going on, but sometimes family want to have that interaction with a family member who is dying. (WHP01)

In the past, pain control was difficult to manage, but thankfully, it was acknowledged that this has improved. The issue of deeming someone palliative has been a recent challenge for Western medical professionals in working with those with cancer at this transition between active and palliative care. This physician shared the complexities at this stage of the cancer journey.

I think Western medicine also has the potential to do harm if the health care providers aren't recognizing that their goals are misaligned with that of the patient. Physicians or nurses still struggle with the transition from active care to palliative because sometimes that transition may happen in the last day or a few days before death. We may be still checking vitals and giving them a lot of medications and poking their finger a bunch of times to check their sugar and we're still drawing blood when we should be just doing things that are for comfort only. If we're holding onto that active treatment for too long, then certainly we have the chance to make the experience worse. (WHP04)

Health professionals felt that a positive, end-of-physical life experience is possible by allowing those who are dying to maintain control over their lives and decision-making. This can happen with Western medicine, which can assist in achieving Minobimaadiziwin. Specifically, some of the end-of-life care provided by Western medicine helps to prolong life to allow a person time to deal with unfinished business.

We have some very useful treatments that may aid the physical nature of holistic well-being and some may also be helpful with some of the emotional aspects as well. In terms of cancer, it may be a matter of life prolonging treatment, but not necessarily lifesaving. At the end of life, some of our treatments can help to provide a person more time. It might be buying more time for decisions or making peace with family. (WHP04)

Another physician shared that being able to facilitate a positive end-of-physical life experience has been rewarding. This includes providing people with choices about their lives and allowing them to go through the death process with less fear, which is an important part of Minobimaadiziwin in staying on that good path into the Spirit World.

I've had very close friends where I've been their physician as well and we've had to go through the dying phase of life, and I've been able to work with them in a way that maintains their ability to make choices. They've been able to make choices at the end of their life, and they've had the kind of death they wanted to have, at home, usually with family. It can be very rewarding if you've got good symptom control and you've been able to impart to them a lot of knowledge about the death process that they've approached the end of their life on earth with much less fear than they would have otherwise. (WHP06)

It seems that participants and key informants felt that Minobimaadiziwin can and should be maintained in the transition from the end of physical life and beyond. Anishinaabe people refer to this part of the spirit journey as “getting ready to go home.”

Taking care of the spirit: “Getting ready to go home”

We shared our personal experiences with and beliefs about life, death and spirit.

Anishinaabe participants conveyed how IH/TM assists in achieving Minobimaadiziwin at the end of physical life. Many Anishinaabe people use elements of IH/TM in preparation for someone’s journey to the Spirit World. We may commence these ceremonies in the palliative stage, if we have not been implementing them already in daily practice.

Sometimes, we have to learn about IH/TM in this stage of cancer.

My mom would like to have a cedar bath when she has passed. It would be nice to know, for her sake, when it should be done, why it’s done and who does it. That’s just something that’s come up in my experience in the last couple of days. That is something that she would like to have done, but I have no information on the cedar bath. (APDC03)

Anishinaabek also employ Christian prayer in preparation for the end of physical life. It was not uncommon for families to depend on a combination of both Anishinaabe and Christian traditions at this stage of the cancer journey.

It was just family in that room after my uncle passed away. We did a cedar bath for my uncle and it kind of helped us standing there watching it. I also went to my aunt’s when she passed away, and I got a chance to be there again at the end. When she passed away, we all held hands around her on the bed. We did the rosary and my cousin was leading it. She almost forgot which prayer was next, “You guys should know this!” they were saying [laughing]. So I got to see both sides. (APDC01)

The ceremonies one may include in preparing for the spirit journey include, but are not limited to: receiving one's Anishinaabe (Spirit) name, clan and colours; having a cedar bath; participating in sweat lodge ceremony; smudging; praying; and lighting the sacred fire at the end of physical life. Some healers acknowledge that it may be that all someone requires for acceptance to occur is for that person to receive their Anishinaabe name.

If they don't have an Anishinaabe name we help them find that name and for some, that's all they're looking for. There was one family where a man wanted his Anishinaabe name. I gave his Anishinaabe name and I asked him to come down to the sweat lodge. His whole family came too. Some of them came in with him and said he connected with something in there where he learned to accept death. (IHP08)

Anishinaabe people continue to maintain and strive for *Minobimaadiziwin* by taking care of the spirit of the person who is passing on. We also benefit by taking care of ourselves through participation in the spiritual aspect of life, regardless of the form spirituality takes. Many of the Anishinaabe interviewed explained that the role of IH/TM is to make sure that people are comfortable physically, by minimizing pain and discomfort, but also by ensuring comfort and balance emotionally, mentally and spiritually. We do this by caring for the person and the family who may be grieving the loss of their loved one. Many alluded to the fact that from birth to the end of physical life, these spiritual ceremonies have a role in taking care of our spirits.

As stated in an earlier section, IH/TM is not exclusively about ceremonies or medicines, but can involve the sharing of Anishinaabe *gikendaasowin* or teachings. Indigenous

practitioners can assist people by providing the spirit teachings and easing their discomfort with death. Anishinaabe teachings as a component of IH/TM are provided to bring people to the understanding that physical death is *not* the end of life for the spirit. For many, the palliative stage is about learning about the transition to something new, and this transition is to be viewed as a new beginning. People are comforted by the thought of meeting with loved ones in the Spirit World.

IH/TM makes you understand that this isn't the last stage, that this is the first stage of a new experience. It's a transition. Our physical life here is transforming, but it's not the end, it's just a new beginning. With the teachings that we have about spirit, it helps people to have that connection and that understanding about what's going to happen to them after they leave the physical world. Having that knowledge, having that faith and comfort, brings that peace for them. (IHP06A)

The Indigenous approach actually helps the person lose fear of what's going to happen. They can have an expectation that it's a transition into another existence. The preparation is more of this life is ending, but there's still a journey to fulfil. There's going to be a reunion with ancestors, people they haven't seen for a long time. In our approach, we say they may even be expecting you now, so they may be making preparations on the other side for you. (IHP09)

Western practitioners acknowledge the contribution of IH/TM to Minobimaadiziwin at the palliative stage. The Western practitioners working on Manitoulin Island have come

to learn that this stage is sacred to Anishinaabe people. One shared that she came to learn that suffering is a part of life and does not necessarily refer to physical suffering, in the Anishinaabe understanding. This understanding reflects a teaching I received from an Elder about how people must remember to celebrate the end of a person's physical life. In this teaching, people were once mournful about the birth of a baby because of all that the baby would have to endure or suffer through in his or her physical life. Conversely, we would celebrate at the end of someone's physical life because the suffering would be over.

Things have gone so opposite to the way that our teachings were. We celebrated that time when our people got to go home. When babies were born, that was our time of mourning because we saw that they had to walk in this life here on earth and sometimes that is not easy. Yes, we celebrated, but we also grieved because this life is not easy. (APDC11)

I think the notion of suffering at the end is a really complex idea. As a physician, I've been taken aback by comments of family that the person's no longer suffering. My first impression was they weren't suffering because we made sure that their pain and nausea were gone and they weren't suffering. Then realizing that maybe they didn't mean that kind of suffering. (WHP04)

Spiritual understandings of death and dying take precedence in the palliative stage. Participants agreed that this stage is where IH/TM, ceremony, family and imparting the Anishinaabe *gikendaasowin* or teachings are critically important.

This stage also meant a time for a people to seek out the wisdom of the person who is passing on because in our culture the Eastern and Western Doorways are the closest realms to Creator. As we're getting close to leaving this physical realm, we're nearing that spiritual realm again of being with Creator. The person is becoming all spirit and they are so close to Creator. They're in a place to be able to receive and pass messages. (APDC11)

In palliative care, it's the emotional and the knowledge aspect, the information and understanding of the situation and what's coming that becomes much more important. I think that is where the family, the community and the traditional ceremonies and medicines that are such comfort to people, come into play. They're really at their foremost benefit at that stage. (WHP06)

Many people learn about Western Doorway teachings while in the process of preparing for funerals. We know that one way of coping with grief is to participate in the end-of-life rituals or ceremonies. In Anishinaabe communities, these rituals or ceremonies can include, but are not limited to: wakes, Sacred Fires, funeral masses, traditional funerals and cedar baths. They involve sending the dying person's spirit to the Spirit World in a good way.

Many Anishinaabe people incorporate wake services prior to a funeral. An Anishinaabe wake can last anywhere from one to four days and can incorporate both Anishinaabe and

Christian spiritual traditions. We addressed the significance of wakes for Anishinaabe people. They allow for grieving and sharing good stories about the person who has passed on. Healing and humour are part of this process. People gather to support one another and the sense of community is appreciated. The time of leaving this physical existence is sacred and the process is complex.

Palliative care is a Western term. Our term is that they're getting ready to go home. That time that the person was getting ready to travel home was a time of celebration. It meant visiting. It meant sharing. It meant getting teachings and knowledge. It meant feasting together with that person who's getting ready to go home. (APDC11)

First Nations' people have it right in that you wake them for the three days and you have the Sacred Fire and someone's with the body. There's a real comfort feeling of community and love and it's not sterile. In my culture, you have to have the body at the front of the church. You walk up, you talk to the family, you sit there, you don't say a word and you walk out the door and you're expected to have gone through your mourning and moved into grieving, and then it's supposed to be healthy. (WHP03)

Why do we have wakes? It's to have the people go through their grief. I usually go and talk to the people or to the family or the person who's dying. You talk to them right away and get their feelings out about what happened. If they can talk, it's all the better because if they don't talk they

hold it in and they can carry that 20 years, 25 years – they’re still hurting, because they’ve never let go. (WHP05)

Invaluable Anishinaabe *gikendaasowin* was provided in the form of Western Doorway teachings by knowledge keepers who wished to share them with others. I have chosen to convey some of the teachings as they were originally shared with me using the voices of those who shared them in Appendix 12.

Many of the ceremonies or rituals honouring one’s transition from the physical life to the Spirit World would be conducted using *Anishinaabemowin*, which is the original Anishinaabe language. Those in this study recognized the importance of using *Anishinaabemowin* at the palliative stage. We shared some of our experiences with the death of family members and how the use of our language is critical. The language can also be a comfort for those passing on, especially at this stage of life. One health professional spoke about the importance of speaking and understanding *Anishinaabemowin*, especially when caring for Elders at the palliative stage. They may be passing on important messages in *Anishinaabemowin*. We may revert to our original language and the information will be lost if the persons caring for us do not have this understanding.

One important thing, when you're dealing with an Elderly person who is dying, they revert to the language. If the younger people – the children – only speak English, they won’t understand. Especially people from here, they would always revert to the language. It happens all the time. I try and encourage people to learn the language, if your parents are older and they

Speak the language, they're going to revert to that language when they die.

The language is very important to be able to understand what they're trying to tell you. (WHP05)

Visiting, preparing and sharing are all a part of the palliative or Western Doorway stage but more importantly, they are within the Anishinaabe understanding of *Minobimaadiziwin*. This includes taking care of one another.

Caring for family and community is *Minobimaadiziwin*

Community members come together to support families when loved ones are ill or in preparation for and after the death of a loved one. Assistance can include providing emotional support when visiting and providing respite to family members who are caring for a sick relative. Many in this study believed that this is something that Anishinaabe families do without question. This care and support are considered aspects of *Minobimaadiziwin*.

I think the palliative care is something that Anishinaabe families already do. Whether you're family or just a friend, you go there and help with whatever you can. It's just something that you do. (APDC06)

From a *Bimaadiziwin* or an Anishinaabe approach to palliative care, it becomes a very family, community approach at that time. The community is coming in to take care of family who is taking care of their loved one. That in itself, is *Bimaadiziwin*; taking care of our family and community. There are things that we're doing that we don't recognize as

Bimaadiziwin. In taking care of the family, we're feeding them; we're giving them rest time; and being emotionally supportive or listening. We are trying to keep those loved ones in a balanced place, despite the grieving. (APDC11)

Sometimes we need to be taught how to provide care for those who are dying. This community health professional shared how she provides emotional and practical support at the palliative stage of cancer. She acknowledged that most Anishinaabe people in her community would prefer to die at home. While the Manitoulin Health Centre has improved in its efforts to accommodate Anishinaabe people and their traditions, the hospital still has policies which make it difficult to have family and community members present at this sacred time.

I try and help the people, to get the services and equipment that they need and to make sure that they get the palliative care services. I've taught them how to care for the dying person. It shouldn't just be the nurse or the one caregiver to do these things. The family can be part of that caregiving in whatever way they can. It makes them feel useful, and they are doing something for that dying person. (WHP05)

Some participants acknowledged that we need to be reminded of our teachings and roles as supportive community members because we are forgetting. Visiting has a special function for Anishinaabe people. Through visiting, we are acknowledging each other's spirit and we are giving life when we share food with each other. This, in essence, is the meaning of *Minobimaadiziwin*. We should never forget the wisdom in this Anishinaabe

gikendaasowin, and the people suffer when there is a disconnection. We are not looking after one another the way we used to and need to continue to strive for Minobimaadiziwin in this area, as well. This Elder shares how a visit is symbolic of something greater.

When you come into our homes, our people automatically feed you and to refuse is sometimes an insult. What the people are doing when they feed you is giving life. They're acknowledging the spirit of who you are as a person when they offer you tea, coffee or something to eat. When you visit our grandmothers and our grandfathers, they always did that in return for giving life. People visit at that palliative stage and the person welcomes that. You hear, "Oh, they're so happy that you came to visit" because it's a spiritual visit, physically you're there but it's a spiritual visit of giving each other life. (APDC11)

Chapter 4 was concerned with the participants' sharing of their cancer experiences, specifically, six aspects of their cancer journey. The chapter presented a collective story from the time of diagnosis to the palliative stage or time of preparation for going out the Western doorway (i.e., the transition from the physical to spiritual world). Chapter 4 is based on the Anishinaabe teachings of Minobimaadiziwin which framed the collective story. This chapter connects to the centre of my *Theoretical Model for Two-eyed Seeing*. It concentrated on the participants' cancer journey but also on the recognition that Minobimaadiziwin is central to the journey through cancer in helping participants to persevere through adversity. Minobimaadiziwin reflected the maintenance of balance in all elements of participants' lives, and it featured prominently in their choices made

within the cancer journey. Finally, Minobimaadiziwin is central to the relational and healing elements having influence on this experience. These influences will be discussed in Chapters 5 and 6.

Chapter 5: Influence of Relationships

Anishinaabe participants described the influence of relationships on their cancer experience. Those key relationships are depicted in Figure 9 as the five ovals surrounding the stages of the cancer experience. The Anishinaabe relational way of being was evident throughout this thesis. Wilson (2008) stated that “this relational way of being is at the heart of what it means to be Indigenous” (p. 80). Anishinaabe people phrase this foundational belief or concept in Indigenous culture as in “All my Relations” (Dumont, 2014). This phrase is a constant reminder that we are connected and related to everyone and everything that surrounds us. The importance of all relationships, whether between people, animals, plants, and spiritual forces, was reflected in the participants’ sharing of stories about their lives, inclusive of the cancer experience. Their relationships filter in and out of the cancer experience at many points along their journey. To examine the influence of relationships more closely, this element was placed in a separate chapter. The cancer experiences of Anishinaabe participants were affected by relationships with other people, the land and spiritual forces. Anishinaabek described five main types of relationships in their cancer experience. They engaged with: Creation, Western practitioners, Indigenous practitioners, community, and family.

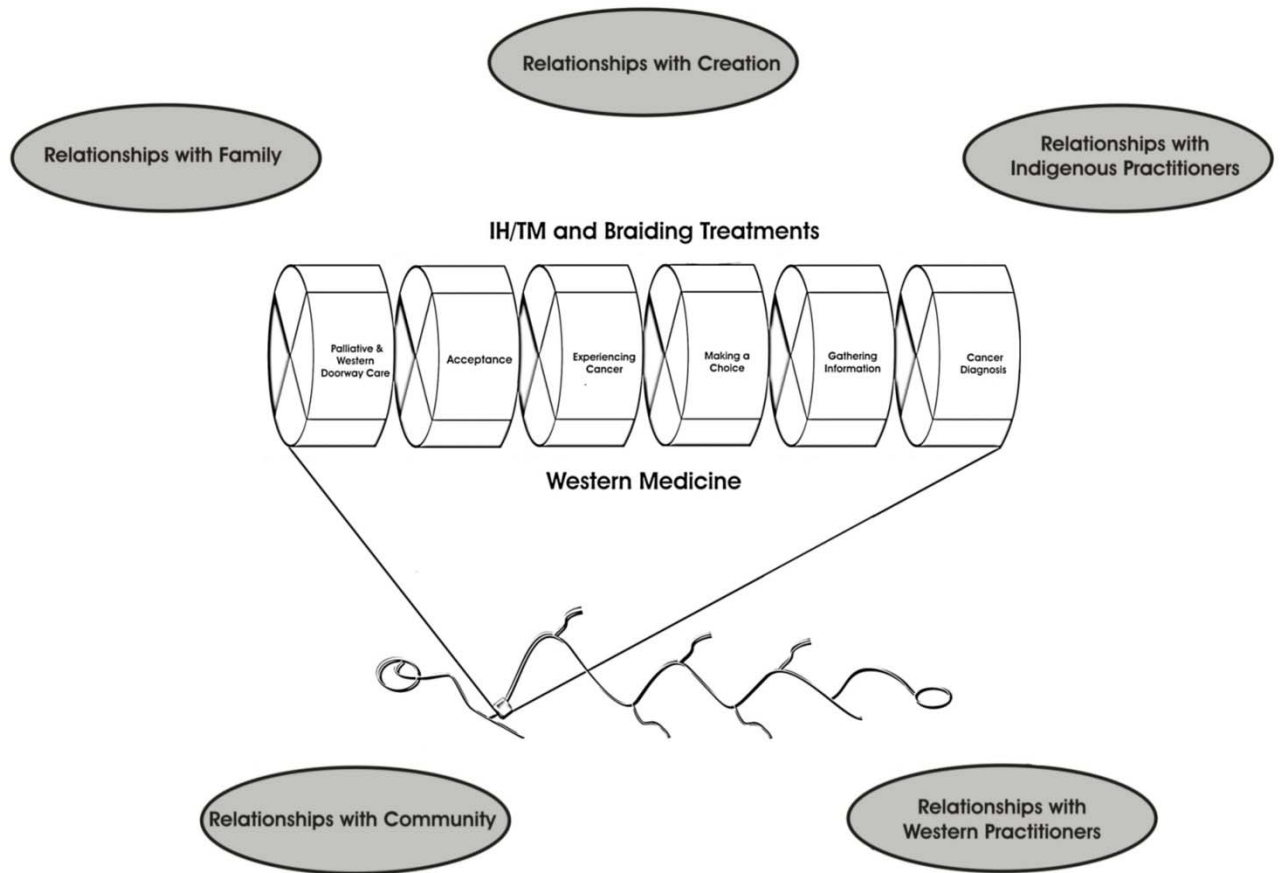


Figure 9: Influence of Relationships

This quote from a health professional encapsulates the importance of relationships in the cancer journey.

You cope with cancer one step at a time, one day at a time. It's to be present in the moment and focusing on what you need to do for today. It's about surrounding yourself with the biggest circle of friends and family to support you and not being afraid to ask for help. When you let people help you, you are helping them cope, but if you deny people the experience then relationships can become dysfunctional. (WHP07)

The participants' cancer journey often began with a diagnosis provided by a Western health practitioner. For many, the dynamics of the doctor-patient relationship will provide a context for the rest of the cancer experience.

Relationships with Western practitioners

Western health professionals can include anyone within the circle of care who works from the biomedical perspective (e.g., specialists, physicians, hospital or cancer centre nurses, community health nurses, physiotherapists, dieticians, etc.). For the most part, participants were satisfied with the medical treatment received at the local health centres; the Manitoulin Health Centre - Mindemoya (Community Oncology Clinic Network satellite); as well as the Northeast Cancer Centre.

The nurses, the technicians, the people in the lab, they made you comfortable. I got a lot more information from my doctor's nurses than I did from the doctors themselves [laughing], but I can understand they do deal with this day in and day out and have hundreds of patients.

(APDC03)

It's their willingness to listen to you or to be genuinely interested in what you're thinking and what's going on with you. They discuss things with you. Whenever I have my scan, the doctor always tells me what's on there, what they're seeing, and they explain it. (APDC07)

Anishinaabe participants described dealings with community health care providers as positive and productive. We felt that the community nurses were available and able to help, and many participants wanted to compliment the local nursing staff.

I would like to compliment the nurses. When I had the bag, the nurse came every day. They are really good. If you need something they always offer. They're doing what they can with what they know. (APDC01)

Mnaamodzawin was excellent, without them could not have made it through. The services are great and I would do a speech on this anywhere if it could help them get more funding. They take your blood work here at home – the best thing as far as I'm concerned. I was going to the hospital for the longest time. I have to get that every week, so I would be looking for rides and having to get up when I don't feel good. (APDC10)

Although the relationship dynamics with Western health professionals were most often described as positive, there were issues with communication and understanding information. These perceived issues appear to have been influenced by cultural and language differences, and also what may be described as attitude toward the patient.

Issues with communication: Anishinaabe perspective

We discussed whether there were any issues or difficulties in communicating with health professionals. Some Anishinaabek felt that our concerns were not addressed in a timely manner. Granted, this may not always indicate an issue with communication with a

particular health professional but, rather, may be a signal that the system is not as effective as it could be.

I was told over the telephone. I had gone for a mammogram and they did the biopsy and the ultrasound all at once and then I was sent home. They told me that somebody would get in touch with me. It was going on two and a half weeks later, and I hadn't heard from anybody. I called my doctor's office and the receptionist said, "We can't give any information over the phone." A few minutes later, my doctor calls me and he's hemming and hawing on the phone. I said, "Nobody called me. Just spit it out!" He said, "You've got cancer." They should make sure that it's done as soon as possible and in a better way. (APDC03)

I was having a hard time when I was diagnosed with the tumour in my lung. I kept going back, "No, the nurse practitioner has to tell you the results. We can't give them to you." What do I have to do to get these results!? I was getting sicker day by day. Finally, the nurse practitioner picked up my report and called, "You have water in your lungs. There is something going on with your lungs and you need to seek medical help right away." That's what I was trying to tell them! Our healthcare system is really bad sometimes. (ADPC12)

Anishinaabe people diagnosed with cancer and health professionals agreed that a physician has to believe that the client is providing legitimate symptoms, or this could disrupt the process of diagnosing cancer. This is a sensitive issue for Anishinaabe people,

especially if pain medication is involved. The prescription drug issue has filtered into our communities and has impacted the relationship between health professionals and their patients, as illustrated by this community nurse.

The doctor may not believe them. Somebody has a complaint, they go and see the doctor and the doctor will say, “Oh, try this” if they’re complaining their stomach is upset. They give them something or think it’s trivial. The person will go back again and again before they do any kind of tests. This is what I’ve been hearing. If it’s the doctor not really being thorough, maybe in his testing, I don’t know. Or, not believing the person. Maybe they think that we’re all hypochondriacs or we’re just after the narcotics, you know, with the drug problem. (WHP05)

Many Anishinaabe in this study, especially the Elderly, revealed that we felt intimidated and rushed when in a doctor’s presence. Sometimes we perceived that the doctor’s attitude was distant or too clinical. We might not have known the right questions to ask or worried about the language used to communicate with the doctors. As a result, Anishinaabe participants felt that we remained uninformed about cancer.

The doctors I find are a little distant. They ask if you have any questions and they don’t go into details unless you ask. I didn’t know the kind of questions to ask. Then I would write my questions down but not know how to word them. I’m still uninformed about cancer. (APDC03)

The concept of *zhagwenmowin* [Translation: imposed shame] was apparent in communications with health professionals. Anishinaabek expressed feelings of

inadequacy when we didn't have questions, when we sensed that it was an expectation of the doctor's. These comments may be indicative of the fact that Anishinaabe people, especially Elders, need time to formulate our questions. In all, this does not bode well for the effective communication of health information. These participants expressed how they felt intimidated and uninformed as a result.

Sometimes I feel that I'm frustrating them because I don't ask questions, and he'll always look at me, "Is there anything I can help you with? Have you got any questions?" I sit there like a dummy and I say, no, everything is okay, but I have this feeling that he wants me to say something and I don't know what it is. (APDC07)

I find sometimes, doctors are too fast, without explaining to you. I'll look at my pills later and I'll think, "What's this for anyway?" I'm the type of person who says, "Oh, I should have mentioned this, or, I should have said this." I had it in my mind but because of the interaction at the time, it just leaves my mind. "Did you ask him this? Did you ask her that?" Tammy* will sometimes say. I say, "No, I forgot." (APDC08) **name has been changed*

At other times, Anishinaabek felt that doctors were not sensitive to the fact that most people lack the medical vocabulary of a physician. It makes it difficult to understand instructions, to ask meaningful questions or to be active participants in our own health care. These participants shared their experience with language differences.

Every once in a while the doctor in Little Current uses these great big words. I'm just sitting there listening to him. He asks, "Do you have any questions?" If he said it in English, maybe I'd understand. (APDC06)

I think when they're given something and the doctor talks to them in his medical professional manner and we don't ask questions. It's not in us to ask questions unless we're with our younger children who have that knowledge to ask. The reason that we don't ask is because it was always disrespectful to do that, *maanoo*, just let it be. (APDC11)

The relationship between the doctor and an Anishinaabe patient often reflects a power differential between levels of socioeconomic status, education and culture. Doctors are often viewed as being very knowledgeable, and participants sometimes felt we should not question them, thinking it was disrespectful in some way. As Anishinaabe people, we do have our own opinions but we are often indirect and do not want to be confrontational or critical. We are conscious of others' feelings.

As Indian people we have to ask those questions, but a lot of us aren't forward, or we skirt around it. We don't want to hurt people's feelings so we aren't direct. That's where doctors have to be educated, the Indian clinics, they have to be educated about that. (IHP01A)

Being a nurse, this Anishinaabe-kwe noticed a two-tiered power differential between herself as a nurse and her physician colleague, and also as an Anishinaabe cancer patient.

In her unique, personal struggle with cancer, she was both a nurse who is often subordinate to the physician and an Anishinaabe person with cancer.

I'm trying to tell you guys that, but you're not getting it! Sometimes trying to tell people who are higher and bigger than you that you need help will do you no good. They're higher up on the totem pole and they think, "You don't tell me what to do." (APDC12)

This nurse-turned-patient felt that she was also losing control of her decision-making power. She had personal expectations but also an insider's knowledge of medical protocol and felt that there are limits on how this can be shared.

He literally just grabbed my chart, thumbed through it and said, "No, I don't think we should do the chemotherapy at this time." Well, I guess you're God - you know? Just because you say we're not doing it, we're not doing it? We didn't do the chemotherapy at that time. I don't know if that was a wrong decision on his behalf or a wrong decision on my behalf, or if I should've said, well, maybe it is time to do the chemotherapy and try. (APDC12)

She questioned her doctors, not to be critical, but to remain informed of her condition.

Her comments speak to the fact that with experience, it is possible to develop confidence in our relationships with health professionals.

I want to say that we did have a good relationship, but because of the fact I have a nursing background, I would ask him, "What's my blood work at?" And he would say to me, "Oh, your numbers are fine." And I'd say to him,

“Well, tell me the numbers?” “They’re fine,” he’d say. We sort of had, not a scuffle, but a different understanding. I was going to be asking this question every time I went there, so I wanted him to have it ready ... It also happened on more than one occasion where I’ve had to diagnose myself or ask the doctor shouldn’t we go this route? They’re not too happy when you’re telling them what to do or how to do it. It all reflects down to them pair of balls that you get along the way. (APDC12)

It seems that improving communication between the patient and doctor is a matter of breaking barriers between cultures and gaining confidence.

Issues with communication: Health professionals’ perspective

There is another perspective in the health care professional-patient relationship to consider. One nurse shared a challenging experience she had with a patient who challenged the system and the approved method of treatment because she was determined to continue living on her own terms and not according to some treatment protocol. This is an instance of how a rigid system can adjust to be more flexible to allow for true patient choice instead of merely seeing the patient as non-compliant.

She just kept doing whatever she wanted to do. Sometimes when doing the treatment it would be, “No, you can’t, you shouldn’t do this. You should wait for a couple of days until you feel a little better.” But she got through it. I think she also taught us to face that challenge. In a way, to look at a person who initially seems like a difficult patient and think, it’s not about the treatment and following it. It’s about her. (WHP01)

Related to this issue of patient choice is the idea of bringing closure to physicians who feel that they could have done more to convince a patient to pursue diagnostic testing or treatment. It has been a particular challenge to accept some patient's decisions to forego diagnostic testing or treatment when the physician believes that to "do no harm" means encouraging them to pursue diagnostic testing to, possibly, prevent cancer. This physician shared her personal challenges in working with those who decide not to pursue diagnostic testing.

The ones I find personally are challenging are the ones that I firmly believe could have been prevented or at least found at an earlier stage.

Those are the cases that there have been discussions with the patient about screening, and they've chosen not to or when early symptoms present not wanting to pursue any diagnostic testing. For me, those are the difficult cases where I think, although people have to choose their own paths, I wonder if those patients look back and think if they should have. What could I have done differently to really encourage somebody to go for testing or to address their fears about it? (WHP02)

In addressing another dimension of the doctor-patient relationship, this physician noted the challenge of being from a different culture than his patients and how this can impact their understanding of the illness. There may be differing perspectives on how physical, spiritual and emotional aspects of the illness are interpreted and how Western medicine is understood. This is reminiscent of the belief held by some Anishinaabe people that cancer is happening to them for a reason. Physicians have a very different view of why someone

has contracted cancer, and this may impact on the acceptance of treatment or what may be termed compliance.

I'm cognizant of the fact that I'm of a different culture to this person who's my patient. I know that they have a different perspective on many things. When you get into spiritual and emotional aspects of their condition, even how they interpret their physical symptoms and signs and how they understand Western medical treatments, there's a challenge there for somebody of a different culture to thoroughly understand what your patient's point of view is. I'm always amazed at the difficult lives of many of my patients, and I think that has affected the way they think about and approach major illness within their life. Sometimes the attitude can be a bit fatalistic because many people think cancer is essentially a death sentence and for that reason, they might not be interested in looking into whether they have it in the first place at an earliest possible stage or trying some Western medical treatments for it. (WHP06)

Racism, whether intended or not, exists in our communities and perpetuates cultural barriers. This undoubtedly affects communication and relationships between health care workers, clients and their families. This racism has been acknowledged by these health care professionals.

There's the racism and bias in the health care community like the rest of the community. Inappropriate things are said that further erode trust. There's not a general welcoming of large families that might want to be present in small rooms usually with two or three other patients in them.

There are very few chairs to sit around, and you can see that the whole family is not welcome. They have policies like one person only can come in the room at a time and yet they have no other facility, no other room near the patient's treatment room for large families to gather. So they're sitting in the hallway and feeling like there's no place for them. (WHP06)

In educating our healthcare professionals we bring people in to speak because often the dilemma is that they don't understand the culture. It's not that they don't want to be sensitive. They don't know what to do and the not knowing creates a barrier for open communication and making that person feel welcome. On the part of the Aboriginal person, it can be interpreted that this person is maybe stereotyping me or discriminating against me because they're not responding to me. Whereas, it's more often that they don't know what to do. (WHP07)

These cultural differences will be further compounded by the fact that there exists a disconnection between Minobimaadiziwin and how Western medicine is delivered in larger hospitals. Anishinaabe people view Minobimaadiziwin as those four elements of life making up the whole person, and we caution against focusing on any one element in isolation. With that understanding, the manner in which conventional health care is delivered is in stark contrast to this Anishinaabe view of holism, and this has been recognized by some health professionals.

The Western medicine that's practiced in large, tertiary care hospitals tends to be fragmented into small, physical domains in the body. You've

got your heart specialists and now you're with the heart specialist or you've got liver cancer so you're in the GI unit ... That kind of focus on the physical part of you that's ill makes First Nations people uncomfortable. Even though that's a big thing that they have a breast cancer, it's a small thing in some sense because they're still thinking of themselves as the whole person. I think it sort of surprises First Nations people that the specialists and the doctors that come to see them are only interested in their breast cancer and the lump in their breast. (WHP06)

Some health professionals found it a challenge that Anishinaabe people do not question or pose concerns about our health care. They may perceive this as an unwillingness to participate in healthcare decision-making or as indifference. This health care professional noted that in her work, the communication with Anishinaabek is indeed different from that with non-Native patients.

There are specific differences that I notice between Anishinaabe people with cancer and non-Anishinaabe people, in the hospital setting. I find Anishinaabe people are very humble and they don't talk about it. They may with some of my Anishinaabe nurses, but I know from my experience that they don't talk about it. They're not ones to complain of pain or symptoms. They're very discrete and how they exhibit those symptoms and how they ask for relief. I'm not sure if that's because I'm not of the culture or when they're here, they're really sick. (WHP03)

Health professionals recognized that Anishinaabe people may not be as vocal in the medical context due to a lack of understanding of medical terminology, some other communication or cognitive barrier, or a message that is not clearly expressed. Some of these concerns were shared in the previous section focusing on the Anishinaabe perspective. However, problems regarding the manner in which the message is delivered imply that there is still work to be done to educate patients.

Sometimes people don't process things initially, or they're not in a space ready to understand. Sometimes, there are communication problems and they do not understand. It's possible that you can think you're communicating something clearly but maybe it's still not as clear as you think it's going to be. I've heard somebody say, "Why didn't anybody tell me I had X?" despite the fact that they had actually been referred to a specialist who treated X. (WHP04)

Similarly, both Anishinaabe participants and health care professionals acknowledged that there are many patients whose first language is not English, which results in a communication barrier. *Anishinaabemowin* is very much a part of everyday conversation for those who live in Anishinaabe communities on Manitoulin Island, especially among the Elderly. Therefore, the patient may not understand everything that is being presented to them when formal English and technical terminology is spoken quickly as noted by this physician.

There are communication barriers. Maybe the older people don't necessarily have good command of English, let alone the technical English that goes with medical language. I try to explain things in words that aren't

too technical and that can be more easily translated into their own vocabulary. I think I recognize that older people, especially, have English vocabularies that wouldn't necessarily include some of the terms that we use in medicine quite freely. (WHP06)

It may be that the amount of information being presented is overwhelming, and we may not be paying attention to details. It is also likely that Anishinaabe people whose first language is not English were not willing to admit they did not understand and did not ask for clarification. The health care professional could be under the impression that because they appear to converse well enough in English, they therefore can comprehend the information. In fact, the person may not process much of the information shared. It often becomes the job of health care workers or family members who are fluent in *Anishinaabemowin* to follow-up with those patients to fill in the much needed information.

Sometimes they don't even know what they are told because the majority of the people who we see are fluent in the language. English is their second language, so they prefer to speak in the language. A lot of times they don't really pay attention when they're told something, or they don't understand it [laughing], *mii gana batch ga kidgweh* [Translation: I think that's what they were saying] they will say [laughing]. I usually have to follow up and I work with the others to find the information with their consent. (IHP04)

The following comments reflect what Anishinaabe health professionals believe about fellow Anishinaabe being aware of, and advocating for, our own health care. Their comments imply that Anishinaabek have the ability to be aware of, and comfortable with, our physical bodies and to be willing to discuss this with a health care professional. For some Anishinaabek, the notion of *zhagwenmowin* [Translation: imposed shame] would have critical bearing on this, as well as our ability and willingness to question Western health care professionals.

They need to learn to speak up. They need to learn how to listen to their body and what their body's telling them. They need to be paying attention to the symptoms that they have and have it checked out. (WHP05)

I find a lot of Native people won't question the doctor just because he's a doctor. I always tell my clients those are good questions. You should ask those questions of your doctor. If you don't feel good with that doctor, go see another doctor. You get a second opinion, there's nothing wrong with that. You're not stuck with one doctor. There's a lot of Anishinaabek that don't question. They just do what they're told to do. (WHP08)

However, in order for Anishinaabe people to find this new assertiveness and to truly break down barriers between ourselves and physicians, trust has to be built and supported.

Trust

Western practitioners acknowledge that trust is a component of building successful relationships in health care. These physicians addressed the issue that Anishinaabe people can have a deep mistrust of the health care system which is related to those distal determinants of health where historical prejudices can be brought to the forefront of people's minds when they have cancer.

There is a mistrust of the health care system that might rear its head when people are diagnosed with cancer. If the outcome isn't as one might have hoped, people may think that it's because the health care system is not trying hard enough because it's a First Nations person or it's a mistrust of the treatment. I understand with the residential school experience that there are lots of reasons to mistrust the system. You've got a difficult situation with cancer, there are a lot of other lenses through which people will view the situation and it's a reminder of past sufferings. (WHP04)

I recognize the whole issue is of trust especially for people who date back long enough that they've seen their trust in the white culture misplaced many times, like residential school experiences and treaties that were not honored. I understand how important it is to try and build some trust between caregivers and care receivers, and that isn't something that you can expect just to take place at the drop of a hat. It's a relationship that has to be cultivated over a period of time and through quite a bit of effort on the part of the caregiver. (WHP06)

The Western practitioners also recognized the fact that much trust is put into a stranger's hands when Anishinaabe patients accept treatment in the hospital. This is an emotional struggle for some as it means giving up some of our freedom.

The trade-offs, I'm sure, are huge because what you're asked to do is give up a lot of your freedom to come over to a white hospital and trust Western medicine all of a sudden. Maybe they've tried to have as little to do with those guys as possible, then suddenly you've got this illness that could be treated and potentially cured, but do you trust them? There's such a long history of abrogation of trust that so many First Nations people have to deal with. Experience tells them not to trust, but they know that they have little choice if they want to give it a try, if there's a possibility that it could be successful. (WHP06)

We discussed whether we trusted our doctors or if we had faith in other health professionals. Anishinaabek felt either a loss of control over our health care decision-making or, conversely, that we had to take control over our own health care decision-making. These participants trusted their doctors' judgement, skill and expertise, but they acknowledge that this may not be the case for all Anishinaabe people.

We have to trust the doctors because they have studied this stuff. We continue to do what we were doing, but give them credit, too, because they know the quickest way to fix things. I think we have a problem where people don't trust doctors ... They've studied this one thing that they're fighting, the oncologists - that's their whole life. I think I believed wholeheartedly when the doctor said, "We're going to have to do this." I

didn't say "Is there any other alternative? Is there something else you could do?" They have gone through medical school, I didn't. (APDC05)

The doctor said she got it all, so I believe her. I trust her. This was the second surgery she did on me. (APDC02)

Some Anishinaabe health professionals may not have this same blind trust in their colleagues. This Anishinaabe health care professional stated that people should not feel intimidated by their doctors. They, too, are learning and as with anything else, there is always room for improvement.

They shouldn't be afraid of those doctors, and I think we have to tell those doctors. I don't trust my doctor; he's too young, doesn't even know I'm a nurse. When those doctors go to school, the amount of palliative care training that they would receive would only be maybe one hour because I've worked with [the medical school], and [national organizations] to develop competencies and the training that they're planning for these doctors. That's where I find out just how limited the hours are they have to go through something. So they don't know everything. (WHP05)

This participant's comment alludes to the importance of aspects of Minobimaadiziwin that are often overlooked, primarily the spiritual. Anishinaabek in this study revealed the relationship they had with Creation, and this relationship was often the precursor to their relationships with Indigenous practitioners or those who specialize in Indigenous healing/traditional medicine.

Relationships with Creation

Although not directly asked, Anishinaabek revealed how a relationship with all in Creation influenced their Minobimaadiziwin and the cancer experience. Those relationships with Creation include relationships with the land, plant life and animals on both a physical and spiritual level.

Anishinaabe people recognized the gifts that Creation presented us throughout the whole year and connecting ourselves to those cycles. Creation would present us with those gifts so that it would keep us in a good way. We'd gather all our medicines, our foods and things that would take us through the winter and each season sort of prepares us for the next. Indigenous medicine is about recognizing that and tapping into it and making it a part of life so that we're always in some sense of balance if we're connected well to Creation. (IHP06B)

Our people are looking for those relationships we once had with the land, with the medicines. If you think about it every plant and tree out there is medicine. They'll go to the tree and offer some tobacco and explain to the tree what we're doing and why we're taking that bark, how it's going to be helping. What happens is that spirit, that medicine comes with us and then we begin to connect with that medicine. That's the difference in healing from our perspective because we connect with the spirit of the plants, the trees and everything else. (IHP08)

IH/TM involves asking the spirits and medicines for assistance. In essence, a person cannot receive help unless they ask for that help. When participating in IH/TM, the Anishinaabe participants recognized the importance of asking for this help and acknowledging that every living thing has a spirit.

You ask that Indian medicine – to help you. When you pick, you lay down your tobacco, and you ask for to have this drink. You tell them what you want that drink for, to help that part of you. (APDC09)

Many Anishinaabek alluded to our relational way of being when we spoke about IH/TM. For them, it was never just the physical medicines. To the Anishinaabe, this way of being encompassed spiritual work that included ceremony, which can be as simple as laying down your tobacco and acknowledging the spirit of those medicines and thanking the Creator.

You have to include the spirit, so that means the Creator is first in everything that you do. *G'Zhe Manido wii nii ga nii* [Translation: merciful, forgiving, loving Creator, spirit of all living things, has to be the one in front, the lead, first] with that tobacco. Tobacco goes ahead, so always that. (IHP07)

Jan Kahehti:io Longboat referred to the many natural doctors Indigenous peoples rely on, including traditional foods we eat, and how they are important for maintaining the connection to Creation (personal communication, January 5, 2012) and, thus, for Minobimaadiziwin. This may also include the physical work required to harvest such foods. For Anishinaabe people, it was always important to eat traditional, natural foods

including berries, wild rice, wild meat, fish and maple syrup. These foods are available locally, in-season, and serve to protect us and prevent illness. The following comments reflect this notion of food as a natural doctor but also our inherent Anishinaabe relational way of being.

There are things that we've always believed that cleanse your body. Deer meat is very healthy. However, my granddaughter, her spirit protector is the deer, and it's like eating a relative if we eat venison. So we don't eat venison anymore; or moose because they're closely related. Whitefish is a medicinal food, a healthy food like blueberries. When we were small, they weren't called medicine but they were good to eat, healthy to eat, it was *nishin* [Translation: it is good] to eat blueberries, *nishin* to eat whitefish; *nishin* meaning good. I think they strengthen the inside of you but they also connect you to nature. You become part of what's out there. The earth heals and cleans itself regularly when the thunders go by, so when it heals itself it also heals you. You're part of the earth so eating the natural foods, like from our area, you become one and you become part. *K'bezhigwameh* [Translation: we are all of one spirit/stand united] and you become one. *Gdoni-bezhigwa-meh-keh* [Translation: we are all of one spirit united with the earth on which everything lives] with, *Bemaduk* [Translation: that that lives amongst us around us in our midst]. You become one with anything that's alive out there. (APDC05)

We tapped 200 trees and it's basically nothing but work. The work lasts a couple of weeks and depending on the year, we get three gallons of syrup and other years we get 25 gallons, but it's a gift so you never question the amount. I think it's medicine because there's something in that syrup that I need. It makes sense to me because for thousands of generations, people depended on it as a food source. I think that it changes us way down deep inside, maybe even at a subatomic level or something, but there's something in there – in the wild rice, the deer meat, the moose meat and the berries. There's something in there that we need. (IHP01)

Anishinaabe people believe that part of connecting with Creation also involves being open or receptive to spiritual messages concerning Anishinaabe *gikendaasowin*. We shared that our dreams can be a source of Anishinaabe *gikendaasowin* concerning IH/TM. Dreams or visions could involve knowledge about the medicines themselves and how to use them. The Anishinaabe also believe that our dreams can be a conduit for connections to loved ones who are now in the Spirit World.

I dreamt about a good friend of mine who passed away last year, Joe*. He was really traditional. I dreamt about him and he came to see me. Growing up they would say if you dream about somebody who is dead you should go to church, that was my first thought. Then it just dawned on me that Joe* came and told me what to do with that cedar. He was telling me what to do with the cedar in that bag. What I did was, I went back to the trees over here in the cedar trees and I put tobacco down and said a little prayer. I said, “*G’Chi miigwech* for Joe* coming to visit me” and then I put

tobacco down. I put back the left over stuff and I felt really good after that.

It's kind of weird, he didn't tell me what to do, but I knew what I was

supposed to do. (APDC01) **name has been changed*

An Indigenous practitioner shared the importance of dreams and how Anishinaabe *gikendaasowin* comes through dreams. He spoke about the fact that IH/TM was never experimental. Healers were presented with knowledge from the Creator about the way to combine medicinal ingredients and which plants to use for illness.

Our people were smart. They were shown a lot of things through dreams.

They didn't go around eating this plant, eating that plant and mixing this

plant, just to see what effects it would have on you. They were shown

these things through the Creator, through their dreams. I used to listen to a

couple of men who were Indian doctors. They explained where they got

this gift, how they got it, what they went through to get this gift. They

would call on the spirits they dreamt about to help them doctor. (IHP02)

Participants have shared that in addition to being a medicinal food source, animals can also carry messages about Anishinaabe *gikendaasowin* concerning health and IH/TM.

One Anishinaabe-kwe shared that at the time of her cancer diagnosis, she had a visit from the black bear, her spirit protector, who provided her with certainty that she was going to be fine.

There was this bear on the side of the road. When it turned around I saw

white markings, like it had a shawl on. It turned around and looked at us

and I said, "*G'chi miigwech, g'chi miigwech waa biidwe in* [Translation:

thank you, thank you for (in the future-don't know what's going to happen) you are going to bring to me] whatever it is you're going to bring me or you're giving to me." When all of this was happening, I kept thinking about that bear. We're of the Black Bear Clan, so when I saw this bear, one with such markings, I knew something good was going to happen. He was bringing me *wen ji zhing gii bii dok* [Translation: the best product/highly prized was brought to me, specially delivered] *wen ji zhing* [Translation: the best product/highly prized]. It could be health, anything good. That night after the diagnosis, I thought about that bear and I said, "Ah, that's what you were bringing me." Everything was going to be fine. (APDC05)

This Indigenous practitioner shared how he used the Anishinaabe *gikendaasowin* he acquired, as a young man, from the beaver and incorporated it into his cancer medicine. His cancer medicine was developed throughout the course of his life.

When I was a teenager I was hunting and I trapped this beaver. I looked at the beaver when I got home. He had all these little lesions on his back, cuts and in those cuts there was that scent gland. They were using it for healing purposes. This is how I learned that these glands were good for healing. I learned about the beaver scent glands from the beaver, I knew right away that was good for healing, so I incorporated that in the cancer medicine. (IHP03)

Some Anishinaabe participants used IH/TM for cancer treatment, but many others employ IH/TM in our daily lives as a way to achieve Minobimaadiziwin and maintain this connection to Creation. The significance of this connection to Creation and spirituality is often accepted by Anishinaabek who seek help from an Indigenous healer.

Relationships with Indigenous practitioners

We discussed the relationships we had developed with Indigenous practitioners and how this facilitated Minobimaadiziwin. Indigenous practitioners can be anyone in their circle of care who works from the Indigenous perspective (i.e., healers, traditional helpers, traditional coordinators, Elders, family members with Indigenous knowledge and other knowledge keepers, etc.). Several well-known Indigenous healers from northeastern Ontario and the United States have maintained a positive rapport with Anishinaabe participants. These participants described their experiences with Indigenous practitioners as positive.

I've heard of IHP05 before. In fact, my aunt went to see him way back when. He's been around for a while and he's a really good guy. He's done wonders for my girlfriend. She's way better than she was, now she's a more happy-go-lucky girl – the girl I used to know. It's nice to see. I'm trying to get my sisters to go see him. (APDC09)

I went in the sweat lodge. I said, "I don't even have a clue what to do here and you know me, I'm asking." I didn't feel shame asking questions. I could ask any questions to any of them in the sweat lodge. He explains everything and he's not pushy. I did not understand some of the processes,

and he said that was not a problem. He was patient in explaining and I never felt bad because I did not understand them. I had a very comfortable feeling and I had full trust in that. (APDC10)

A testament to the healer's ability is often a personal recommendation from those they have helped. Those who have worked with healers refer to their power or strength, which has everything to do with belief in IH/TM, Indigenous healers and whether IH/TM will be a part of someone's circle of cancer care and healing.

He is strong or powerful. We have one word for that, *mpshko zii* [Translation: an energy that is alive within a living being that shows itself in the strength it provides] which means both strong and powerful but in English it sounds almost aggressive when somebody's powerful, it's almost a negative. In traditional medicine, when they're strong or when they're *mpshko zii* that means they can fix and take care of you or know what's wrong. (APDC05)

Trust was a component of meaningful relationships with Western health professionals and Indigenous practitioners alike.

You have to believe in IH/TM and trust the healer

Most participants, even those who did not use IH/TM, stated that IH/TM requires a belief in the medicine as well as trust or faith in the healer with whom you are working.

I am a firm believer in the Big Drum. I have seen a lot of miraculous things that the general population would not believe. I have seen it and experienced it, so I know it works. (IHP01A)

To me, what Western medicine can't do, our own medicine people can. I think you have to trust and you have to have that faith in that healer, that's the most important part of it. (WHP05)

The Anishinaabek in this study ascribe to a variety of spiritual beliefs, which had a direct impact on whether or not they believed in IH/TM or Indigenous healers. Generally, we trust and value traditional medicines even if we do not use them in our own cancer journey.

I think I tend to believe it. Before these doctors came along there had to have been something there. (APDC06)

I have trust in them, and that's the reason why I take them. I always believed in Indian medicine because that's what Anishinaabek relied on all the time, a long time ago. They didn't run to the doctor whenever something was wrong. Even in the Bible it states that God put herbs and medicines on this earth for our healing, so that backs up Anishinaabek medicine. For every kind of illness there is, there's medicine, that's what the Anishinaabek used to say a long time ago. So I believe them, when they say that. (APDC08)

We spoke about trust and the level of comfort with practitioners providing Indigenous healing. As in all facets of life, we cautioned that not all who claim to be healers are legitimate or trustworthy, and they can have the potential to hurt other people. As a result,

the patient has a responsibility do some research about the healer, as this Anishinaabekwe can attest.

If I see a sweat lodge, I have to trust it before I go in it because I've been in a couple where we just absolutely froze in there and this was a sweat lodge. In one, the Grandfathers wouldn't heat up, as hard as the men tried, they wouldn't heat up. We found out much later it would not have been a good thing to go in. If people go in there for a joke or fraudulent means, it affects everybody. (APDC05)

One knowledge keeper cautioned that things can get complicated if the healer who is giving advice is dishonest.

When these traditional healers recommend things, if they're not honest, they can hurt people and their families. What these fakes don't realize is when they do stuff like that it goes back on their families, their kids. You had to be almost fluent to be a healer because one mispronunciation of a word changes that whole meaning and you could hurt somebody. (IHP02)

He stated that there was a time when he would have gone to a healer and done everything that was recommended, without question. Now, on the rare occasion when he seeks the assistance of a healer, he will do a thorough check of their reputation. He will seek help only from people he really trusts, especially for something as serious as cancer.

Sometimes seeking out an appropriate healer is a matter of looking beyond your own community, because we do not necessarily value our local healers if we know a little too

much about them personally. This can necessitate seeking assistance from outside healers.

I think we have to bring in outsiders because you are never a prophet in your own time or in your own place. They're going to remember that you skipped school or you tripped somebody playing hockey when you were in your early teens. It's too close of a community that we don't forgive each other. (APDC05)

Another participant shared that she discontinued her work with a healer, not because of a lack of belief in IH/TM, but because of a lack of trust in that particular healer. He was a member of her community, and she shared how others in her community influenced her decision.

Knowing probably the kind of life he's led. He didn't lead a very good life. They said that he was a self-appointed traditional person, and to me, you earn that. When this guy started, there were some older people still alive at the time, "Who does he think he is?" they said. I don't know what they knew that I didn't know, but these are old people that I'm talking about, they know. (APDC06)

In addition to speaking the language fluently, a healer should be able to tell you where, and how, they acquired the gift of healing. This Indigenous practitioner explains:

These medicine people, every time they start doctoring somebody, he's got to say in Ojibwa where, and how, he got the gift. The next guy comes

along, he's got to explain again, in Ojibwa, where and how he got the authority to do that, with each one he does that. (IHP02)

Investigating by asking other people who have worked with the healer in the past is recommended by many. The Anishinaabek often have good habits of checking things out before committing to what has been offered.

When I finally decided to go that healer, I'd heard about him and I had to check him out first, of course, so that I would trust him. You don't go just to anybody or just because somebody said you should go see this healer. I won't do that. I want to know about that person from what I hear from other people who have been there. (WHP05)

Just as Western medicine has regulatory bodies to guide its practice, IH/TM also has systems of regulation. There is a community-based system of regulation that has been in existence for as long as medicine people have been doctoring. There are those healers who are considered effective and safe. There are also those who are considered dangerous and have little credibility. People can depend on this informal regulatory system when looking for a suitable healer.

Now, you better speak Ojibwa better than I do, and I'm pretty fluent. You better explain to me where you got your gift and how you got it before I start taking your advice. I haven't been to a medicine man in twenty years. I am going to check you out and believe me, people like Sam* and myself and other '*Shinobs*, [Anishinaabe people] we have a whole network,

people of different communities, and we pretty much know who's who and who's not. (IHP02) **name has been changed*

Since there have been court cases involving the fraudulent or misdirected use of IH/TM, healers encourage those seeking help to thoroughly research any healers under consideration.

The ones out there who are fraudulent, they learn how to work the system and they're not really traditional healers by any means. The sad thing about it is that they have learned how to trick and fool the people. There are cases now of people who end up charged and are told not to do this kind of work anymore. One was banned from doing this work, but there are still people out there gullible enough to go and see him. To me, it's the fault of the people. They should be the ones checking them out, really checking out things. (IHP08)

Community support for IH/TM has been an important cornerstone in word-of-mouth advertising. Community members who have experienced the benefits of IH/TM became reliable sources for the Anishinaabe participants who used IH/TM. In many cases, we were approached by fellow community members about our interest in seeing a healer.

I heard about the healer through the Sheguiandah First Nation, where I was working at the time. They came to me and asked me if I would be amenable to having the help of a healer. They could provide it, and they were very sincere, the band members, staff, the Chief, everybody.

(APDC10)

Minobimaadiziwin is understood as including the notion of taking care of one another. The relationships we have cultivated in our communities have proved indispensable for those experiencing cancer.

Relationships with community

Many participants acknowledged and shared the positive support received from our communities, including the children. This comment from an Anishinaabe-kwe illustrates how critical a sense of humour is in Anishinaabe communities.

The first time I went to visit the kids at the daycare, one of the kids said, “[Gasp] What happened?!” My co-worker said, “She fell off her bike.” [Laughing] So that was a good answer and that’s what I’ve been using. “I fell off my bike.” [Laughing] It was so funny, I had to smile. (APDC01)

At times, community support has been facilitated through social media. It has been a recent trend to post updates on our medical status or that of our family members who are ill. Many have posted fundraising efforts and messages of support. Social media has also become a source of support for many people who feel isolated through their cancer experience.

Something else that keeps my spirits up is Facebook. It sounds crazy, but it does. Throughout my cancer experience, I kept people aware of what was going on with me. Lots and lots of people care about me and my kids. Instead of them always having to come up and ask, I felt it’s better if I put a blurb on Facebook, so people would see and know how I’m doing. It’s

also good company for me. If I felt alone, I just had to go on there, and I could chat with all my friends that are on my Facebook. (APDC10)

It has been this collective support, in-person or online, that has made a contribution to much of the healing in our communities. These Anishinaabek emphasized that our communities, even with all their faults, form a collective spirit which is greater than our own. We can draw from this collective power when we need it.

We have to be able to recognize helpers in life because nobody is strong enough to do it alone. That's why I like being a member of this community with all its warts and assholes. It's all part of it. I believe the collective spirit is stronger than individual spirit. (IHP01)

Our way has always been the collective is more important than the individual, but we balance that. If you have a strong collective, we are well taken care of, but now we struggle because we've taken on so much of the outside. (IHP06A)

We shared some of the ways our communities have been sources of support during the cancer experience. This support was appreciated, and there was a feeling of collective spirit when least expected, as described by these participants.

Lilly* doesn't really know me, but she called just to see how I'm doing and what she can do to help me. She told me, "If you ever need help or need somebody to talk to, I'm here." She wanted to be supportive and she said she needs it too, that I'll be able to understand what she went through.

Ann* offered to drive me, but I told her you're going to be waiting all day.
"I don't care", she said [laughing]. You know how Ann* is. (APDC01)

**names have been changed*

It affects everybody. It affects your community. You don't realize your community is behind you all the time, but they are. When you need them, they're there. (APDC09)

Health professionals have also noted that there is a wealth of community support within Anishinaabe communities. One nurse, who has worked in both First Nation and mainstream health care settings, observed that people living in First Nation communities received better all-round care than others who did not live on a First Nation. She attributed this to the ever-present Anishinaabe community support.

From my experience, I find there are more community support services on-reserve than off-reserve. Sending someone home to a First Nation community on the Island as compared to CCAC, they will get better and more holistic care to meet the individual needs of that patient going to the First Nation community health service than they will in non-First Nation communities. It's like a cookie cutter approach to every patient. On a First Nation, it's what is that patient's needs, and the services are modified to meet them. (WHP03)

We have witnessed support that you just can't imagine. Sometimes we just need to make a call to the reserve to say that this is what we're faced with,

and this is what we need, and financially, the support, the transportation, the coordination, the community rallying, it'll all kind of get organized so quickly. (WHP07)

Anishinaabe participants and health professionals focused on future directions or recommendations which may help future community members with cancer. It was almost unanimously agreed that a cancer support group specifically for, and led by, Anishinaabek was needed on Manitoulin Island. We feel that the support group could be community-based and function as a place to discuss medical or practical issues like childcare, financial resources, drug coverage, travel, personal care or just to support each other emotionally. Although we may be reluctant to come out at first, we still would prefer this option when we are ready to talk to someone rather than to worry family members about our cancer.

I think that just getting together would help. I went to see Lilly* to find out about cancer. She told me, 'I had no support.' She didn't know who else had cancer, so there was no support for her. (APDC01) **name has been changed*

I hate cancer and I hate what it's doing to our community because there're a lot of people who have cancer now. Our community needs to be ready for this. This community is so big, it's getting bigger and it's not a healthy place. In the next ten years, I'm hoping that there's going to be a cancer place here too, where you can get things like social work. You need that

person to talk to. We need somebody that understands what cancer is.

(APDC09)

While participants shared that there was a need for more cancer support, we can still rely on those who provide informal support to others with cancer.

People who have cancer call me to talk or to vent, and I don't mind one bit. I encourage them to be positive, to find a positive and if they can't, I try and help them do so. I want to help others as much as I can now. It heals me and helps them. (APDC10)

I don't take that experience lightly at all. To this day it's remembering those Grandfather Teachings that anyone that seeks out that help, you do that, you open your arms and your heart to helping them. (APDC11)

Health professionals have also shared where they can see positive developments in the area of support and where further work is required for people on Manitoulin Island. They agreed that cancer support is an under-resourced need. A cancer navigator who could assist with services was suggested. At the time of data collection, the health care systems on Manitoulin and at the Northeast Cancer Centre were working collaboratively to hire an Aboriginal cancer patient navigator. They now offer this service through the Northeast Cancer Centre.

Community support notwithstanding, the family remains a source of support, love and understanding throughout the cancer experience for many Anishinaabek.

Relationships with family

We explained the role of the family in our cancer experiences and how family members helped us cope with cancer. Although we commonly received support from our families, at times some members of our families could not offer support. Finally, we discussed our changing roles within the family unit when experiencing cancer.

Sharing the burden of cancer with family

When diagnosed with cancer, participants went through a range of feelings including shock and disbelief. These feelings often extend to family members. The wife of one cancer survivor shared her experience.

We were grieving, too. This doctor told us, and we were just in total shock. I think we were like that for a little over a week, maybe. We just moved through life. For me, it was like I was under water, [crying] – because I didn't want to lose him. (IHP01A)

The majority of Anishinaabe participants in this study were women, and this fact has special relevance in the interpretation of the data. Being women, we often hold the roles of caregiver, matriarch or dutiful daughter and are often the source of support for others. Therefore, we had difficulty leaning on our families for support and worried about how this would affect their Minobimaadiziwin. Despite this, we felt it necessary to share the burden of cancer with our families. This Anishinaabe-kwe's words convey how she wanted her family to share not only in hearing about her cancer experience, but also to engage in her emotional response to it.

I was honest with everybody right from the beginning about how I felt. I wanted them to let me know how they felt, too. “Don’t keep it in, let me know.” I said, “I know you guys don’t like me talking about my cancer, but it’s good to share.” I opened up if they asked me how I was feeling. I would talk about how I was feeling that day. If I was angry, I would tell them I was angry, and I would say, “If you’re angry, tell me so we can be angry together.” (APDC09)

We expressed that it was important to be open with children, as well, and that honest conversations with children were best, especially when coming directly from the parents. This was a way to share positive messages about cancer, conveying the message that cancer can be treated. We recognized that denying them information is not really protecting them. In fact, as one Anishinaabe-kwe noted, the children need to learn about cancer. As with other types of learning, teaching these lessons earlier, rather than later, was considered to be the best practice.

I don’t hide anything from my kids. I told them straight out, “This is what it is.” I think they need to hear it, and I think they need to hear it from their parents as opposed to going out and hearing it from somebody else, “Oh, I heard your mom is sick.” They need to hear that cancer’s not a bad word. I look at my cancer as an ordinary disease that can be cured. (APDC03)

I didn’t tippy-toe around them with my cancer. I told them, “Mama’s sick. I’ve got cancer.” You can’t hide anything from them, and you’re not really protecting them by not telling them what’s going on. You’re teaching

them what cancer is and what it does. They're smart. I had a get-together, and that's when I talked to them. I just told them, "I'm going to get the stem-cell transplant and when I do, it's going to give me at least another 5 to 10 years with you guys. So you better smarten up and get your schooling done!" I've still got a lot of humor. (APDC09)

Other Anishinaabe-kweok [Translation: Anishinaabe women] found it difficult to speak to their families about cancer. There are a variety of reasons for this, but wanting to protect them from undue worry was very common. At least half of the Anishinaabe women I interviewed said that their families did not want to talk about cancer. Despite this, the women expressed interest in talking about their cancer experience with someone and also to continue nurturing.

I didn't want to [tell my family]. I am a very independent person. I didn't even tell my husband that I was diagnosed with cancer. I kept it to myself until it was confirmed. Then, the day I came home, I told him. I just kind of felt there's really nothing anybody can do at this point, and I'll just keep it to myself. (APDC08)

This Anishinaabe-kwe had concerns about how cancer might affect her family and how they would cope with this additional stress.

I think it's very hard on them. Two of my kids have anxiety issues, and I worry about what a stress this must be for them. I think that's why we don't talk about it. When I go for a check-up I just say, "Oh, everything's fine and everything's still the same and that's it." (APDC07)

Sometimes, we were reluctant to tell our families about the cancer because we did not want to become a burden and wanted to remain independent. We expressed that it was difficult to ask for help if you had been independent your whole life. It is not that family is not supportive, but the thought of being a burden to anyone weighed on our minds, as these women aptly described.

They just want to take care of me, and they wanted me to go live with them. But if I go to them, it's like I'm giving up and I'm going to let them do everything for me. I don't like that feeling and I don't want to be a burden maybe to them, they've got their own lives to live. I've witnessed a death in the family that was a home death with cancer, and I don't want that for them. (APDC07)

I think the hardest part is asking for help. I don't really want to put them out, and they have their own family and kids. I try to stay out of their way. But there are times when they're there for me. (APDC12)

The sense of worry extended to concerns about our families' Minobimaadiziwin after we are gone. It was revealed that some people tend to hold on when they should feel free to go out that Western Doorway. As we considered making this transition, we predict that our worries about family members could make this difficult.

You worry – you think who is going to take care of my kids? Who's going to be there for them, because they always come and see me, and we talk. When they need help, I'm always there for them. (APDC09)

Once we acknowledged this illness and were willing to share it with our families, we found that our families usually provided the support we required for maintaining Minobimaadiziwin throughout the cancer journey.

Support from our families

All of the participants shared that there were always members of their families on whom they could rely and in whom they found strength. These women felt fortunate.

I'm finding strength in my husband. He has given me strength. He does everything for me, and he's always just right there if I need him. He doesn't complain when I need him to drive, when we get up in the middle of the night when my mom calls. He's just there and he's my rock.

(APDC03)

I don't think I could have come through so much if it weren't for my sister. I was living back there in my own place, and she said you can't stay alone anymore. She says, "You come and live with me. We'll be fine." I think she had to ask a couple of times before I finally thought about moving here with her. (APDC06)

Participants often involved family in decisions about health care, trusting their judgement and valuing their opinions.

We discussed it as a family, and we decided that the other treatments would be too hard on me at my age, so I opted for the pill tamoxifen.

(APDC02)

My brother told me, “Take any kind of medicine that they’re willing to give, whether it is traditional medicine, Western medicine or anything that’s available, use it.” (APDC13)

Indigenous and Western practitioners agree that family is central to a person’s support network throughout the healing process and in achieving Minobimaadiziwin. This physician describes how extended family members rally around the patient to provide support at the hospital and at home.

When you’ve got a Native patient with cancer in the hospital, the ward is filled with people. We try to choose rooms that can accommodate the numbers or to decrease traffic down certain hallways. There is a lot of rallying, especially when you hit that palliative stage – so difficult to manage at home. Yet, families are doing around-the-clock care because the nursing care that’s provided is limited. A lot of families step up and support by living with them or just taking care of them as a group. In general, I’d say it’s been a very positive experience to see the families interacting. (WHP02)

It is equally important for the family to feel like they are making a contribution to the person’s healing and wellness when healing involves IH/TM. This also helps the family to heal and feel useful, directing their thoughts to hope rather than despair.

I think for someone that’s sick, family is a support system. They support the ones who are sick by getting medicine, helping them in going to sweat

lodges, making sure there's somebody there to be a fire keeper, watching over things and getting things for that person. I think family is really important. (IHP08)

I encourage the family to participate in the ceremony. What I like to tell a family is this, "I'm involved with the client in giving a teaching, or I'm doing a ceremony. It helps me if the family members or supporters are observing what's going on because they'll see things I won't see because I'm so busy." So the family gets the sense that they're contributing. (IHP09)

While family involvement is generally welcomed, there are times when family support is not forthcoming. In the following sections, we share how some family members can unintentionally impede the quest for Minobimaadiziwin.

Family can be a source of conflict

Not all family members can provide the same level of support as others, as they may be dealing with their own personal issues or are not coping well.

I've got lots of support from my family, and we're walking this journey together, so we're all trying to make the best of it. One of my brothers can give me more support than the other, but that's fine because we don't all take it the same way, and we don't all react the same way. (APDC12)

My sister can't deal with emotions. She'll say, "Ah geez, I don't want to hear that." My oldest son, he's very emotional, he's not well. So, I try not to burden him. He's got his own medical problems that he's going through right now. (APDC06)

Indigenous practitioners shared that working with families can be difficult, especially if family members have not worked through their own personal grief about the illness or death of a loved one, compounded by other unresolved grief. This unresolved grief can be the result of historical trauma such as the residential school experience, issues of abuse or other detrimental effects of colonization that Anishinaabek have endured. This can be overwhelming for some people and may lead to avoidance of a loved one's cancer experience.

We found that they all handled the news differently. His sister Marie* cried for a few days. His other sister, she was always kind of negative, she handled it a different way, she stayed away. (IHP01A) **name has been changed*

You look at the model of grief, and family can go into all those areas. But because of our history as Anishinaabe people, we already have unresolved grief issues. When it's combined with this new grief, it's overwhelming for some of them. Some of them just shut down, some of them won't even partake in the care of the individual because they can't. (IHP04)

There can also be issues around honouring our choices and what our family is willing to accept when we have differing spiritual beliefs. It can be a challenge for family to accept our decisions if they are based on a belief system that is not congruent with their own.

I never had regret. In my mind, this way was right for me, and I was trusting in all that we are as a people, and I trusted our knowledge. I remember feeling that I didn't doubt what I was doing despite how some of my family felt. (APDC11)

It has been challenging helping the families to respect the person's wishes and what they want when they go out the Western Doorway because we have so many different religious affiliations. That's another source of conflict. I always remind people to listen to what that person wanted. I also tell people make sure you write down what you want. (IHP04)

Western practitioners concurred that family can be a source of conflict, especially around treatment decisions or with opinions on how palliative care should be approached. This can be especially apparent when larger families are involved. As this physician describes, some family members may not have participated in decision-making from the start, and this creates turmoil and provides a further challenge in achieving Minobimaadiziwin.

Sometimes the family can also be a burden. If it's somebody that's lived away and they parachute in towards the end bringing in their own feelings of regret that they hadn't been there more, they can add more turmoil. Maybe the patient and the family members have reached some decisions, and then the person who parachutes in has the attitude that, "You're not

doing enough for our parent” where they're addressing that emotion either to health care providers or to the other family members. Or, “You can't just let the person die” that you must try these heroic things even though it's not appropriate. (WHP04)

There are also situations in which family members intervene to the point of making a person feel disempowered. Participants in this study expressed that we did not appreciate feelings of pity or overbearing care that some family members displayed.

When I came home my sister practically tied me to the chair, and she'd say “No, you can't do that.” I'd say, “But I can walk.” And she'd say “Only in the house. Okay you were up 15 minutes, now go and lie down.” (APDC05)

They're here checking on me constantly. Sometimes my parents are telling me to rest too much. It's natural, but you get tired of hearing it. (APDC10)

Many times family members are unsure of how to treat a person who has cancer. They can become too solicitous and make you feel like an invalid, as this Anishinaabe-kwe related. She believes that that is one of the reasons why many people do not want to talk about cancer.

Sometimes family can be too solicitous. Being an independent person, I don't like that. I don't like that feeling of, “Oh you poor thing,” because I am not a poor thing. Maybe that's why people don't talk about cancer because everybody starts to look at you as an invalid or a weakling. You

can't do this or you shouldn't do that. Can you eat that? All of a sudden it's different, and I don't like that [laughing]. (APDC05)

An Indigenous practitioner shared that this excessive concern can make those who are on the receiving end feel guilty for having burdened the family. It is also easy to feel the loss of our independence and control over own destiny.

I think when they go into palliative care they may feel their loss of power, a loss of control over their destiny. A lot of times I've had people tell me basically, they feel bad about making people look after them, becoming a burden or a responsibility. (IHP09)

Related to this notion of responsibility, caregiver guilt was noted by one Western practitioner. She stated that there can be a shift away from Minobimaadiziwin if family are too focused on the individual with cancer, especially when a lot of care is required.

Sometimes people are able to maintain a good balance for themselves as a caregiver, and sometimes that kind of gets lost. They can get really focused on the person who has cancer and they maybe stop taking care of themselves. Guilt can be part of that where the person might be just intrinsically being too hard on themselves. "If I'm going out for a walk and other people see me, they're going to think badly of me because I'm not in the house taking care of my mother." (WHP04)

It was noted that longstanding roles within families can change when someone is diagnosed with cancer. In the next section, a cultural definition of the overburdened caregiver is discussed.

Apadaagigan and letting go of our caregiver roles

A cultural definition was provided for the idea of one person continually being designated to resolve difficulties or to take care of things on behalf of the rest of the family. In Anishinaabemowin this role is referred to as *apadaagigan*. This Western practitioner suggested that the family should be involved in the physical care of the person who is ill, rather than leaving that responsibility to one individual.

I think it is important to participate in the physical care. Involve everybody, not just one person being left to do everything. I think if you involve everybody and help, it seems to fall into place. (WHP05)

The Anishinaabe women in this study were often the matriarchs and or held the responsibility of being the designated caregiver. It was common that when we had to look after our own health, we often had to let go of this caregiver role. We had to learn to rely on other family members to take on this role.

My family really, really needs me. When I was sick, I had to turn them down. Even in taking care of Mom, I had to give the job to my sister, but she's doing a good job. (APDC01)

It proved to be a challenge for those appointed with the role of *apadaagigan* to delegate to others the responsibility of being a caregiver. This was often a necessity when we were too ill to continue fulfilling this role. This Indigenous practitioner explained what this term meant to her:

We found there was always one individual who was left carrying the load within the family. That person usually ended up becoming ill because the

family appoints this one individual to do everything [laughing]. The next thing you know, nobody is pulling their weight. We started supporting those people who are the key caregivers within the family unit.

Ezhigushkozut [Translation: to be heavily burdened] they figure this is a strong person and they can manage [laughing]. It's there in our language *apadaagigan* is that one who is designated in the family to take that lead all the time but you get exhausted. (IHP04)

We reflected on the role of “go-to-person” in our own families. Some happened to hold the role of *apadaagigan* and explained how this was impacted by cancer.

We lost our parents so they were always so used to coming to see me all the time to talk to me. I helped with a lot of emotional things that they were going through – my brothers and sisters. I was always there, and then I got sick. I'm seeing what it's doing to them right now. They've got lots of anger inside them about me having cancer. (APDC09)

He didn't want to tell his family because he didn't want to worry them, and I left that up to him. It's kind of like, his word goes. He's got 11 brothers and sisters, and he kind of raised them. (IHP01A)

Despite being diagnosed with cancer and trying to manage the care of her own family, this Anishinaabe-kwe provided as much care as she could for her mother who was in the palliative stage of cancer. She shared that it is challenging to hold this role while experiencing cancer.

My mom was just telling me on the weekend, “I like it when you take care of me.” If she’s spits up into the spit thing, I’ll go and wash it right away. When my sister was there, she just kind of sat there until I cleaned it [laughing]. But she’s got five kids and so she’s got a lot on her plate, too, and then trying to be with my mom at the same time. (APDC03)

This Anishinaabe-kwe also exemplifies what is referred to in the gerontology literature as the “sandwich generation,” usually women who are the primary caregivers for aging parents, but are still responsible for the care of their own children (Brody, 1981; Spillman & Pezzin, 2000).

Chapter 5 reflected on the influence of relationships on the person with cancer, specifically, relationships with Creation, Western and Indigenous health care practitioners, family and community. The participants shared a variety of language, cultural and communication barriers to achieving Minobimaadiziwin (i.e., well-being or balance) throughout the cancer journey. These barriers exist within wider systemic issues regarding Anishinaabek history with colonialism and assimilationist practices. These wider systemic issues, in turn, influenced Anishinaabe patients' relationships with and participation in Western and Indigenous healing. Participants shared the importance of community and family relationships, and challenges to Minobimaadiziwin stemming from these relationships. Anishinaabek felt supported by family and community. This support involved respecting and taking care of one another, which participants have related to the teachings of Minobimaadiziwin in the previous section. Chapter 6 will examine the influence of types of healing on the cancer experiences of Anishinaabek.

Chapter 6: Influence of Healing

A second influence on the cancer experience considered in this study was the type of healing chosen for the treatment of the cancer. The two types of healing depicted in Figure 10 are Indigenous healing/Traditional medicine and Western medicine, which are not mutually exclusive. As with the influence of relationships, the influence of the type of healing filters in and out of the cancer experience. Some people have used IH/TM throughout their lives and not just during this important part of life's journey. Thus, I have placed this in a separate chapter. The following discussion of the influence of type of healing on the cancer experience concerns accessibility and how each type of healing was perceived by the participants. The next sections focus on Western medicine's influence on the participants' cancer experience.

IH/TM and Braiding Treatments

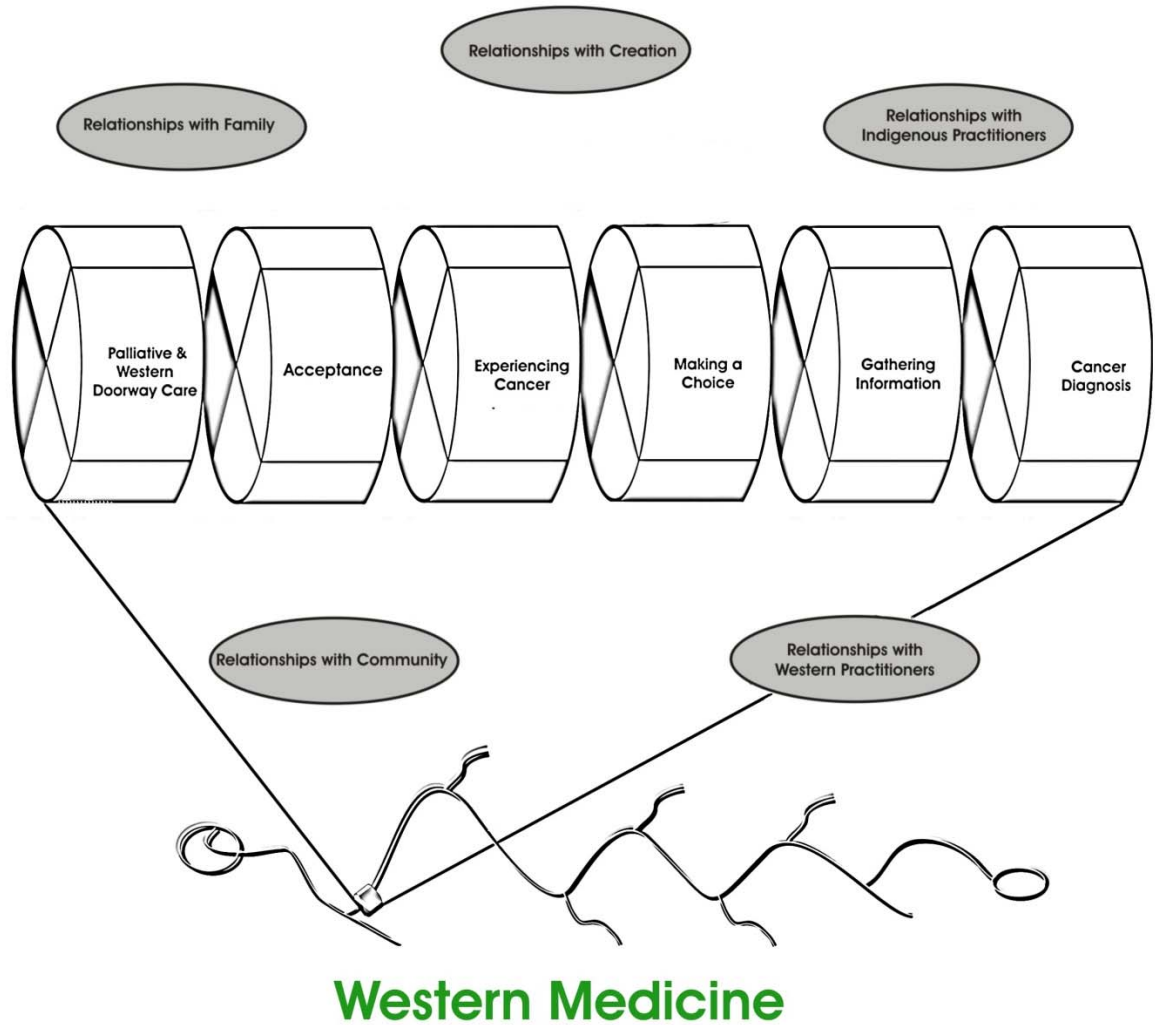


Figure 10: Influence of Healing

Western medicine

The participants discussed the experience of using Western medical treatments for cancer. Their stories provided commentary on the barriers to accessing Western medicine, as well as our perception of the treatment experience on Manitoulin Island and at the Northeast Cancer Centre in Sudbury, Ontario.

Access issues for Western medicine

Western medicine played a significant role in the cancer treatment for all thirteen Anishinaabe participants. However, access to Western medical treatments has been problematic for a variety of reasons noted by both patients and health care professionals. From the health care providers' perspective, barriers were identified in accessing: diagnostic services; specialist care; and in-home or hospice care. From the perspective of Anishinaabe people diagnosed with cancer, the barriers included: travel to treatment; availability of required medication at local pharmacies; and navigating government policies.

Who is responsible for our cancer care?

In order to begin the process of cancer treatment with Western medicine, one has to be under the care of a physician. However, both Anishinaabe participants and health care professionals have stated that it is not uncommon for Anishinaabek to be without a family doctor. It appears to be the case that Anishinaabek will access health care only when they are very ill and rarely in a preventative manner. However, once we are in the system of cancer care, we see a number of doctors or specialists. This Anishinaabe-kwe appeared to be unsure of who was responsible for overseeing her health care as a result of not having a family doctor.

I got jilted around from doctor to doctor because I didn't have a family doctor. (APDC12)

Some health care professionals feel that it is the responsibility of the patient to find a family doctor to oversee their care. One physician commented that people can be their

own barrier by not taking control of their own health. She encouraged Anishinaabe people to take control of their health before a health crisis. One of the ways she suggests is that we should demand consistency in our health care by requesting the services of a family doctor.

In my opinion, people are not taking control of their own health. There is a separation between Aboriginal and non-Aboriginal patients. It seems to be acceptable for Aboriginal patients not to have their own family doctor. I see that now because I do a lot of walk-ins and I ask people, so who's your regular family doctor? "Oh, I don't have one. I never really thought I needed one." Not that the family doctors are the be all and end all in any way, but we work as a team. A lot of the care and prevention comes through family doctors and comes through that consistency with somebody. When I see somebody in a walk-in clinic, I don't necessarily talk to them about preventing cervical cancer or ask did you do your mammogram? Did you do your colon screen? That's not the purpose of a walk-in clinic. People need to say, "You know what, I have a right to have a family doctor, somebody who knows me and somebody to advise me."

(WHP02)

Once in the system of cancer care, there have been difficulties in accessing diagnostic tools for cancer as well as access to specialists' services for residents of Manitoulin Island. With the plethora of medical professionals including the physician, specialists and other cancer care professionals, the question as to who should assume responsibility for overseeing cancer care is revisited.

Access to diagnostic and specialist care

This section reflects the experiences of health professionals working on Manitoulin Island and how Anishinaabe patients are affected. One barrier mentioned concerned wait times for diagnostic testing or specialist care for rural, northern Ontarians. On Manitoulin Island, we do not have access to CT or MRI technology. We are often sent to Sudbury for such diagnostic imaging services. The following comments reflect a disparity in services for those living in rural areas.

If you were admitted in a Sudbury hospital, you'd have that CT within an hour or two. Equipment like the CAT scan or MRI not being available locally is a challenge for quicker diagnosis. (WHP03)

We may have also experienced the issue of wait times and the triage process. This physician's comment alludes to a possible inequity in the allocation of service for those living on Manitoulin Island.

Waiting for beds, hypothetically, people should be able to access things evenly from across the region or system, but it's not our impression sometimes. I think a certain amount of shuffling with triage happens. So a person might have had their name on the list earlier, but then this other person is more urgent and so they go in. (WHP04)

This same physician further commented that patients may not be aware of the work that a physician is doing to get them into a specialist's care. She spoke about the attitudes of some cancer care specialists in their refusal to use technology that could increase accessibility or an unwillingness to take on patients without a tissue diagnosis of cancer.

It's been very helpful to have some specialists that can do things by video conference, but not everybody is prepared to do that. With people where you haven't got a solid diagnosis yet, it can be really hard to find somebody to accept them. You can be spending a lot of time trying to contact somebody and make your case of why they should take the patient. Different specialties may be thinking, 'Well, if I accept that person into my specialty service, then they'll be there for ages and there'll be less surgery I'll be able to do. So, I'll see them if they come in under medicine instead of under me, and then I can just go consult them and they won't be blocking up a bed of mine.' (WHP04)

This physician also shared that certain cancers can be complicated, especially when someone has been diagnosed with multiple cancers. She alluded to the fact that there is a gap in how physicians and specialists coordinate their care because there is no one person to oversee decisions about whose responsibility the patient is. This can create problems within our cancer experience, especially in the diagnosis phase where we feel most vulnerable.

It's really not very easy to get into the system without a tissue diagnosis, so that's a challenge. If you've got somebody who's got different kinds of cancers, sometimes that's a challenge. There may not be somebody that's comfortable overseeing the picture from oncology. Maybe they've had a bone cancer and they've had a this-cancer and a that-cancer. They get discharged from this person, and there isn't always somebody that's giving us guidance as to the big picture. (WHP04)

Upon being diagnosed with cancer, the next phase of the journey concerns cancer treatment. Anishinaabe participants have identified barriers in cancer care which included travelling to and from cancer treatment and accessing the required medication.

Travel to cancer treatment

At times, Anishinaabek have experienced problems in travelling to treatment if we lack financial resources or our own transportation. In order to access medical care, we often travel 30 minutes or more to the specialist clinic or chemotherapy provided at the Mindemoya satellite clinic of the Manitoulin Health Centre. Travel time may vary between two and three-and-one-half hours to access services at the Northeast Cancer Centre in Sudbury, Ontario. Some participants have been required to travel as far as Toronto for cancer treatment and consultation, which is more than five hours in travel time.

One day my sister said to me, “The hospital called. You have an appointment at Princess Margaret tomorrow morning at eight o'clock.” We were gone by 8:30 that night for Toronto. (APDC06)

My pulmonary hypertension was treated at Toronto General, so when my specialist found out I had cancer, he said, “I want you down here so that we can have close interaction.” They are right next door to each other; Princess Margaret and TGH, that's why I'm down there. (APDC07)

Anishinaabe patients are provided with some monetary entitlements; however, we must determine whether we are eligible for travel funding for health care. This funding must be

accessed through a multi-level funding system beginning with inquiries to our private or employer insurance plans, and then we proceed with inquiries at the provincial and federal levels of government. At the provincial level, the Northern Health Travel Grant Program (Ministry of Health and Long-Term Care, 2012) permits Ontarians to apply for medical travel reimbursements through the Ministry of Health and Long-Term Care. At the federal level, Health Canada – First Nations and Inuit Health Branch (FNIHB)’s Non-Insured Health Benefits Program (NIHB) provides funding for medical transportation (Health Canada, 2014), and this is administered through some First Nation Health Centres. This complex system is difficult to navigate, and we are often overwhelmed with the amount of paperwork involved.

The frustration with the current funding process was felt by some participants and is reflected in this comment:

Health Canada thinks they’re doing such a big thing. I haven’t even filled out a medical form in six months! I’m so tired, and they are cumbersome things that we have to deal with. You’ve got enough paperwork from your doctors to deal with, let alone do that! (APDC10)

This difficulty accessing funding for medical transportation (i.e., gas, meals and accommodation) is compounded when Anishinaabe clients are also unsure of what assistance is available. The information provided requires detailed reading and comprehension of complex and lengthy text to understand the many restrictions. This Anishinaabe-kwe stated, “I don’t even know what’s out there or what kind of service I could have applied for.”

In most cases, travel expenses were the client's responsibility and were to be paid out-of-pocket, with a possibility of reimbursement later. Information published by NIHB stated that it can take between six and eight weeks to reimburse expenses, and this is dependent on an accurate paper trail. This was an overwhelming process for those clients who were suffering from the effects of treatment. In addition, many Anishinaabek did not have the money to pay travel expenses upfront.

It's a problem if you're beyond the borders of the allowable place you can go to for health care. It certainly is a problem for me. On our reserve, you can get a medical ride only to Sudbury. When I go to Toronto, I have to pay for it. I have to apply for the Ontario travel grant. Then I have to get the driver who's going to take me there for that price. It's hard because some people will say that's not enough money for me to drive all the way down there. (APDC07)

For somebody who doesn't have the funds, there's the case of where do I stay once I get to Sudbury. When I was in the semi-private room, there was this Anishinaabe-kwe there from M'Chigeeng. She had surgery for her cancer. It was winter and the man with her said, "I had to sleep in the car last night; I was cold; I had to warm up the car now and again." He only had enough money to stay x number of nights, but she still needed more doctors' care. I thought that was sad. (APDC08)

The barriers in access were not limited to traveling to treatment. In the Western system of cancer treatment, there is the potential for required medication that is expensive, not covered through insurance or NIHB, and far beyond what most people can afford.

Access to medication: We're caught up in red tape

Even if the Anishinaabe patient is eligible for drug coverage, there is a lengthy process of inquiry. These entitlements must first be accessed through our personal health insurance plans, if available. The next level of inquiry would be through the federal government's bureaucratic process. Some of the drugs used in cancer treatment are very costly and may not be covered through our employer or personal health insurance plans or through NIHB. We also cited problems accessing required medication due to lack of availability at local rural pharmacies. This Anishinaabe-kwe shared her story.

I asked the pharmacy for medication, but they didn't have it, and they had to order it. They didn't have the cancer medication! I had quite a few medications that were prescribed for me. Then there was another one I had to go and get myself because it was only in Mindemoya and there was nobody I could ask to go and get it. (APDC01)

Another Anishinaabe-kwe had difficulty accessing a chemotherapy drug that was prescribed for her cancer treatment because it was not covered by NIHB. There was some delay in starting the course of drug treatment because her husband's insurance provider also refused to cover the drug which was classified as uncommon. NIHB's policy stipulates that they are a last resort payer, and this funding is only accessible if all other avenues have been exhausted. This Anishinaabe-kwe's story also demonstrates that some

patients are unsure of or uninformed about the appeals process. NIHB itself has three levels of appeal. A patient can be denied three different times, and NIHB estimates that a single appeal can take up to three months to process (Chiefs of Ontario, 2013).

They said that I had to start off with a chemo drug called Velcade. I was supposed to start that right away in September, but there was this great big block and Indian Affairs wouldn't pay for my Velcade. We tried to use my husband's insurance that he pays into at the school here, and they didn't want to pay for that Velcade, either. The hospital told me to come in and we talked about it. They told me that nobody was going to pay for the medicine. We didn't know how to go about appealing this. Mary*, at the clinic, called me back, she said "APDC09, the cancer hospital's going to take care of it for you. They're going to pay for it." So the cancer hospital helped me there. They paid for it – not our insurance. (APDC09) **name has been changed*

Some cancer treatments are inaccessible because they are expensive. If Anishinaabek have insufficient funds to find their way to treatment, it will be next to impossible to acquire funds for medication that is not covered by NIHB or private insurance plans. A second Anishinaabe-kwe found that she was not eligible for a particular cancer treatment. She would have to be financially responsible for those treatments, and it would mean spending her lifesavings to pay for them. She considered this but was only on the medication for a short time before she was deemed palliative. She shared her experience:

The last treatment that I took came down to funding. Who's going to pay for this? Do you qualify for this or not? This last treatment, which was

working at one point, was \$5,000 for 30 days of just one treatment. I only stayed on it for two weeks and then that's when I ended up in the hospice. They more or less wrote me off and said it wasn't going to work for me now. Sometimes, it'll boil down to thinking, okay, I might have a little money on the side and the doctor told me that this next treatment that we're going to try, I may not qualify for and it's going to cost so many thousands of dollars. Do I take my whole entire lifesavings and put that on the table and say this is it, do or die? But the way that things have been going, I will end up saving that money for my funeral. (APDC12)

A final accessibility issue identified by health care professionals concerned the challenges to providing care at the palliative stage of cancer on Manitoulin Island.

Access to palliative care at home

In terms of Western medicine and access at the palliative stage, there were challenges shared concerning the continuity of care on Manitoulin. Specifically, it was noted by this health care professional that it was difficult to keep up with the volume of people being discharged from the hospital to our communities.

I think the long term care is at its capacity with chronic illnesses across the Island in Aboriginal communities. It is a busy area here. The hospitals discharge people and they want them home. If people say I want to go out the Western door at home it can be challenging. The hospital will discharge them anytime, including weekends, and then you have to come to work and arrange all that. You've got to make sure all the orders are

done, so the person is not suffering in pain unnecessarily because the orders haven't been written. (IHP04)

Similarly, there have been issues raised concerning health care staff, expertise, and equipment for palliative care in the home on Manitoulin Island. These health care professionals commented on some of the issues concerning palliative care from the health professionals' perspective.

I've had First Nation patients that we're trying to get them home to die because that's where they want to die. But the system just isn't set up to be fast. We have to get the equipment, get the meds and get everything else in place. I will not send anyone home unless I know we're set up 100 percent. I know it's a challenge right now for homecare with the funding. The bigger funding bodies need to recognize our challenges as rural communities in trying to provide this type of care and trying to get the medicine in and trying to get the equipment in. Even down to trying to train and retain staff, is always a challenge. (WHP03)

There have been problems with trying to seamlessly access the CADD [Continuous Ambulatory Delivery Device] pumps for infusions for pain relief. There are logistic problems with that, not just for the Anishinaabe people. There have been discussions around, 'Are there enough nurses trained in the community to help the family with that?' Or sometimes, 'Is this a safe home to set the person up with this medication, or is there a fear that the medications might get diverted?' We are working on trying to

solve some of those barriers but when it's a rush, then that's a problem too.

Sometimes people suddenly decide that they want to die at home, and sometimes it's hard to get things in place fast enough to make that happen.

(WHP04)

In the following sections the participants share perspectives on what cancer treatment itself means for overall well-being or Minobimaadiziwin.

Cancer treatment: A trial and error approach

Some participants have expressed that Western treatment for cancer was not a cure, but a temporary solution that bought time. This Anishinaabe-kwe who was diagnosed with cancer had recently lost her daughter to cancer. She summed up her thoughts on Western cancer treatment.

I think that it serves its purpose temporarily, but if it doesn't lead to an overall cure, it just seems to be a temporary fix. Of all the people I've known lately who have died of cancer, they went through all that Western medicine, but it was only a temporary fix. As time elapsed, it seemed to recur in their life again and gradually it led to their final days and in passing. As far as Mnaamodzawin, it did do its job for a time for you to feel well again. I'm just thinking of my daughter. After she had all that, she went through a phase where she was just sick and tired, but then again she was well after a period of time again, until the next time. (APDC08)

Anishinaabe participants echoed this notion of Western cancer treatments buying time.

We opined that Western medicine was based on a trial-and-error process. We hoped the

treatments would rid us of cancer and were often willing to contend with the negative side effects of the cancer treatment. Some were willing to risk the side effects in hopes of a cure or reprieve from cancer.

It looks like a shotgun shell effect. They give them 20 different medicines, boom! It'll hit everything in the body, but there are side effects to each one of those. (IHP05)

In hindsight, there were others who have used the medicine and questioned whether the suffering from those side effects is worth the overall loss in quality of life. One person shared her mother's cancer treatment experience. She believed that if people had more information about the drugs being prescribed that they might not consider taking them because they would want the best quality of life for the remainder of their time.

I was taking care of her and looking through the list of prescriptions and then realizing they sent her home with a chemo cocktail. These pills have terrible side effects, they're wonder drugs, no doubt, but they have terrible side effects. You ask, what is the drug is supposed to do? What are the side effects doing? Do you think it's really worth it for the quality of life? I struggle when I hear people say someone died of cancer and meanwhile that individual was just going through a chemo treatment. I don't think you have to be a rocket scientist to figure out that maybe the chemo was that last kick that they could have done without at that stage. (IHP03A)

The lack of success with cancer treatments was terribly frustrating for some Anishinaabe participants, and Western medicine's overall worth was questioned. In terms of what

Western medicine has done for her Minobimaadiziwin, this Anishinaabe-kwe nearing the Western Doorway was frank.

When it comes down to the bottom line, it didn't help out at all because there is no cure for cancer. You lose all your hair and sometimes you're forcing yourself to eat and whatnot. For the amount of chemotherapies that I have been through, even the doctors are at their wit's end because they don't know what to do anymore. With regards to chemotherapy, the doctor tried everything possible, but nothing's worked. (APDC12)

In Anishinaabe teachings, balance has prominence in our understanding of the world. Participants also valued Western cancer treatments and felt that the outcomes of those treatments led to our Minobimaadiziwin.

Cancer treatment: A valued physical intervention

It is recognized that when we are faced with a life-threatening illness, it can be difficult to recognize or speak about the positives in our journey. Many aspects of Western medicine have been beneficial for Anishinaabe participants involved in this study. Before her passing, one participant demonstrated how appreciative she was of the care she received at both the Manitoulin Health Centre - Mindemoya site and the Northeast Cancer Centre. She held a fundraiser for the Mindemoya satellite chemotherapy unit.

People at the Cancer Centre are so great. They will help you, and you just need to ask because they have a plan for everyone. (APDC10)

Anishinaabe participants and health professionals agreed that Western medicine focuses on the physical aspect of a person's being and has both preventative and curative aspects

for cancer. Health professionals shared how Western medicine contributes to a person's health and Minobimaadiziwin. Gains have been made in preventing the progression of the disease for people who go for regular screening. There are also treatments that can potentially cure this illness. This physician highlighted some of Western medicine's significant contributions.

Western medicine has focused more on the physical. We have become much better at curing certain conditions, infections and things, so Western medical experts are good at figuring out what is wrong with people physically. We have intensive treatments to get people better quickly from many diseases that we couldn't have before, and in effect that improved people's well-being. In addition, we know that there are certain conditions that we can pick up at a very early stage by screening and preventative examinations and tests. If we can get people in to participate in screening programs, we can help them deal with illness at a stage when it's much more remediable, and we can prevent them from going through a lot of physical and emotional suffering of those conditions. (WHP06)

As this health professional attests, the treatment modalities employed in Western medicine have been validated against the gold standard of clinical trials in hopes that they will cure cancer or prolong life.

Western medicine is the scientific application of medication to improve a medical condition. When we think of treatment modalities, we're talking about surgery, radiation therapy, and systemic therapy. We determine which Western medicine works best for cancer patients, and it is done

through clinical trials. Through the scientific application of clinical trials drugs are tested for possibly curing cancer, prolonging life and improving quality of life for symptom management. (WHP07)

Even though Western medicine alone may not be the best fit for maintaining Minobimaadiziwin in our lives, we acknowledge that this form of medicine has great value. We recognize that Anishinaabe people have used and should continue to use whatever is available to them, along with the caveat that a person should be comfortable with those suggested treatments. There are knowledge keepers who value both types of medicine and acknowledge that Anishinaabe people may need Western medicine to prevent the spread of cancer. This practitioner stated that people need to be educated about the value of both Western medicine and IH/TM to permit choice.

We have to remind ourselves that our approach isn't adversarial but complementary to Western medicine. In fact, Western medical approaches will fit in our model. People who are looking for Minobimaadiziwin are encouraged to maintain the Western healing that they're receiving. We've forgotten so much about our medicines. In all honesty, it's helpful to say, "Okay, go and see a doctor who can prescribe this medicine for you because not all healers can remember everything that we use in this modern time." (IHP09)

Western practitioners reflected on how Western medicine is making steps toward delivering more holistic health care especially in palliative and end-of-life care services

on Manitoulin. Our health care professionals are working to ensure that we can maintain Minobimaadiziwin in the palliative stage of cancer.

I do know there is a big emphasis now on providing care within the home. On the Island, we have a symptom relief kit when there's somebody who's palliative in the home that the nurses can then access. It has all the potential treatments for those end-of-life symptoms. We've been trying to make positive steps to provide treatments to the physical being but provide it in an environment that is supportive to the whole of their well-being.

(WHP02)

It has been acknowledged by many that Western medicine is effective in many areas concerning our physical selves and that Indigenous healing/Traditional medicine promotes Minobimaadiziwin in other areas. This process of including both types of medicine has been termed "braiding treatments."

IH/TM and braiding treatments

We discussed our experiences with Indigenous healing/Traditional medicine (IH/TM) and how our cancer experiences were influenced by braiding IH/TM with Western medical treatments for cancer. In this section, Anishinaabe participants describe the phenomenon of IH/TM from their experiences. We consider the access issues for IH/TM. Finally, we share our experiences in braiding the two approaches.

IH/TM involves the Great Mystery: We don't need proof

IH/TM involves what some would term a spiritual intervention. This intervention can manifest in a variety of ways. For instance, a healer may have prior knowledge of things, before we have shared them. A medicine person revealed to one Anishinaabe-kwe that her treatment was not successful, prior to receiving this news from her doctor. There is often no scientific explanation for how IH/TM works. Anishinaabe people refer to this as the Great Mystery or the work of the spirits, as explained by a healer:

It goes in line with our traditional ways. The spirits did it, I didn't. That's the whole part of the healing besides the medicine that we incorporate into that type of situation. We call it the Great Mystery. We don't know how it works, but we know if we do these certain ceremonies, if we say these certain prayers and give this certain medicine that it works. It's all based on our tribal and traditional ways. This Great Mystery was given to us by the Great Spirit. We still have people that can count on and use that regularly. (IHP05)

This Indigenous practitioner emphasized that IH/TM has been a trusted method of healing for Anishinaabe people and must be accepted on faith. We do not need to know how it works, and we should not question it. Instead, we should be thankful for the healing received.

A lot of it is about your faith, your faith in that medicine and in the Creator. Just say thank you for your life and be grateful. Just say thank you to the medicine that you are here and don't question it anymore.

(IHP06B)

In response to the oft-expressed ideal of evidence-based medicine, this Indigenous practitioner aptly stated:

Most healers, if not all, would say we don't need to prove this. The proof is it works. Anishinaabek use it, it works and that's our evidence.

(IHP06A)

The Anishinaabek who employed IH/TM for the treatment of cancer shared with me about their many healing experiences. It was felt that the braiding of IH/TM with Western medicine facilitated Minobimaadiziwin. I have decided to share some of these stories in which Anishinaabe attributed their healing to the inclusion of IH/TM.

I had a healing experience. It was all these people who prayed for me. I went to Garden River for a ceremony, and my granddaughter was there for her buffalo dance. During that time, they also called for people who were ill. There were prayers from my church and from the traditional group who were having their ceremonies at the time. They had all this prayer going on, and then I went down to Toronto, and I couldn't have the surgery. They said it had kind of stopped, it hadn't grown or it was growing so slowly that I didn't need any medication. They'd just have to watch it. To me, I think that was a healing because cancer is rampant.

When people have it, it goes so fast through them. They didn't get rid of it but it brought it down with all the prayers and the healing ceremony at Garden River. The Creator said, "What in the heck is all this coming up here? All hero, hero, hero just for this one person, I'd better get busy and do something." (APDC07)

For the cancer in my head and liver I went to a traditional healer. He did the rattles and other things on me. He provided tea for me to drink which I finished and we did a sweat lodge. The liver tumour disappeared within 5 weeks. I couldn't believe it, neither could the doctor. I told them what the healer did and the doctor said, "That could very well have been. It's not there now." I knew I had beaten one thing and it made me stronger.

(APDC10)

The following participant is a survivor of brain cancer. She was in stage 4 when she left her home to travel west to see a healer. The healer and his family took her in and provided IH/TM. She was diagnosed with cancer two times in her life and for the second diagnosis of cancer she opted not to use Western cancer treatments. Instead, she asked her doctor if he would agree to monitor her condition. He was supportive of this and her decision to follow through with IH/TM.

I don't know how I survived that, but I don't question it. Only very few have understood that process that I went through in relation to the ceremonies and the medicines. I think as a people we need to trust in that. We need to trust in Creation because that's where our medicines come from. (APDC11)

An Anishinaabe healer shared the story of what he terms his most memorable cancer healing

I was in Toronto and this woman came to see me. She had a cancerous tumour in her brain. It was the size of a golf ball and in a position between

her brain stem and the mid-brain. With the surgery, she had a 30 percent chance of coming out of it with little damage. She was going to have some damage, regardless. We worked with her, and I said, “Well, why don’t you go to have the surgery. Let us work with it. Maybe we can make it less of a problem for you before you go to surgery.” So we gave her medicine and worked with her for four days. I left Toronto and came back to Minnesota. I remembered the day she was having surgery so the day after that, I called the hospital and they didn’t have any record of her. I just let it go and then I’d run into her and I asked, “Well, what happened to your surgery?” She said, “I haven’t forgotten you, but we were out celebrating and we’ve been celebrating ever since.” She said she went that morning for her surgery. She checked in and they did an MRI. A half hour later they came back and did another MRI from a different angle. Then they did one from the top, they did one from the back. Finally, she said, “Tell me what’s going on.” They had the MRI from the previous 17 or 18 days where it was a little bit bigger than a golf ball and that day that was smaller than a pea. That’s how far down the spirits got it when we were working on her. There was hardly anything there and she didn’t have to have surgery. She never had the problem with headaches and the brain problems anymore. The spiritual work that was done took that away from her. (IHP05)

This acknowledgement of the spiritual intervention involved in IH/TM is what some consider the component which facilitates Minobimaadiziwin. The following section

addresses how IH/TM can complement Western medicine to bring the Anishinaabe person closer to realizing Minobimaadiziwin.

IH/TM is more than a physical intervention

Anishinaabe participants and health professionals agree that IH/TM involves more than physical healing and can improve one's outlook on life, providing the confidence to continue with Western treatments, as this participant can attest.

That ceremony gave me confidence for the next part of my healing with the Western science, which was taking out my entire kidney. It felt like I had the spirits on my side, no matter what happened. (IHP01)

IH/TM helps to support the mental, emotional, spiritual and physical aspects of the person. These Indigenous practitioners explained how IH/TM assists in achieving Minobimaadiziwin through an activation of all four elements of our being.

There's a role for you to be part of your healing journey where you need to do some of those areas yourself. In the spiritual aspect, acknowledging your spiritual helpers and doing your own spiritual offerings. In terms of emotions, what are we doing to release some of the grief associated with illness or imbalance. Looking at the physical aspect, what are you doing to retain that physical wellness, exercise, walking and being as active as possible. In the mental, try to the best of your ability to think *naa naa gideh eh dum, naa naa gdeh ehn mowin* [Translation: taking the time to use your heart/feelings and really thinking in a logical way about of all the factors in order to come up with your decision] which is thinking

holistically, in our language. We use our mental capacity to think before we do things that could actually create the imbalance in our lives. (IHP04)

Anishinaabe healing is not just physical. Healing comes in many forms, at least four. We work with them to have them recognize that you don't just simply give up. You do what you need to do in all parts of your being: to heal physically, mentally, emotionally and spiritually. At the same time, you accept what unfolds on that journey. (IHP06A)

For some Anishinaabek, IH/TM is also about acknowledging our sense of self-worth, breaking down that *zhagwenmowin* and fostering pride in being Anishinaabe. It might involve endorsing who you are as an Anishinaabe person. Many Anishinaabe people who belong to the Midewiwin lodge go through an initiation ceremony, as this participant explained:

I was preparing for that ceremony to endorse who I was as Anishinaabe and seeking that life and that process. They had to do a sharing about what that ceremony was about, and it was being done in our language constantly. (APDC11)

IH/TM does not always involve the use of ceremony or medicines. It can involve the sharing of Anishinaabe *gikendaasowin* or teachings. This practitioner helps by changing the mindset of the Anishinaabek who seek healing. He frames this as improving self-concept. His tool is the *Miikaans* [Translation: little roads] Teaching. Problems with self-concept can affect all areas of life, including our health. As others have noted, holistic

thinking recognizes that deficits in one area will inevitably create issues or problems in other areas. The notion of improving self-concept as a goal of IH/TM addresses that internalized *zhagwenmowin*.

I guess the strongest thing I do is to have them be of a determined mindset.

I remind them of everything that can be used for healing, all the things at their disposal. Bare minimum, it's just to make someone feel better about themselves. I tell them the Seven Stages teaching so that they can have a reference as to how life could be. They can see that their life can be good.

We give them the whole picture. (IHP09)

Western practitioners acknowledge that Western medicine does not fully understand the connection between the mind and the body, where IH/TM may address the bigger picture, as these practitioners shared:

I think it provides a greater meaning for the individual. If they're only looking to rid themselves of a disease, that's only looking at a small part of it and Indigenous or traditional healings help to give a purpose to those other things. I think, potentially, there're a lot of impacts that we don't really understand. It allows for being able to see one's health journey as part of a bigger picture. (WHP04)

Traditional healing and healers focus attention towards more than just the physical aspect of people's health. They use traditional ceremonies, foods and stories to help people feel better emotionally to contribute to better physical healing. They use of tobacco, cedar, sweet grass and sage in

ceremonies. They're all brought into play in ways that honor the fact that a person's healing has more to do with their overall balance in their life than just killing off certain cells or fighting an infection or a purely physical battle within their body. (WHP06)

It is recognized that since IH/TM involves a willingness to work on all parts of our being. IH/TM is also understood as being a part of daily *Minobimaadiziwin*, so it is preventative in nature.

IH/TM is preventative and should be part of daily life

As the participants observed, once involved with IH/TM, we should continue with instructions given by a healer because IH/TM is never about an instant cure.

I learned through daily living, and that it wasn't just for this time. It was also ingrained in me to learn that you have to do this every day. It is not just once a week or for as long as 10 days as you would take antibiotics. It was ingrained that I have to do this daily for my well-being, for that *Bimaadiziwin*, that good way of life. These things don't happen instantly. I think that's what happens sometimes in our society. Western medicine is you take this and you'll get better, it seems instant. For our medicines, it's never about instant healing, because we're taught that our life is a journey of healing and that healing doesn't end. It only ends when you leave here physically. That has changed the way I look at sickness. (APDC11)

It addresses all of you, physically, mentally, emotionally and spiritually. It helps to put that into your daily life and you are encouraged to use it all of the time. Anishinaabe medicine is about incorporating or using it as a preventative tool. It will help with detoxifying in the spring or getting yourself ready in the fall for the cold and flu season and boosting up your immune system. It's about putting that into your daily life instead of waiting until you get sick. (IHP06A)

Striving for Minobimaadiziwin involves daily self-awareness and in order to heal, it will require work.

IH/TM comes from within and requires commitment

Indigenous practitioners emphasized that we are our own source of healing. The healers and helpers are there to facilitate the healing process that comes from us. This healing journey takes time, commitment, faith and, at times, a lot of hard work. There will be others like family and community to support us along the way, but there is work for us to accomplish on our own, as these participants expressed:

Ceremonies were a constant. For one of the ceremonies, there were tasks that I had to do. I remember working at trying to complete what I was asked to do and using whatever strength I had to do that within daylight. It was winter, so the daylight doesn't last very long. When I came home, I had instructions from the medicine people that I was seeing at that time. There were two men and two women that I was under pretty much

constant instruction and care by. I had to follow through, and it didn't stop when I left there. (APDC11)

I would say most, if not all the answers we seek are within us. Often, we look for things outside and we can receive help through helpers and healers, but all they do is bring it back to you. The healing that you seek, you already have that within you. We just need our guides, those Elders who have those good medicines and knowledge. (IHP06A)

As long as you feel like there's movement in your life, you're healthy. If you get to a point where you feel stuck, that's when you need someone to give you a push, and that's what the healer does. The healer doesn't necessarily heal you. He gets you moving again, he gives you a little push, maybe a ceremony, maybe a medicine so you move through life again and you continue on your path. (IHP09)

As one Indigenous practitioner mentioned, all Anishinaabe people have Indigenous knowledge. She concurs with other practitioners that our healing comes from within, and through use of IH/TM we can come to depend on what she calls "ancestral knowledge" or what others have termed "blood memory." It's about bringing the knowledge of our ancestors into the present because we can't go back. Bringing the knowledge of the past into the present can happen in our dreams, it can happen in ceremony and when we continue to use IH/TM. Some Anishinaabek have retained cultural continuity and have been able to tap into this ancestral knowledge and Anishinaabe *gikendaasowin*

concerning IH/TM. There are others who have lost their cultural connections for a variety of reasons, and this has impacted access to IH/TM.

Access issues for IH/TM

Access to information about IH/TM was a common concern among the Anishinaabe participants in this study, and we explored the reasons this might be so. Many of these are the result of historical injustices or government attempts at assimilation, which caused cultural dislocation and loss. One Anishinaabe-kwe was clear that IH/TM was not a part of her belief system.

I was raised by nuns at the residential school. I always tell people culture and tradition won't save your soul – Jesus will. (APDC02)

Another revealed the injustice of having her First Nation status revoked and its eventual reinstatement, which allowed for a difficult return to her First Nations community.

I wasn't a Native for many, many years because somebody decided they wanted to make a decision on my life, wanted to control it (APDC04)

Through these injustices some Anishinaabe people have been disenfranchised and lost cultural connections over time. Participants who were not familiar with IH/TM because of this disenfranchisement and the resulting loss of cultural connections expressed interest in IH/TM, if provided a chance to learn.

I would probably be open to using it. Sometimes our medicine has been used in making Western medicine, and I know that. There may be some truths in, you know, using Native medicine. I'm open to try it. (APDC03)

However, even if we express interest, some do not know how to access IH/TM. A further concern was raised concerning the fact that many of the trusted Elders who held that Indigenous knowledge are no longer here to teach, as these participants described:

I don't know anything about it. I've never been to a healer or a medicine person. It's just not out there, and it's got to be out there for people to know about it. We need to be taught. I was never taught, and I do not see it being taught, not in my community. They say they live by tradition, and that but I don't really see it. (APDC03)

I don't know that many people who use the Anishinaabe *mshki ki* [Translation: healing powers of the earth/medicine]. The ones that I used to know, most of them are gone now so there's really nobody to ask. (APDC06)

There was a belief among some Anishinaabe participants that we are not being resourceful or proactive enough to learn about IH/TM. These participants believed that our communities may be small but are well-connected with resources that we may have not recognized. Some consider this way of thinking to be a 'cop out' or laziness on the part of the person who is refusing to seek out this information. The other explanation may be that people have succumbed to the assimilative processes of church and state over time, as articulated by these participants:

If people really wanted to learn, they would. It's a cop out. They want to try, but then there're churches and different things that are really hindering them. They're putting their own barriers up there. (APDC04)

It's part laziness because there are people, you just have to look. You just have to go and ask. You can go anywhere and you will eventually find someone. Everybody knows somebody in another community – the Indian world is not that big. (IHP06A)

Some Anishinaabe participants stated that we require assistance in accessing IH/TM. We have often sought this help in our communities through word-of-mouth, but it is also available through some of our health centres. When Anishinaabek choose to involve IH/TM in their healing journey, they learn how to acknowledge and use the medicines:

When you provide medicine, it leads to that spiritual aspect because you have to acknowledge the spirit of that medicine. It's the teaching for them because a lot of times our people have not even looked at their own medicines. They begin to understand the meaning of that medicine, what it's going to do for them and what they need to do to acknowledge that medicine. Our healing ways are reciprocal so we need to give and then we receive, so there's always that constant exchange. It's good to see that people are learning but unfortunate that they have to be ill to learn some of these things. (IHP04)

The key to accessing this kind of help from our Elders lies in asking and doing this in a good way. This knowledge keeper mentioned that we have to remember the Anishinaabe Seven Grandfathers Teaching of bravery and to use our voices to ask for help:

Asking for that spiritual guidance and for the person's helpers to assist in dealing with that illness *wii bagwa sen dung* [Translation: the act of asking

for something that may or may not be answered fully. You have no control but you ask anyway] that's when you ask, *kwii bagwa sen dum* [Translation: you ask for something that may or may not be answered fully. You have no control but you ask anyway]. You ask all of your helpers from your dodem. Ask them and they will come and help you. (IHP04)

Access to IH/TM can also be blocked by other groups, institutions or historical factors and a general lack of personal belief or faith in IH/TM. There are some Anishinaabe people who have questioned the underlying motives of the Western medical establishment, particularly the link between cancer treatment and the pharmaceutical industry. Some are concerned that Western medicine is being marketed as the only solution to a variety of medical problems plaguing Anishinaabe people.

I don't think anybody will ever know what cancer is. They're so close, but sometimes you almost think that our health care system doesn't want to find a cure because of how our pharmacies are going to be affected and whatnot. You hear all the horror stories on that side of the picture, too. (APDC12)

At a time when our communities are suffering with high rates of drug abuse, we have concerns about the increasing reliance on drugs for well-being. One healer shared a number of stories about how access to IH/TM is being blocked by major pharmaceutical companies and patents.

Our medicine and our philosophy are different, but we're bombarded by pharmaceutical companies that dictate the way even doctors treat their patients. These pharmacies and pharmaceutical companies throughout Canada and United States are multi-billion dollar businesses and they're not going to let anything threaten that. They say you've got to take this pill for the rest of your life. You're never going to get off this pill - that's a long time. (IHP05)

It was more or less my way or the highway, with the oncologist. Once I had said no to the tamoxifen, the door was shut. (IHP03A)

One healer expressed that it is challenging to host healing ceremonies or to teach community members about IH/TM in some communities, as some can be divided by their spiritual beliefs. In some communities, they are far more adamant about not accepting IH/TM, even if those belief systems originated with the Anishinaabe. Within such communities, it is apparent that the impacts of colonialism still plague us and that the influences of state and church are strong, as these healers shared:

We're so engrained with Western thinking. It's there and it's a colonialist mentality. Colonialism has a very strong hold on the people, and it's about power and control. (IHP07)

I went and did the sweat lodge up in one community. There are so many people that are brainwashed by the Church. Even though it was the Chief's property, somebody went over there and they cut the poles at the grounds.

He was kind of embarrassed to tell me, “IHP08, somebody cut the poles.”

I said, “We’ll just build another one” [laughing]. (IHP08)

Our people internalized shame or *zhagwenmowin* when we were told that IH/TM was taboo and fundamentally wrong. Anishinaabek are still influenced by these historical injustices regarding IH/TM. Those who practice IH/TM have mentioned that many who choose to participate do so furtively, for fear of unfair judgement by others.

I think the biggest barrier is the belief, *debwenmowin* [Translation: to believe in the truth]. Historical factors have caused our people not to believe in our ways. We have a high number of people that don’t believe in it. It goes back to *debwenmowin*. Sometimes people don’t believe in our own people at the local level. Or, they don’t want anybody to know that they actually believe in it so they hide it. It went underground, *bi zha gwen ma, zha gwen ma nishnabena* [Translation: learned shame, shamed Anishinaabe] they don’t want anybody to know, that shame, we are ashamed. (IHP04)

Some Anishinaabe participants differentiated between traditional medicines and Indigenous healing. Traditional medicines are still a part of the lives of many Anishinaabe participants in this study despite the fact that we may not have faith in ceremonies or healers. This quote from a participant speaks to this distinction:

I just don’t believe in it, nothing to do with ceremonies, but there’re times when I’ve taken Indian medicine, like *wiikeh* [Translation: a root that is described to make the earth sweet] if I have a cold or sore throat. The old

faithful medicine that my parents used to use was *Abzeechigun* [Translation: a medicine that corrects illness/brings you back to health/immune boosting]. There are still a few people who make it and I always manage to get a haul of it from somebody. I believe that *Abzeechigun* has healing powers for the kind of illness I might be experiencing. To me, it's certainly something that leads to well-being. It's been around for a long time and was relied on heavily by the Anishinaabek long ago. We didn't run to the doctors like we do nowadays. Our parents and grandparents did to the best of their knowledge, to try and make someone well again. (APDC08)

However, it was noted by Indigenous practitioners that the spiritual aspect of healing cannot be extracted from IH/TM and this too is *zhagwenmowin*. As one healer shared, the Creator must always come first in everything we do, *G'Zhe Manido aabidig wii nii ga nii* [Translation: merciful, forgiving, loving Creator, spirit of all living things, has to be the one in front, the lead, first] along with the offering of tobacco. Thus, the spiritual component is necessary for healing. Many Anishinaabek are returning to Anishinaabe *gikendaasowin* in their quest for Minobimaadiziwin. Much of the IH/TM has been lost, and some Anishinaabe people have had this knowledge and have only recently started to use or relearn it. This returning has been referred to as *biskaabiiyang* or a "returning to ourselves" (Geniusz, 2009, p. 9). The loss of cultural knowledge and the refusal to acknowledge the spiritual aspect of IH/TM can also be attributed to *zhagwenmowin* [Translation: imposed shame]. These Indigenous practitioners share the importance of "returning to ourselves:"

I started re-learning about all the plants that I was taught years before when my parents were alive. I hadn't really used them myself so I did not put my knowledge into effect. Native people seem to have lost their use of the medicines for quite a while. It's starting to come back now, and it's coming back to me all the medicine that my mother taught me. (IHP03)

In terms of our Indigenous healing, we're just starting to pick up our healing methods. All those historical factors came into play like if you want to be Native, you've got to be ashamed to be Native. The people won't acknowledge that spiritual, that *debwenmowin* [Translation: to believe in the truth] who we are as Anishinaabe people and the gifts we have. (IHP04)

Access to IH/TM and any chance of braiding can also be impeded by institutions or Western health practitioners and the health care setting, whether intentional or not. This ultimatum presented to an Anishinaabe person speaks to the unwillingness of some health professionals to open the door to braiding IH/TM with Western medicine:

I had a friend who was given the predicament, either you take this pill from me or you take your pathway of your Native medicine man.

(APDC12)

One health care professional stated that the hospital does not inquire if someone would be interested in IH/TM. She reasoned that not all Anishinaabe people would have those traditional values and that most people who were interested could access IH/TM in their

community. It might be problematic if choice is not provided at the outset, since the hospital is very often the first point of contact for Anishinaabe people and the Western health care system. This is what may be required as a first step for successful braiding of the two medicines. Her comment, however, suggests that other spiritual traditions are welcomed:

Not every First Nation person is traditional, so it's a really fine line to ask them whether or not they are. We'll ask, do you want a pastor in, do you want a minister, but we don't ask if they would like a healer or a traditional person to come in. (WHP03)

We have also realized that access may be limited by the availability of healers. We often travel to see these healers or request that the healer visits our community.

Our traditional healers are passing on. So much knowledge about those medicines is being lost. You're dealing with travel and for people who don't have those means it can be difficult. Sometimes all those things are still done in secret. (APDC11)

We are still learning and there're only little pockets of Elders that still have that knowledge about the medicines. There are only very few and to be able to access them or to even access those medicines is sometimes very challenging. (IHP06A)

Access to IH/TM may be limited by our communities who may sanction only certain healers based on personal experience or preference. Sometimes this community

authorization of healers is hindered by lateral violence within our communities. We tend not to value healers in our own communities, and by perpetuating rumor or gossip about them we discredit them and ruin their reputations. Anishinaabe participants in this study referred to a healer who is well-respected by many, but not necessarily by his own community members. These comments speak to the existence of lateral violence, where we can harm and oppress our own people, as we are oppressed:

I did go and see a healer but he was not able to do anything. By then I'd already heard that he was no good. I thought to myself, well maybe he just put something black in there, maybe he put ashes in that glass because I was hearing all this negative stuff. Knowing probably the kind of life he's led, too, he didn't lead a very good life. I heard that he was charging people money to do that. Mind you, I didn't have to give him any money.
(APDC06)

I just don't believe in it. I hear of this one medicine man and I've said that's the last person I would go to. Just judging him, I suppose, for his background. I just know of that person as a result of my conversations with other women. (APDC08)

In addition to considering community sanctions, recommendations or criticisms of healers, we also have to contend with governmental pre-authorizations in order to access medical transportation benefits. We may be deterred by the government's red tape in accessing IH/TM services. One healer disclosed how even misinformation can block access:

One of the places where I go the people said, “We need a referral to see a traditional healer.” To me, that’s frustrating, but people will come on their own, with their own monies if they have a belief in our ways. (IHP08)

Finally, fear is often expressed when we are facing an unknown and this can also represent a barrier to the use of IH/TM. Much like the fear expressed when facing a diagnosis of cancer, we can fear participation in IH/TM because it is something unknown.

Some people tend to think it’s no good – so automatically, they don’t use it. A lot of people just don’t understand it and people are scared of it. (APDC10)

This fear extends to worry about potential adverse interactions between IH/TM and Western treatments for cancer as this participant articulated:

I would consider our medicines, but I’m taking so much medication that I’m scared to take more stuff. It might not agree with me and I don’t want to cause any disruption with my medication. I actually did go to my nephew and he gave me this herbal drink for my cancer, but I discontinued that. I was scared to try extra stuff. (APDC07)

This Northeast Cancer Centre staff member recognized that there has to be respect for a person’s culture, but patients are still encouraged to tell their medical team any other medicines they are taking. Thus, the fear of adverse interaction remains:

We do recognize that there has to be respect for the person’s culture, so we encourage people to be upfront with the medical team if they are

taking medicines because there can be reactions with the chemotherapy.

(WHP07)

Indigenous healers have explained that people who are taking medication prescribed by their doctor need not worry about the medications interacting in a negative way:

Whatever they're taking from the mainstream is not going to contradict what they are taking from the healer because it's not the healer that prescribed the medicine, the spirits that prescribe the medicine so that's not going to harm them. (IHP04)

This can be difficult for some people to accept, especially if they have had little or no previous exposure to IH/TM and Anishinaabe culture. In order to address the access issues, to facilitate patient choice and to facilitate the possibility of braiding treatments, there must be communication and opportunities for learning.

Braiding cancer treatments

Anishinaabe people with cancer and health care providers working from both perspectives can appreciate the value of braiding IH/TM with Western medicine. The following quotes represent the three viewpoints of those interviewed regarding braiding treatments:

We're living in a world where these two are together and we've got to learn to use them together. They fit because of the era we're living in. The other thing, too, is that there're certain things that the healers can do and can't do. Also the doctors, there're certain things they give up on and the healers will fix. (APDC05)

We need them both because of where we are as Anishinaabe people. We also need that *Zha ga nash* [Translation: Western or white man's] medicine to arrest some of that disease. We need to use whatever is available to help us, as long as it's comfortable for that person. The reality now is that our chronic illnesses are high and as Anishinaabe people *gi no ndeh se meh* [Translation: shortage] we're still lacking some areas and some of those diseases are foreign to us. So we have to use some of this mainstream *mshki ki* [Translation: healing powers of the earth/medicine] like the chemo and radiation to eradicate that illness. (IHP04)

Absolutely plays a role. I can't tell you, though, to what extent it does because that's such a personal thing for people. I personally think people that benefit most are the ones that somehow find it within themselves to blend both forms of medicine. I do think they get something from traditional medicine that I can't offer them with my medical background, but I also believe I have something to offer that traditional medicine can't. I think people benefit best with a blend of the two. (WHP02)

It appears that involving both Western and Indigenous health care providers in the discussion has fostered successful braiding for Anishinaabek with cancer. We found that there are Western practitioners who support the use of IH/TM because it involves more than the physical healing. These doctors showed support by encouraging us to consider or continue our use of IH/TM.

In most cases, they were very receptive. The oncologist said, “Continue what you do traditionally. Continue with the traditional medicines.” She said “Oh, that’s good” when I said “I will continue to do this and do that, as I get stronger.” (APDC05)

I did talk to the doctor when I found out about my cancer. I asked if I could see a healer as I was going with this treatment. He said that, yes, I could and that’s why I use both of them. (APDC09)

One participant did have difficulty with her choice in braiding the two types of healing. This was mainly due to a lack of availability of common Anishinaabe medicines in the urban hospital setting. Although Health Sciences North does have a Medicine Lodge, the following comment from a participant indicates that information about the Medicine Lodge and associated services is required.

I was in the hospital and didn’t get a chance to put any tobacco down. I didn’t get a chance to drink any cedar or to wash my hands with cedar, nothing. I didn’t even have *Abzeechigun* [Translation: a medicine that corrects illness/brings you back to health/immune boosting] up there. (APDC05)

There were healers whose clients have shared that there are still health professionals who were reluctant or critical about the use of IH/TM. This suggests that dialogue between Western health professionals and Indigenous practitioners is necessary to build respectful relationships.

She was telling them she was going to see a Native healer; they were telling her, “Oh, you don’t believe in that hocus-pocus. You don’t believe in that witchcraft. That’s voodoo.” (IHP05)

A lot of times doctors don’t believe that you’re being helped. There are doctors calling traditional healers quacks, “What do you want to go and see that quack for? That stuff doesn’t work.” (IHP08)

The willingness to facilitate braiding depends on the messages that both Western and Indigenous practitioners convey and receive about braiding. This will involve information sharing, as recognized by this participant:

It’s not a question of asking if it’s okay, because the doctor knows nothing about it. Unless the doctor is an Indigenous doctor, they know nothing about the Indigenous medicine or the beliefs, nine times out of ten. For me, it wasn’t me asking him, it was me telling him, and they were very interested to learn. I think that there should be more communication about the medicine and healers and what it is they do. (APDC10)

This Indigenous practitioner was in the unique position of working with Western health professionals on a daily basis. He shared that his clients usually shared other types of medications they were taking, but if not, he encouraged them to do so. This practitioner recognized the need for open communication:

It’s important in that braiding that the communication is there. You don’t work in isolation especially around medications, and you need to be aware

of how one might work with another. You need to inquire and clients need to share some of the things they're doing before you suggest anything so you can help, not hinder. (IHP06A)

In an effort to foster successful braiding, we have shared cancer treatment plans with our healers also and have included them in health care decision-making. We have made collaborative decisions to postpone the course of traditional medicine until after systemic treatments were completed. As such, braiding can involve participants consulting with our healers regarding the optimal time to use IH/TM. Others have used IH/TM as preventative medicine, either prior to or after Western cancer treatments.

He told me if I was taking pills I wouldn't be able to take the traditional medicine. We decided to wait. I told my uncle to go ahead and make the medicine, then after chemo I could start taking it to help me. (APDC01)

I'm using both medicines because IHP05 did say that those two are all right. You don't have to just stick to one. You can use both to a certain point, but you have to ask your doctors first. I have asked the doctor if it is okay to take the Anishinaabe medicine, and I just started drinking herbal tea because when you're on chemo you can't drink herbal teas. (APDC09)

These Indigenous practitioners encouraged open communication with their clients about braiding for safety reasons – theirs and ours. Healers have mentioned the need to take precautions when braiding IH/TM with Western cancer treatment protocols because they

are cognizant of the harmful effects of Western cancer treatment on both the clients and themselves.

One of the things that we run into with traditional practice is that sometimes that radiation hinders us from doing what we need to do with the person. When they have radiation and chemotherapy it's a poison to us also. We take that into us. When our spirits won't allow us to do that because of the poison and danger to us as human beings, we back off, but we still pray for them, and we still do the ceremonies and help them as much as we can. In some cases, collaboration, we do what we can, and they do the therapies, and we have good results with that. (IHP05)

Part of the protocol is to know if they have taken chemotherapy.

Sometimes when we're working on people we ingest what we draw out. If they had chemotherapy or radiation they have to make that known, otherwise it will make me sick. I try and go before they have treatments.

After treatment, juniper helps to clear that out of the body. (IHP08)

Western medical professionals have facilitated successful braiding through a variety of means. The Manitoulin Health Centre has attempted to become more culturally sensitive by creating policies regarding IH/TM and providing education opportunities for new staff members. A conscious effort was required for acceptance of IH/TM in this health care facility, as related by this health professional:

New nurses that haven't had that experience, when traditional medicines are brought in they may say, "Oh, no, you can't take that medicine

because that may interfere” or “It’s not what the doctor prescribed.” This seems to be people’s first response unless they’re educated about our internal policy. If we haven’t educated, if that was missed in the orientation somehow then with smudging it’s, “Oh, no way! You’re going to set off the fire alarm!” (WHP03)

Regarding the use of traditional medicines in the hospital, the Manitoulin Health Centre has implemented a policy to address patients using medicine that is not doctor-ordered. They work on the premise of patient consent where they are requested to sign a form. In the Manitoulin Health Centre, the notion of personal choice is, at least, recognized:

We get them to sign the consent and we alert the doctor. I don’t think I’ve ever seen an instance where it’s been, you better not give it to them because it’s going to do this or that. I can think of times where the nurses were probably against it, until a year ago. This policy is here for a reason; it’s a personal choice. (WHP03)

Both the Manitoulin Health Centre and Health Sciences North have attempted to facilitate the braiding of IH/TM with Western medicine through implementing policies to permit smudging ceremonies and providing medicine lodges or spiritual rooms with exhaust fans. Specifically, Health Sciences North has also allowed for smudging in the radiation bunkers:

In terms of the spiritual aspect, we’ve certainly had a lot of ceremonies in the cancer centre. So people will request a ceremony in the radiation bunkers, as a means to cleanse the room and to feel that they are

comfortable in receiving treatment in the room. Those kinds of cultural remedies or practices are certainly encouraged. It's something that has to be integrated with conventional medicine. (WHP07)

Similarly, the Manitoulin Health Centre provides time for families to give cedar baths and attempts to accommodate large families:

When a person passes away we don't send them off to the funeral home right away. They can stay here for 12 hours. We wait for family to come. They're more than welcome to do cedar baths. They're more than welcome to smudge, and we have a spiritual room now. (WHP03)

Chapter 6 reflected the influence of choice in type of healing on the person with cancer. The chapter outlined access issues from the Western health professionals' perspective including discussion over who assumes responsibility of the patients' cancer care; access to diagnostic tools and specialist care; and accessing palliative care in the home. From the perspective of Anishinaabek, access issues involved: travel to cancer treatment; access to medication; and navigating government bureaucracy. For Anishinaabek, Western medicine was a valued intervention in this age of high chronic illness, but was also seen as focusing solely on the physical aspect, whereas IH/TM complemented their cancer care with its holistic, preventative and deeply personal focus outside of the cancer experience. The meaning of IH/TM for Anishinaabek was shared, as well as access issues for IH/TM. Barriers to IH/TM included systemic factors, historical injustices, and their own *zhagwenmowin* [imposed shame]. Despite these barriers, all three participant groups saw a benefit to braiding Western medicine and IH/TM. To their credit, the Manitoulin

Health Centre and Health Sciences North have both begun to implement change to be more accommodating of Anishinaabe cultural needs.

These initial positive steps toward the successful braiding of Western medicine with Indigenous healing/Traditional medicine will improve cancer care. Minobimaadiziwin depends on the inclusion of and balance among those four elements of our being.

Participants recognized that for Anishinaabe people, Minobimaadiziwin would not be realized with Western medicine alone. It is the inclusion of Indigenous healing, traditional medicine and recognition of our spirit that will foster Minobimaadiziwin.

Chapter 7: Discussion

This dissertation aimed to explore the lived experience for Anishinaabe adults of Manitoulin who braided Indigenous healing/Traditional medicine (IH/TM) with Western medicine and those who used Western medicine exclusively for cancer treatment. A secondary intent was to examine whether including Indigenous healing in this process brought Anishinaabe people closer to *Minobimaadiziwin*. In order to appropriately meet these objectives, I embarked on an Indigenous inquiry of two-eyed seeing using an Indigenous research paradigm and a participatory approach as my foundations. This Indigenous inquiry involved conversations with 30 individuals who shared an interest in the study. A conversational approach was appropriate as it honoured the oral tradition and relational nature of Anishinaabek people and also had the co-creation of knowledge as an objective. Specifically, this approach enabled an informal dialogue with the aims of sharing story while helping others. A meaning-making framework, based on Anishinaabe *gikendaasowin* concerning *Minobimaadiziwin* was employed to interpret the stories gathered and facilitated the co-creation of a collective story. This process of co-creation involved going back to the participants and the community advisory committee for direction and approval.

The collective story for Anishinaabe people concerning cancer and *Minobimaadiziwin* served to address the primary question posed, that is, what is the lived experience of Anishinaabe people with cancer who braid Indigenous and Western cancer treatments, and of those who use Western medicine exclusively. The story illustrates how Anishinaabek collectively viewed their cancer experiences with input from health professionals working from both Western and Indigenous perspectives. The reason for

this multi-faceted approach was to respond to the concern that there was a knowledge gap regarding the lived experience of Indigenous peoples and their use of Indigenous healing/Traditional medicine for cancer treatment (Maar et al., 2009; Struthers and Eschiti, 2004). The story and the resulting dissertation will be of assistance to those concerned with the improvement of cancer care and policy with respect to Indigenous peoples. The remainder of this discussion is focused on relating larger themes which transcend the findings to include the broader context of Indigenous health, specifically outlined in my *Theoretical Model of Two-eyed Seeing*. Since the study is concerned with the improvement of cancer care, several recommendations are presented, as well as observed limitations, strengths and future directions in this area of research.

In order to discuss these findings in a cogent manner while answering my original research questions, I return to my *Theoretical Model for Two-eyed Seeing* as a framework for discussion. This discussion will begin with a focus on the centre of the model; that is, with the cancer experience of the individual and the participants' understanding of Anishinaabe *gikendaasowin* concerning Minobimaadiziwin. This provides the foundational knowledge and insight into the remaining discussion on those larger themes within the collective story of cancer and the influences on this experience.

Balance and the path of life to Minobimaadiziwin

King, Smith and Gracey (2009) acknowledge that while most Indigenous health research has focused on non-Indigenous definitions of health, Indigenous peoples often have broader definitions of well-being that extend beyond the confines of physical health and illness domains. As such, the results chapters of the present thesis were structured around

a gifted teaching referred to as the *Miikaans* [Little Roads], Seven Stages, Path of Life, or Minobimaadiziwin teaching. The participants in this study viewed Minobimaadiziwin as being about balance and the ability to live well physically, mentally, emotionally and spiritually. They shared that one must work at maintaining a state of equilibrium in all four of these elements in order to achieve Minobimaadiziwin. Participants reflected on the interconnectedness of the four elements of their being, where a change in one area will reflect changes in the other areas of their lives. Other researchers have found that this concept of holism prevails in the Manitoulin Anishinaabek (Manitowabi & Shawande, 2011). The concept of Minobimaadiziwin provides a contemporary understanding of health and well-being, especially with respect to traditional healing (Manitowabi & Shawande, 2011). For my study, it appears that the Anishinaabek in the Manitoulin area continue to conceptualize Minobimaadiziwin as holism and balance. As such, this Anishinaabe *gikendassowin* serves as an appropriate teaching tool for health care providers. I believe it is important to emphasize that the concept of Minobimaadiziwin transcends the cancer experience and reflects an understanding of living well throughout one's life, prior to and beyond the cancer experience. For many participants, understanding Minobimaadiziwin also concerns the choices which are made every day in order to stay balanced and for one to remain on the path of Minobimaadiziwin (i.e., the Path of Life or Way of a Good Life).

Minobimaadiziwin had several interpretations which were articulated by participants in this study. Many Anishinaabek believe that this path and, consequently, one's life purpose, was collaboratively decided upon between the individual's spirit and the Creator prior to commencing the physical journey on earth (Appendix 12). This life path would,

at times, be complex, and thus would not be without challenges or obstacles to overcome. Manitowabi and Shawande (2011) also made the connection to this understanding of Minobimaadiziwin, specifically to the *Midewiwin* notion of a “path of life beset with obstacles and a state of unhealthiness” (p. 454). These authors extended this understanding to their participants’ recollections of the effects of colonialism on the present state of their lives and “the need to mitigate these powerful and contemporary forces undermining their way of life” (Manitowabi & Shawande, 2011, p. 454). In my study, I have taken the liberty of interpreting one of the “Little Roads” or obstacles as cancer. Cancer can be understood as a change in an individual’s path that must be, first, acknowledged and, second, overcome to achieve that state of well-being. Viewed as a metaphorical “fork-in-the-road” or as “a teacher,” cancer requires acceptance, choice and action in order for someone to achieve Minobimaadiziwin. My research furthers the current understanding of Minobimaadiziwin with the participants’ extension of the term choice and the concept of relationality or “living from the heart.” In this study, choice has been interpreted at four levels. The first level is the realm of the individual and the notion of individual choice in attempting to overcome this challenge of cancer. I contend that this involves personal responsibility in health care decision-making and health-seeking behaviour, but it also involves the concept of relationality and one’s responsibility to all of Creation. At the remaining three levels, choice is examined in an effort to mitigate the systemic structural barriers and colonial health policies which perpetuate inequity. Choice reflects the interplay between the distal-macro-social, intermediate- intermediate-social, and proximal-micro-social Indigenous determinants of health within my *Theoretical Model for Two-eyed Seeing*.

Choice and personal responsibility for Minobimaadiziwin

The level of the individual at the centre of the model is the first level of Minobimaadiziwin, and it relates to personal responsibility which, although not stated directly, can be inferred from several participants' comments in my study. The teachings I have been given also reflect this concept of personal responsibility for choices in treatment and how patients will interpret their cancer experience. It is believed that although every person has had a conversation with the Creator about his or her life path and purpose, the Creator gave each person the gift of free will and freedom to choose how they will live and follow their own path. This is succinctly stated in the Anishinaabe language by one of the participants as *kiingwa* [Translation: it's up to you].

From the perspective of Indigenous healing, the concept of personal responsibility is intrinsic. In IH/TM, healing is believed to come from within and requires time, commitment, faith and work. Some of the work involves finding a compatible healer. This involves seeking out those who have accessed Indigenous healing to get reliable recommendations. Once a healer is found, he or she serves as a facilitator or guide in the healing process. Anishinaabek can also rely on family and community, but ultimately, the individual is the source of the healing, through the person's spiritual connection to the medicines, their spirit helpers, and other aspects of their being. With IH/TM, one is expected to commit to change and to acknowledge one's place and relationships with all in Creation. This can involve re-establishing their relationships with the land and the medicines through a spiritual connection and asking the spirits for assistance. It can also involve eating traditional foods to strengthen the physical body and also their connection

to all of Creation. Many participants expressed that relationships with all in the natural and spiritual world are important to the Anishinaabe conception of Minobimaadiziwin.

Relationality, responsibility and Minobimaadiziwin

For Indigenous peoples, personal responsibility should always be considered in the context of relationality since changes are never isolated and will affect the lives of others. As mentioned earlier, Indigenous notions of health include balance, which “extends beyond the individual realm such that good health and healing also require that an individual live in harmony with others, their community, and the spirit worlds” (King, Smith & Gracey, 2009, p. 76). Striving for “the way of a good life” was also found to depend on how Anishinaabek treat others and is of great significance in the overall cancer experience. The Anishinaabek participants revealed that using the heart to guide one’s actions is one way of ensuring that one lives in Minobimaadiziwin and that this entails treating others with respect, love and kindness.

This interpretation relates to what other scholars have found concerning Indigenous peoples and the concept of Minobimaadiziwin. In her treatise on the health and politics of Cree *miyupimaatisiun*, Naomi Adelson (2000) alludes to personal responsibility in the Cree equivalent *miyupimaatisiun* “being alive well.” Her definition ties *miyupimaatisiun* to Cree identity and the significance of holding on to what it means to be Cree. Adelson (2000) explains that one has a number of responsibilities in ensuring that they are in *miyupimaatisiun*, as one of her Elder informants explained, “they [are] *miyupimaatisiun* because they lived the Indian way, which was good for them ... the people said that’s the reason why they were strong and healthy because they didn’t use anything from the white

man” (p. 59). In striving to be *miyupimaatisiiu*, the Cree ensure that they are able to: skillfully gather, hunt, and eat Cree food procured from the land, water and sky; learn precautions to stave off the cold conditions; and maintain the physical strength required to carry out tasks necessary to survive. There was great value in “maintaining the viability of the group through sharing with those in need” (p. 99). Adelson (2000) further remarked on the centrality of the spiritual relationships between the Cree, the animals that are hunted, fished or trapped and the Spirit World, for *miyupimaatisiiun* or “being alive well.” Therefore, *miyupimaatisiiun* is not meant to be interpreted as “individuated biological fitness or wellness, but is always contextualized within individual and community beliefs and practices” (p. 99). In a similar vein, Hart (2002) described *mino-pimatisiwin* in his work on an Aboriginal approach to helping. He holds that there are several values which one must exemplify in order to achieve *mino-pimatisiwin*. These include sharing, respect and treating every person as a valuable member of the community. Moreover, Hart (2002) addresses the idea of relationality through spirituality where he emphasizes the connection among all things, including individuals, families, communities, and the greater nation.

In my study, relationships among Anishinaabe participants with cancer and their health care providers, families, communities and Creation were acknowledged as being important in the cancer experience, and it was equally important to ensure that family and community members who support loved ones with cancer maintained their *Minobimaadiziwin*. More widely, I believe the notion of personal responsibility can extend to a broader, functional context. Rather than being taken as selfish and self-serving for purely individual wellness, the individual has personal responsibility to learn

to live in Minobimaadiziwin for his or her family, community, and all of Creation, thus exemplifying the collective good and for all Anishinaabek (Dumont, 2014). Gracey and King (2009) also highlighted an interpretation of this broader notion of personal responsibility in their statements, “Local communities, their representatives, and health committees should be encouraged to contribute to and take responsibility for their health (p. 72) ... [It is] also important to enable, train, and encourage Indigenous people to take responsibility for programmes and services that affect their health and for them to work closely with existing health care systems” (p.73). It is my contention that in choosing to employ both IH/TM and Western medicine for Minobimaadiziwin, and continuing to share these experiences with others, Anishinaabek are making strides toward empowerment and self-determination in the area of health care. They are bringing forth the Anishinaabe way of being to the next generation.

Buyx (2008) acknowledges that personal responsibility has often been criticized for its apparent imposition of blame on the vulnerable. She invites the medical community to include the idea of personal responsibility in their health care decision-making and posits a theory of justice known as solidarity.

Solidarity encompasses a sense of togetherness between the members of a specific society or community, reflecting multiple interdependencies between people ... people in a solidary system care for each other ... caring does not imply personal closeness rather the abstract idea of being part of a system deemed precious and important ... [it] entails elements of receiving but also of giving and contributing ... the obligation of each

individual to the whole ... Solidarity is a value that presupposes at least a certain level of agreement about the good life ... (Buyx, 2008, p. 872).

Although Buyx (2008) was writing specifically about the issue of personal responsibility for health as a rationing criterion for health care resources, I argue that these same principles can be applied to the importance of choice in the contemporary health context since they appear, at least on the surface, to reconcile with principles of common good, reciprocity and Indigenous understandings of Minobimaadiziwin. The decision to include Indigenous healing/Traditional medicine (IH/TM) in cancer treatment is an example of personal responsibility in seeking out health care that meets the specific needs of Anishinaabek. My findings suggest that for some Anishinaabek, IH/TM played a role in achieving a state of well-being or Minobimaadiziwin. It was expressed by many participants, Anishinaabek and non-Anishinaabek alike, that IH/TM served to address all parts of the person's being, the physical, mental, emotional and spiritual. Regardless of spiritual tradition, the teachings of Minobimaadiziwin are an undeniable part of the daily reality when coping with cancer and life in general. Also noted was the importance of these positive experiences being shared by Anishinaabek who have walked with cancer, in order to emphasize how they maintained Minobimaadiziwin. In this way, Anishinaabek become the caretakers of their teachings; they have personal responsibility for their own health – a component of Buyx's notion of solidarity. This follows Gracey and King's (2009) recommendation that "Indigenous people should be encouraged, trained, and enabled to become increasingly engaged in and take responsibility for their own health and well-being" (p. 71). In a broader sense, they are taking care of each other, honouring creation, and are "being part of a system deemed precious and important" for

the next seven generations. As Anishinaabe Elder Jim Dumont (2014) so eloquently states, “[our] lives are connected inter-generationally as ‘strings of lives’ connecting us to our ancestors and to those yet unborn.”

External influences on choice and Minobimaadiziwin

However, it would be imprudent to believe that the Creator’s gift to exercise our own free will to make such choices occurs without external influences. As discussed earlier, my *Theoretical Model for Two-eyed Seeing* demarcates three levels of influence surrounding the individual’s cancer experience. Personal responsibility, lifestyle choices and health-seeking behaviour are determined by many factors and will be examined within the context of the distal-macro-social, intermediate- intermediate-social, and proximal-micro-social Indigenous determinants of health. Buyx (2008) argued that free choice occurs along a continuum and that there are “many degrees of freedom of choice” (p. 872) and furthermore that “these choices are influenced by multiple factors including socioeconomic status, socialisation and education, family influence, social and peer values” (p. 873) to name a few. In order to examine the significance of personal responsibility to generations of Anishinaabek, I revisit the link between the Indigenous determinants of health and Farmer et al.’s (2006) term, structural violence. Farmer et al. (2006) define structural violence as those “social structures – economic, political, legal, religious, and cultural – that stop individuals, groups and societies from reaching their full potential” or “put them in harm’s way” (p. 1686) within health care systems.

Structural violence and barriers to Minobimaadiziwin

With respect to the present study, structural violence is representative of systemic barriers and colonial health policies which prevent Anishinaabek with cancer from achieving Minobimaadiziwin and which perpetuate inequity. The following discussion concerns the interplay between those barriers situated in the outer three levels of my *Theoretical Model for Two-eyed Seeing* and their influence on the Anishinaabek cancer experience.

To facilitate this discussion and to provide a deeper look at the primary research question, I will highlight three cross-cutting themes deemed barriers to Minobimaadiziwin which transcend the findings. They include: 1) *Zhagwenmowin* [Translation: imposed shame] and its relationship to colonialism as a systemic barrier at the distal-macro-social level; 2) structural barriers to accessibility for both types of healing for Anishinaabek at the intermediate-intermediate-social level; and 3) language, culture, trust and belief as relational barriers at the proximal-micro-social level.

A thread woven throughout this research and evident throughout the collective story was the Anishinaabe concept of *zhagwenmowin* [Translation: imposed shame].

Zhagwenmowin originates from sources such as power imbalances, racism and paternalistic policies. *Zhagwenmowin* is a direct result of paternalistic colonial forces which have perpetuated shame in some Anishinaabek to this day and include but are not limited to: assimilationist policies, the residential school legacy, the Indian Act, and not surprisingly, modern health care policy. This imposed shame and the roots of health inequity stem from Indigenous peoples' collective, traumatic histories with government, education systems and religious institutions, which were the tools of assimilation (Loppie-Reading & Wien, 2009). It has been noted by many authors that colonialism has

the strongest influence on all other determinants of health (Jacklin & Warry, 2011; Loppie-Reading & Wien, 2009), has been referred to as the “cause of causes” (Czyzewski, 2011), and is one of the root causes of health inequity (Allan & Smylie, 2015; King, Smith & Gracey, 2009). The need for health professionals to understand the effects of colonization is imperative (Gracey & King, 2009). Colonialism as a distal, Indigenous determinant of health impacted the individual’s cancer experience by shaping how Anishinaabek accessed cancer services, thereby influencing the individual’s overall Minobimaadiziwin.

In my study, Anishinaabek related *zhagwenmowin* to the cancer experience through an association with past trauma inflicted during the residential school era. Participants shared their understanding of why they got cancer, and these reasons were attributed to the physical, mental, emotional and spiritual aspects of their being. In keeping with their understanding of Minobimaadiziwin, when one area of their being had been affected and was left unresolved over time this caused imbalance they believe contributed to the development of cancer. Participants referred to “unspoken, unresolved grief, rage, guilt and shame” from these past experiences with colonialism in residential schools. Moreover, participants shared that other Anishinaabek may have the belief that cancer is a result of “something in their past that they feel guilty about” and because of *zhagwenmowin*, cancer is kept a secret.

Health professionals participating in the present study, Indigenous and non-Indigenous alike, have emphasized a connection between stress, trauma and cancer, and maintain that a more holistic focus for cancer and health care is necessary (i.e., that a person’s history

be included in the care plan). This would imply that there are proper referrals being made to professionals specializing in mental health or to Indigenous practitioners who value a holistic approach to healing. The alleviation of mental stress by dealing with unresolved trauma for Anishinaabek can indirectly be viewed as a preventative measure for cancer. However, it is evident that this aspect of the self is not always addressed. Generally the notion of *zhagwenmowin* and its relationship to colonialism has yet to be acknowledged and addressed by those working in the area of Anishinaabek cancer care. When Anishinaabek do not disclose possible symptoms as a result of their *zhagwenmowin*, cancer will not be detected. There are implications for screening, early diagnostic, and cancer education efforts within community health centres and provincial cancer care programming, including surveillance. I affirm that a holistic approach to education and prevention for cancer care is required to address the root causes of cancer including colonialism for Indigenous peoples. Much can be achieved by including culturally-safe, Indigenous approaches to health and *Minobimaadiziwin*. These connections were emphasized in the *Aboriginal Cancer Strategy II*: “Traditional values emphasize the connection of spiritual, physical and mental wellness. It is a small step from that insight to knowledge of how cancer affects the body and how to prevent it” (Cancer Care Ontario, 2012, p. 27).

As noted earlier in this discussion, the notion of personal responsibility for one’s health within a Western context, particularly within cancer prevention, has been criticized for placing blame on the victims of cancer (Minkler as cited in Buyx, 2008). Regardless of this criticism, participants in this study were expected to be personally responsible in the cancer care context – they were reminded to become advocates for their own health, to

become informed health consumers, and initially, to acquire the services of a family physician who will oversee their care. With this line of thinking, it was implied that each person is expected to know their body best and should be able to negotiate the health care system and state their concerns to a health care professional. The prevention emphasis is placed on the patient's being able to do a "self-scan," to monitor changes in one's health and to speak comfortably about their bodies to a relative stranger whom they may not trust. As a case in point, agencies such as the Canadian Breast Cancer Foundation are now encouraging women and men to be "breast aware" rather than relying on breast self-examinations as preventative measures. They are stressing the importance of gaining familiarity with how one's breast look, feel and change over time so that unusual changes may be detected and brought to the attention of a health care professional (Canadian Breast Cancer Foundation, 2015). It is apparent that some Anishinaabek in this study were at a disadvantage in communicating with health care professionals because they felt intimidated, harboured feelings of inadequacy and may have felt *zhagwenmowin* as a result of past experiences relating to colonialism.

While the distal-macro-social level reflects the legacy of colonialism, the proximal-micro-social level reflects the power differential between the physician and patient. From both perspectives, the Anishinaabe patient may experience *zhagwenmowin* so that they may have "lost their voice" and been unable to articulate their health care needs in a satisfactory way. Conrad and Barker (2010) cite the work of Freidson (1970) and Foucault's (1975) contribution of knowledge as a form of power which has bearing on the present discussion. Namely, that illness is: shaped by how we interact with others; based on our cultural backgrounds; based on our ever-changing knowledge of cancer; and

based on “relations of power” (Conrad & Barker, 2010). This shaping of illness has definite consequences for how cancer is experienced as well as the potential for how cancer care can be delivered. It is my contention that skilled health communication can be taught, thereby minimizing the effect of colonial, systemic and power structures on patients. This, I believe, can be facilitated through demonstrated respect for patient decision-making, including the decision to employ IH/TM in the treatment of cancer. Empowering patients to choose appropriate healing methods can increase their personal responsibility, agency and investment in their own *Minobimaadiziwin*.

Agency, empowerment and respect

Agency is the ability to act independently and to make choices. Many have alluded to the importance of both agency and non-passivity in the health care arena (Conrad & Barker, 2010). I believe that agency, empowerment and respect are all key within the context of cancer and, hence, in achieving *Minobimaadiziwin*. Further, it is my contention that taking personal responsibility for one’s health care decisions (non-passivity) regarding the use of IH/TM is a reflection of the *Minobimaadiziwin* teachings. Many Anishinaabek in this study reported there was a lack of agency permitted in the health care system, specifically with respect to the use of IH/TM. Conversely, some Anishinaabek participants expressed that there is always a choice but making a choice involves finding and using one’s voice, thus overcoming *zhagwenmowin*.

The proximal-micro-social level of the model focused on relationships between patients and others, including physicians and healers, and on what was required for empowering patients to make appropriate choices. A concern of some participants was the lack of

choice in the type of health care they could employ for cancer treatment, in addition to policies and practices that were perceived barriers to Minobimaadiziwin in overall cancer care. The design of the current Western system of health care itself poses a barrier in the initial stages of cancer diagnosis. Participants point to problems with the physician consultation regarding their cancer diagnosis and stated that there is little time to ask questions or to consider other options for health care. The participants unanimously agreed that decision-making happens in haste and that there was one health care option made available to them in the Western health care context. The Western health care system currently provides no formal option for the use of IH/TM or braiding it with Western treatments for cancer. Despite the availability of the Medicine Lodge at Health Sciences North, patients did not mention using this facility. It was apparent that this is not happening for a variety of reasons, including the fact that their use of IH/TM was not the doctor's business, fear of skepticism and judgement, but overall it was expected that their doctors would not understand. Furthermore, there was the additional burden of feeling that if they did not make the choice to go forward with the recommended Western medical treatments that they would indeed become ill.

A seminal article by Shelley et al. (2009) aptly titled, '*They Don't Ask Me So I Don't Tell Them,*' supports much of what was found in the present study. Shelley et al. (2009) stated that in the many studies they reviewed, nondisclosure about patients' use of traditional medicine and complementary and alternative medicine (TM/CAM) was common, especially in minority groups such as Native Americans. Shelley et al. (2009) also reported that in the interaction between the doctor and patient, it was up to the patient to initiate this discussion, yet another example of personal responsibility in health care. In

the Shelley et al. (2009) study, patients stated that when the topic did come up, they did not expect their doctor to be an expert on TM/CAM. The Shelley et al. study article addressed why clinicians did not engage in discussion about TM/CAM. These included erroneous assumptions made by physicians that their patients were not using TM/CAM because they did not bring it up. A finding in the Shelley et al. study which was similar to my findings was that patients fully expected their doctors to have a lack of understanding about traditional medicine. The physicians in the Shelley et al. study stated that their skepticism about TM/CAM came from a concern for the patients' safety.

On the part of the Western practitioner, and related to this issue of patient choice, is the encumbrance by the physician who may feel that they could have done more to convince a patient to pursue diagnostic testing or Western treatment. Admittedly, this convincing is further pressure on the patient to follow through with Western medicine and a hindrance to their willingness to pursue IH/TM. It is one of western medicine's basic axioms to "first do no harm," and this is why it is compelling for physicians to want to treat patients with what they believe is the best medicine. Adams translated Hippocrates's words in *Of the Epidemics*: "The physician must be able to tell the antecedents, know the present, and foretell the future, must mediate these things, and have two special objects in view with regard to disease, namely to do good or to do no harm" (Sullivan & Baranek, 2002, p. vi). It has been a particular challenge to accept some patients' decisions to forego diagnostic testing or treatment when the physician believes that to "do good or do no harm" to the patient is to encourage them to pursue diagnostic testing in order to possibly prevent or cure cancer.

In the present study, the health care professionals did not directly ask if someone is currently using IH/TM or would be interested in being referred for IH/TM. This, I believe can be problematic for a number of reasons. A hospital or doctor's visit is often the first point of contact for Anishinaabe people with the health care system. It may be that for successful braiding to occur, this inquiry and line of questioning may be necessary. I believe it would open communication regarding IH/TM and represents a positive step to a culturally safe, patient-centered approach to health care for Anishinaabe patients. It also promotes empowerment as well as respectful and honest relationship development between doctor and patient. As Gracey and King (2009) have noted, "Better communication is key to improvement of health" (p. 73). There is a need for physicians and other health professionals working with Anishinaabek to move toward cultural competence according to St. Pierre-Hansen et al.'s (2010) cross-cultural client safety continuum. A first step toward culturally safe health care is the acknowledgement and willingness to change negative attitudes about IH/TM. It was also evident in the present study that Anishinaabek often make choices based on their physician's "permission" to pursue both IH/TM and Western medicine. The physician's acceptance of braiding IH/TM with Western medicine has a great impact on the Minobimaadiziwin of Anishinaabek who choose this option. This would involve respecting patient choice and eventually moving toward what St. Pierre-Hansen et al. (2010) refer to as congruence/integration. Western health care professionals at this end of the cross-cultural client safety continuum would embody the empowerment of Anishinaabe patients to choose healing models that are appropriate and specific to them.

Structural barriers to Minobimaadiziwin

Although many would argue that Western treatments for cancer are a positive supplement to healing for Anishinaabek, Jacklin and Warry (2011) caution that it is important for health care professionals to acknowledge Western medicine's role in the on-going process of colonialism. It is equally important to realize that modern health care policies continue to serve as barriers to Minobimaadiziwin and choice in what meets the specific needs of Anishinaabek. Overall, barriers exist within paternalistic health care practices and policies, including Health Canada's – First Nations and Inuit Health Branch's Non-Insured Health Benefits Program. Their fiduciary responsibility is for drug benefits, medical supplies and equipment benefits, while medical transportation and access to traditional healers can create barriers. There are several problems with the delivery of the NIHB program outlined in the present study and in the CPAC (2012) national report. The problems often stem from the fact that many Anishinaabek appear to be unaware that they are entitled to such travel benefits, including travel to see a traditional healer. A case in point, no specific mention of NIHB's *Traditional Healer Services Travel Policy* was made by participants employing IH/TM in this study, and participants were unaware of "what was out there for them" in terms of financial assistance throughout their cancer experience. It is argued that this governmental policy, among others, continues to perpetuate health disparities between Aboriginal peoples and their Canadian counterparts. These policies can therefore be classified as agents of "systemic, structural or institutional racism" (Allan & Smylie, 2015, p. 5). Furthermore, the unfair distribution of benefits may also be characterized as structural violence.

The following findings relate specifically to the form and function of the NIHB policy and its impact on the Anishinaabek cancer experience. In this study, participants cited evidence of an inability to access some of the more expensive, yet required, cancer treatment drugs and of having difficulty travelling to cancer treatment facilities due to financial constraints. Although the federal NIHB program provides coverage for medical transportation, this support is not always forthcoming due to a lack of coordination in paperwork between health institutions, which may cause delays in reimbursement (CPAC, 2012). Participants emphasized that the acquisition of Non-Insured Health Benefits requires a cumbersome application process, difficulty accessing benefits and lengthy wait times for reimbursement. It is well documented that unemployment rates can be as high as 80% in some First Nation communities (CPAC, 2012). This makes paying out-of-pocket for travel expenditures next to impossible for many Anishinaabek. Participants have shared that even when transportation funding is provided it is often inadequate to cover parking, meals and accommodation. These financial constraints leave Anishinaabek vulnerable and are indicative of the many changes required in health care policy infrastructure to improve access to cancer care for Indigenous peoples.

Beyond financial constraints, improving access to essential health information was an issue for Anishinaabek. Although not specifically mentioned by participants in this study, the NIHB documents are notoriously complex (Hankard, 2013) and are fraught with difficulties in accessing benefits (CPAC, 2012), which indirectly impedes access to cancer care both in terms of travel to treatment and access to required medication. Access to these benefits depends on one's ability to comprehend and demonstrate bureaucratic finesse (i.e., completing a multitude of forms over time and following proper procedures

to meet policy requirements). A CPAC national report (2012) indicated that the frustrations Aboriginal Canadians had with NIHB were the same regardless of living in rural, remote or isolated communities, which suggests that the problem lies with the bureaucratic process, not with the distance travelled to cancer treatment facilities. Rightfully, participants in this study voiced their frustration at being caught up in this bureaucratic process rather than focusing their energy on healing. Many of the Anishinaabe participants diagnosed with cancer who participated in this study were in the midst of traveling to cancer treatment and taking care of their responsibilities at home and that attending to a mass of paperwork to acquire benefits should have been the last thing on their minds. Minobimaadiziwin requires that an individual attend to balance in all areas of his or her life, but this becomes increasingly difficult when structural barriers are consistently a part of the healing journey.

It is apparent that at the distal-macro-social level, determinants such as income and education impeded access to some required cancer treatments and, I suspect, cancer screening and prevention initiatives. For example, literacy problems may have impeded access to appropriate cancer care services. The hierarchical distribution of resources (i.e., income) and power differentials (i.e., education) within the health care system continue to create inequities for Aboriginal peoples (Loppie-Reading & Wien, 2009). Moreover, Gould et al. (2009) noted that such disparities may also lead to further disparities in the health outcomes for Anishinaabek diagnosed with cancer. A conclusion that can be drawn from such findings is that a further and more direct approach to cancer education is required to create equitable access to health literacy material. It was evident that the information that is currently provided may be *misinformation*, or it may not be presented

in a way that is conducive to Anishinaabek learning styles, especially when participants revealed that the information provided was not accessible (i.e., it was there, but was missed or it was not available). As a case in point, one participant mentioned that while the information may have been available, it did not “register in her mind” at first, and as a result, she missed essential pieces of information. This situation landed her in the hospital due to complications with her cancer treatment protocol. This ineffective education often stems from poorly written, confusing government information.

To satisfy my own curiosity, Flesch-Kincaid Grade Level readability tests, which are commonly employed in health literacy research, were performed on the documents *Your Health Benefits*, a joint publication of Health Canada’s First Nations and Inuit Health Branch and the Assembly of First Nations as well as *A Guide for First Nations in Ontario: Navigating the Non-Insured Health Benefits & Ontario Health Program Benefits*, a publication of the Chiefs of Ontario. These documents, meant to help First Nations people living on-reserve to understand their eligibility for health benefits, had Flesch-Kincaid grade levels of 12.6 and 9.8, respectively. This essentially means that both documents were assessed for the number of words and syllables per sentence. These reading levels were found to be above the accepted standard reading level of Grade 6 to Grade 8 for health literacy documents (Badarudeen & Sabharwal, 2010; Terblanche & Burgess, 2010).

While Anishinaabek in this study have not specifically mentioned these documents, they have been disseminated in many Anishinaabek communities to assist patients in comprehending the complex system of health services provided by Health Canada – First

Nations and Inuit Health Branch's *Non-Insured Health Benefits Program*. Furthermore, once in the cancer system, the learning curve is steep and will undoubtedly depend on a high degree of fluency with the English language. This apparent disregard for appropriate reading level has serious implications for how important information is received and applied to the cancer experience by Anishinaabek patients. The complexity of the information currently being provided, as well as the overwhelmed and exhausted state of many individuals with cancer, highlighted the need for improved efforts at knowledge translation between health care providers, governments and Anishinaabe people diagnosed with cancer.

Critically reflecting on these issues, it is evident that the findings in the current study are virtually identical to national findings in CPAC (2012) report concerning First Nations Cancer Control. Specifically, the most detrimental structural barriers for Anishinaabek are not merely the travel to and from Northeast Cancer Center nor to its satellite clinic, but rather the current state of Anishinaabe communities, including high unemployment or under-employment, lower educational attainment and some root causes of cancer such as colonialism, that is, historical trauma, loss of Indigenous ways of knowing and being, and *zhagwenmowin*. Overall, the dictatorial manner in which NIHB operates is reminiscent of the colonialist practices of a government with little or no concern for the well-being of the First Peoples of this country. This colonialist health policy and the practices surrounding it echo the sentiment in the powerful words of many Chiefs including Ogimaa Wiikwemkoong Unceded Territory [Translation: Wikwemikong's Chief], "we have become beggars in our own land."

Structural barriers to timely cancer care for Manitoulin residents were also identified by Western health care professionals. It was noted by a physician that it is not uncommon for Anishinaabek to be without a family physician to oversee their care. This has great implications for cancer screening and continuity of care over time. It was mentioned by a physician that it was a responsibility of the Anishinaabe patient to find a family physician and to “demand consistency in their care.” The issue of access to family physicians is not unique to Manitoulin and appears to be a national problem for First Nations people. An electronic survey conducted by the CPAC (2012) revealed that less than 50% of respondents indicated that they had access to doctors within First Nation communities. This lack of continuity in care has been linked to low cancer screening participation and to late-stage cancer diagnosis (Minore, Boone, Cromarty, Katt, Kinch & Power, 2002). As mentioned earlier, finding a family doctor can be problematic as a result of some patients being silenced by *zhagwenmowin*. There are underlying issues of trust which will be discussed in the following section on relational barriers to *Minobimaadiziwin*. I propose that there is a need to educate Anishinaabek about the function and purpose of having a family doctor. It should be understood that, much like IH/TM, Western medicine can be seen as a preventative measure rather than a reactive one in order to improve cancer outcomes. I also believe that this issue goes beyond cancer care and most likely involves a larger health human resource issue in rural and Northern Ontario, which is beyond the scope of this study.

Other issues of access mentioned by Western health care providers concerned inequities for rural northern Ontario residents, including the Anishinaabek of Manitoulin Island. Such inequities involved the allocation of services, wait times for diagnostic testing,

“waiting for beds,” as well as referral and access to specialist care. It was stated by one physician that, “People should be able to access things evenly across the region or system, but it’s not our impression sometimes.” This physician shared valuable insight into the background work that a physician accomplishes before patients are referred to specialists’ care. This work, at times, can involve a non-collaborative attitude and inconsistencies in specialists’ processes. For example, some specialists will refuse to employ technology such as video conferencing which, in turn, improves access to their care for Anishinaabek living on Manitoulin Island. Similarly, it was noted that it is extremely difficult to refer a patient to specialists’ care without a tissue diagnosis. With the current stipulations to specialists’ care, it becomes difficult to diagnose and treat cancer in a timely manner. These findings are similar to the results of the CPAC (2012) national report, suggesting that the systems of cancer care are not meeting the needs Canadian Aboriginal peoples and require remediation. An additional finding in the CPAC study, not mentioned by health care professionals in my study, was that many cancer care specialists will only accept referrals from physicians.

Finally, health professionals identified a gap in the coordination of cancer care. One physician noted that in the case of a complicated cancer such as multiple forms of cancer, there may not be someone providing direction from the tertiary care oncology setting to the primary health care providers. This physician further stated, “They get discharged from this person, and there isn't always somebody that's giving us guidance as to the big picture.” The findings of both the current study and the CPAC national report suggest that improved collaboration is required between health care providers working in First

Nation communities and in the larger, tertiary care settings like the Northeast Cancer Centre.

Due to privacy concerns, current cancer care delivery places responsibility squarely on the patient. The necessary information for follow-up care is delivered to the patient and the physician, without a community health care contact. At present, the client owns their discharge information and it is taken for granted that the patient understands what is expected in terms of treatment as well as the implications for their cancer care at home. What might be beneficial is for community health care providers to be included in the circle of care and they, in turn, can assist in reinforcing some of the essential information for the patient. In 2013, the Northeast Cancer Centre hired an Aboriginal Patient Navigator who works with patients, families and communities through the cancer journey. It is expected that such linkages will have an impact on and potentially improve the quality of follow-up care within the Anishinaabe communities. While the communication issues between community, primary and tertiary care of Anishinaabek patients may appear to be beyond the scope of the present study, it is hoped that cancer care providers at all levels of care can recognize that strengthening collaborative efforts and relationship-building among themselves can be improved with the input of IH/TM practitioners. Such braiding can create holistic, culturally safe care that can help ensure their patients' Minobimaadiziwin.

The distal macro-social level also observes health within the capitalist world-system (Singer & Baer, 1995) and interacts with the intermediate-intermediate social level with respect to government and health care policy, thus reinforcing the hegemony of Western

medicine. The impact of the hegemony of Western medicine in concert with colonialism has had profound implications for IH/TM. Jacklin and Warry (2011) aptly summarize the impact of government intervention and its effect on IH/TM: “State actions placed health care in the hands of the colonizers and undermined culturally based conceptions of disease, illness, and treatment rooted in Indigenous knowledge. As this medical paradigm shift occurred, authority over Aboriginal life was increasingly placed in the hands of the colonial government, which sought to abolish Aboriginal culture and identity” (p. 377). In effect, these actions and the introduction of new diseases that were “curable” with Western medicine further contributed to a loss of faith Indigenous people had in their own methods of healing. These historical injustices underscore the meaning of *zhagwenmowin* in the current study. *Zhagwenmowin* is reinforced when Indigenous peoples are told that IH/TM is ineffective, wrong, evil, hocus-pocus or associated with devil-worship. As a result of colonialism, Indigenous knowledge keepers have had to hide and protect IH/TM for fear of persecution. This has resulted in much of the Indigenous healing knowledge being fragmented and repressed (Martin-Hill, 2003). Colonized education systems (e.g., Western-based curricula and residential schools) have also contributed to the stigmatization of IH/TM and, consequently, to the *zhagwenmowin* about Indigenous methods of healing.

The hegemony of Western medicine and prevailing negative attitude toward IH/TM by some Western health professionals was evident in the recent media coverage of two Aboriginal Canadian children diagnosed with cancer. It is apparent that IH/TM remains unaccepted by most physicians and that many hospitals do not have protocols in place for its use to support Western medical treatments for cancer. In a statement published in the

National Post, a lead oncologist reportedly defamed IH/TM stating that these treatments were “100% ineffective and anyone who says traditional medicine works should be thrown in jail” (National Post, 2014). As a result of such attitudes, colonial history, modern health care policy and *zhagwenmowin*, many will continue to suffer a loss of cultural connection to Indigenous knowledge and healing methods.

There were several barriers to IH/TM noted by participants in this study. Indigenous practitioners have stated that medical professionals were, at best, critical of or reluctant about their clients’ use of IH/TM. Some have even hypothesized that the use of IH/TM is being blocked by institutions, specifically, in the partnership between Western medicine and the pharmaceutical industry. On the part of Western practitioners in this study, there is recognition of their own ignorance of IH/TM. Moreover, health care professionals and patients alike have expressed that IH/TM is discouraged for fear of harmful interactions between traditional and Western medicines. These findings imply that there is little contact between practitioners of IH/TM and Western medicine. Furthermore, it can be inferred that there is a reluctance or failure of physicians or other Western health care professionals to refer Anishinaabek patients for IH/TM. Therein lies the problem in braiding IH/TM with Western medicine and in collaborative relationship-building. It is clear that a decolonizing of the understanding of IH/TM is required for any progress to be made in braiding these healing methods for *Minobimaadiziwin* or to empower Anishinaabek to choose braiding if this meets their needs.

This lack of association between practitioners of Western medicine and IH/TM is problematic for several reasons, including access to traditional healers through NIHB’s

Traditional Healer Services Travel Policy. As mentioned earlier, the fact that no participants in the present study mention this policy shows a problem of access. Hankard (2013) addressed several barriers to accessing traditional healer services: physician attitudes, their lack of support regarding and refusal to make referrals for IH/TM, and the need for NIHB traditional healer access policy. The NIHB policy holds physicians as “the primary gatekeepers in the traditional healer access process” (Hankard, 2013, p. 4). The same dictatorial, colonialist, bureaucratic NIHB processes apply to the *Traditional Healer Services Travel Policy*. Any person interested in acquiring assistance through the NIHB traditional healer access policy must be willing to persevere through a lengthy preapproval process. They are required to obtain a referral from a nurse or physician willing to sign a preapproval form if the reason for referral is deemed a legitimate medical concern. They must also obtain clearance from their Chief and Council who are put in the awkward position of sanctioning certain healers. Finally, the person must obtain final approval from NIHB administrators who have proven to be inconsistent in their administration of their policy (Hankard, 2013). Hankard describes the NIHB policy as one which “allows the government to have it both ways. On one hand, it appears publicly supportive of First Nations traditions and culture by maintaining it, but on the other hand, by making it so inaccessible; they do not have to properly fund it” (p. 18).

Jacklin and Warry (2004) addressed the rhetoric of self-determination found within the *Indian Health Transfer Policy*, a policy designed to devolve certain elements of administrative control for health care to First Nations. This policy, however, has been criticized and for the purposes of the present study, can be interpreted as an “umbrella barrier” particularly with regard to the adequate provision of holistic services in

Anishinaabe communities. The delivery of any programs including braiding of IH/TM with Western medicine for Anishinaabe people diagnosed with cancer are severely impacted by the *Health Transfer Policy*. The federal government currently refuses to fund any traditional medicine programming, and this puts limits on how many Anishinaabek communities can meet the specific health needs of members within a culturally safe system. Despite the success of many traditional medicine programs in other areas of health care, the federal government continues to refuse to support them, citing liability factors (Jacklin & Warry, 2004). This “umbrella” *Health Transfer Policy* is another example of colonialist policy which perpetuates inequity in the delivery of adequate health care services for Canada’s First Peoples. It handcuffs First Nations and forces them to administer programs according to government policy with an inadequate funding base, one that does not permit the delivery of services for Minobimaadiziwin. Furthermore, this policy allows the federal government to appear to support the self-determination of Indigenous peoples, while at the same time it appears not to want to spend the money to make this a reality. Instead, the Anishinaabe administrator becomes the new face of the colonial government. As a result, any attempts to make IH/TM a viable part of healing in the current system of cancer care will require the braiding of ideas as well as the braiding and sharing of dedicated health resources and infrastructure.

Any and all of the factors discussed in this section can be interpreted as structural barriers for patients’ access to both Western medicine and IH/TM for Minobimaadiziwin. The findings of the present study also addressed what I refer to as relational barriers to Minobimaadiziwin, which included language, culture, trust and belief. These barriers and their effects can be viewed at the proximal-micro-social level of my *Theoretical Model of*

Two-eyed Seeing. However, as with all of the other barriers to Minobimaadiziwin, this level impacts not only the individual but also interacts with the other levels of determinants, including the distal and intermediate.

Relational barriers to Minobimaadiziwin

Overall, Anishinaabek were satisfied with the Western medical treatment they received, but they have acknowledged that they still feel uninformed about many aspects of cancer and that they were not confident in interacting with physicians. Participants revealed that they did not know how to explain their symptoms, and this may have had implications for a timely diagnosis of cancer. This may have been due to a language barrier, especially for Elders who are more comfortable explaining themselves in *Anishinaabemowin* [Translation: Anishinaabe Language]. This has important implications for the understanding of an often overwhelming amount of information. Medical doctors are held in high regard and occupy a position of power. It is often intimidating to ask questions and to advocate for oneself and one's family, and many felt they could not meet the expectations of their doctors. They shared that, in response, some physicians were either terse, spoke quickly or employed medical jargon which did not help them understand their condition or course of treatment. *Zhagwenmowin* was viewed as an impediment to communication with health professionals or with other persons in a position of power as a direct result of colonialism and paternalism. This may have had implications for the consent process where Anishinaabek may have agreed with their doctor regarding treatment decisions without being the true stakeholder in that decision-making process.

In response to the finding that Anishinaabe patients often feel rushed and do not have the confidence necessary to ask appropriate questions of physicians, it has been suggested that this requires direct teaching. Simonds et al. (2011) suggested that everyone's expectations need to be shared at the outset of the visit and that this communication skill be taught by medical personnel. Kalbfleisch (2009) recommended that a “communicative broker” be employed to improve communication and assist in the interaction between the patient and doctor. It might be helpful if the role of “communicative broker” be associated with that of the Aboriginal Patient Navigator and that ideally, this role would be hosted within the Anishinaabe community and be held by a community member with skills in *Anishinaabemowin* [Translation: Anishinaabe language]. This could improve the continuity of cancer care in terms of translation as well as enabling patients to use their voices and develop confidence in future health-care interactions. A concrete suggestion for this role is to provide a list of standard questions and train patients (Kalbfleisch, 2009) in posing these questions to health care professionals.

Although Western health care professionals have recognized that these problems exist in the delivery of information and overall communication with Anishinaabek, changes in the behaviour and attitude of some health care providers remain to be seen. There is evidence that these problems persist in cancer care for Anishinaabek on Manitoulin Island, certainly my findings suggest that few are making the adjustments to improving their communication with Anishinaabek. Indigenous patient and physician communication has been addressed by several researchers (Browne & Fiske, 2001; Kalbfleisch, 2009; Kelly & Brown, 2002; Shahid, Finn & Thompson, 2009; Shelley, Sussman, Williams, Segal & Crabtree, 2009; Simonds et al., 2011). Despite the fact that research, information and

recommendations on improving communication with Indigenous peoples have been adequately disseminated in a variety of academic journals, these same communication issues appear to persist. This quote highlights this concern: “Much of this has been stated many times before, with little action or provision of resources to match the recommendations and promises” (Shahid, Finn and Thompson, 2009, p. 578). The perpetual behaviours and the refusal to redress practices are also regarded in this context as a form of systemic racism (Allan & Smylie, 2015; Reading, 2013).

Western health care professionals in this study talked about the challenge of being from a different culture and not understanding the patients’ perspective. One example was the inclination of many Indigenous persons not to be forward or direct and not to pose questions for fear of appearing disrespectful. Instead, many Anishinaabek will defer comments or questions and may even think “*maanoo*” [Translation: just let it be].

Western health care professionals have admitted to having difficulty with the lack of concerns or questions posed by Anishinaabek, and this may be erroneously assumed as indifference or an unwillingness to participate in health care decision-making. Western health care professionals should understand that when approached by Anishinaabek, this represents a significant compromise on the part of the Anishinaabe person in terms of where they have decided to place trust. It may be easy to minimize the concerns of Anishinaabek, as they will often agree that they are wasting the physician’s time and are not overly concerned with their own pain. As one Elder shared, pain is relative and Anishinaabek know that there is always someone with greater suffering. It has been well-documented that Indigenous peoples will not seek out what the health care system has to offer until it is already too late (CPAC, 2012). It should be recognized as a flaw in the

health care system that “the squeaky wheel gets the grease.” One only has to observe the overburdened state of the health care system in any hospital emergency waiting room (CPAC, 2012) where too often, people who are in dire need of health care services but lack an authoritative voice to request them, will experience a delay in access until it is too late.

There are several suggestions I propose that Western health care professionals can improve their communication and relationship building with Anishinaabek, thereby improving treatment compliance and outcomes for cancer care. These suggestions have been supported in literature (Kalbfleisch, 2009; Shahid, Finn & Thompson, 2009; Simonds et al., 2011). The first suggestion involves taking the time to develop meaningful, trusting relationships between the Western health care provider and Anishinaabe patients through listening, sharing stories and using humour and *Anishinaabemowin* where possible (Kalbfleisch, 2009; Shahid, Finn & Thompson, 2009). Researchers have also highlighted the need for teaching a protocol for physician visits including expectations of both the physician and patient for mutual understanding as well as how to empower patients to ask questions (Kalbfleisch, 2009; Simonds et al, 2011). It is acknowledged that time is a precious commodity in the Western health care setting, but closing the growing gap of health inequity between Indigenous people and their Canadian counterparts through relationship development should become a priority (Gracey & King, 2009). I firmly believe that investment in this type of relationship would also increase the potential for braiding IH/TM with Western medicine since patients would be more willing to disclose information to a trusted source. This would also lead to physicians

gaining familiarity with and interest in IH/TM, specifically, its use, purpose and meaning for Anishinaabe people.

Efforts to disseminate information should include a variety of methods that accommodate different learning styles (i.e., providing both textual and graphic information). This becomes essential for people who have literacy problems or other cognitive impairments. One suggestion provided by a participant and community health care professional was to create a “to-do-list” for quick reference (e.g., a fridge magnet) which uses simplified language and visuals to present the complexities. The use of straightforward, plain language, with the “injection” of some *Anishinaabemowin* [Translation: Anishinaabe language] and humour could improve comprehension and build a rapport with patients. Many communities have Anishinaabe language classes which are open to anyone interested in learning about the language and culture. Health care providers should not be exempt from learning about culture and the communities of those for whom they provide care. Partaking in community-based initiatives to revive culture and language would not only build trust and improve relations with Anishinaabek but might also foster interest in learning about braiding IH/TM with Western medicine for health care professionals. This extension to health care professional development will be further discussed in the following section on cultural safety and structural competence.

The mistrust that many Anishinaabe people have with colonialist systems, including the health care system, have been well-documented (CPAC, 2012; Jacklin & Warry, 2011). In the present study, Western health care professionals acknowledged deep mistrust, which is often attributed to the historical injustices that impinge on the everyday

experiences of Anishinaabek, including their interactions with health care providers. It is interesting to note that most of the Anishinaabek participants diagnosed with cancer appeared to trust their physicians' judgement and shared that they provided the best advice possible. However, there is reason to believe that this trust may be placed in Western health professionals only out of necessity – that is, Indigenous people have little choice but to place their trust in this system and its practitioners because there are no other options available to them. This understanding of trust may relate to *zhagwenmowin*. Anishinaabek health care professionals who participated in this study have been “afforded a voice” but did not necessarily trust their colleagues or the health care system in which they work. It is evident that relationships between Western health care providers, their Anishinaabe colleagues and their patients require attention and remediation to address structural violence.

On the other hand, some participants did not always feel that their concerns were believed by their physician. Larsen's (2009) notion of the “legitimization of chronic illness” is a phrase which has bearing on the issue of trust and relationship development between physician and patient. I extend this concept to include cancer. I believe this has had an impact on some participants and has damaged relationships with health care providers. Instances were mentioned in which symptoms were not acknowledged by health care professionals, and this broke trust. Browne and Fiske (2001) reported that Aboriginal women were at risk of being dismissed by health care professionals. On the one hand, this may be due to a patient's unwillingness to complain of pain or suffering. In the present study, some patients initially felt that their symptoms were dismissed or ignored. Participants alluded to the prescription drug issue plaguing Anishinaabek

communities as a reason why physicians may not have trusted or ignored their symptoms, as expressed in this comment: “Maybe they think that we’re all hypochondriacs or we’re just after the narcotics, you know, with the drug problem.” From the physician’s perspective, there were system barriers which impeded the process of accurate diagnosis, which also had bearing on the trust issue. The delay in the diagnostic process and not legitimizing cancer both conjure a climate of mistrust. Either way, in the absence of trust the process of diagnosing cancer will be problematic and will also be a barrier to relationship development. The legitimization of symptoms and overall trust that must be cultivated between the patient and physician should be founded on respect.

The findings suggest that belief in IH/TM is the central requirement, and in order to engage with this method of healing, a belief in the medicines, spiritual resources and ultimately, a relationship with Creation is required. Relationships with Creation were inclusive of land, plant life, animals and beings both on a physical and spiritual level. This belief also extends to the relationship between Anishinaabek and Anishinaabe *gikendaasowin* [Translation: knowledge, information, and the synthesis of our personal teachings] and the purveyors of those teachings (i.e., knowledge keepers, healers or Indigenous practitioners). Indigenous peoples across the world who employ IH/TM have a similar overarching attitude: “If you don’t believe it [IH/TM], it won’t help you” (Shahid, Bleam, Bessarab & Thompson, 2010, p. 1; van Schaik & Thompson, 2012).

Participants in the present study shared that IH/TM also involves a belief in the healer. *Mpshko zii* [Translation: an energy that is alive within a living being that shows itself in the strength it provides] is similar to the skill and competency that is required of Western

practitioners. Other studies concur that IH/TM depends on a belief in the skill or strength of the healer (Mehl-Madrona, 2008). Anishinaabek in this study relied on word-of-mouth to access this type of healing, which implies that they must rely on the honesty of the informant and trust in their assessment of a healer's reputation. As in all facets of life, not everyone is who they claim to be nor is everyone trustworthy. The reputations of healers and IH/TM have been damaged by other healers, lateral violence within Anishinaabe communities and, not surprisingly, the *zhagwenmowin* that many Anishinaabek harbour as a result of colonialism. These factors can be barriers to IH/TM that can deter physicians and patients from participating in braiding IH/TM with Western medicine. Another ramification of this cultural dislocation is that many Anishinaabek have turned away from and deny their own methods of healing completely, and consequently may block others' access to IH/TM.

Cultural safety and structural competence

Jacklin and Warry (2011) and Gracey and King (2009) argued that an understanding of colonialism as a determinant of health for Indigenous peoples is essential to overall health improvement and health equity. They further argue that this can be accomplished through cultural safety and cultural competence. Numerous studies have encouraged investment in cultural safety to help offset colonialism and structural inequities experienced by Indigenous peoples (Aboriginal Nurses Association of Canada, 2009; Allan & Smylie, 2015; Maar et al., 2011; Smye & Browne, 2002; Smye, Josewski and Kendall, 2010; St. Pierre-Hansen et al., 2010). Some studies have even gone as far as recommending that cultural safety training be mandated at all levels of health care, including oncology (Shahid, Finn & Thompson, 2009). St. Pierre-Hansen et al. (2010)

understand cultural competence to be subsumed within a continuum of cross-cultural client safety. Cultural competence is on the high end of this continuum where only “congruence/integration” surpasses it. It is at the level of congruence/integration where I discern that braiding IH/TM with Western Medicine may sit on this continuum of cultural safety. Allan & Smylie (2015) referred to cultural safety as an Indigenous approach to improving Indigenous access to health care, since it recognizes the colonial and sociopolitical contexts in which the inequities are perpetuated. The idea of cultural safety as a method for improving health fits within my *Theoretical Model for Two-eyed Seeing*, since the Anishinaabe person’s cancer experience is seen within contexts beyond the individual and proximal-micro-social levels. Instead, cultural safety promotes awareness of forces emanating from the intermediate and distal-macro-social levels. Cultural safety training for health care professionals could be an appropriate response to some elements of structural violence. Therefore, it is suggested as one recommendation to improve cancer care treatment for Anishinaabe people.

The plethora of studies on cultural safety noted above contain several recommendations which have special significance to the present study. Smye, Josewski and Kendall (2010) proposed competencies for cultural safety training which address several of the barriers to Minobimaadiziwin mentioned in the previous section and include understanding colonialization, Indigenous determinants of health and the way government health policies perpetuate inequity. This awareness would prove invaluable to minimizing structural barriers to Minobimaadiziwin. Also noted were respect for the cultures, languages and lives of Indigenous peoples; a focus on culturally safe communication as a foundation for relationship-building; reciprocity; and collaboration with Indigenous

peoples. Other models of cultural safety have included the requirement of making Indigenous patients a partner in healthcare decision-making (Health Council of Canada & DeSouza as cited in Allan & Smylie, 2015). These foci would serve to minimize some of the relational barriers to Minobimaadiziwin. Smye, Josewski and Kendall (2010) also pointed to the significance of health care providers' recognition of IH/TM as a legitimate option for health, in concert with Western medicine. As an element of cultural safety, this competency would appear to support and facilitate braiding these methods of healing for Minobimaadiziwin.

Kirmayer, Gone and Moses (2014) discussed structural competence in their work, *Rethinking Historical Trauma*, therein redefining cultural competency to include understanding and engagement with those structural forces that influence health beyond the individual interaction between physician and patient. They assert that this would produce change within health care institutions and systems and have recommended that health care professionals supplement their knowledge of cultural safety with an understanding of structural competence. Metzl and Hansen (2014) have also theorized medical engagement with structural competence to address inequity, basing conceptual model on interdisciplinary studies such as medical anthropology; the notion of *structural violence* (Farmer et al., 2006); and studies from medical sociology (Rose, 2011) that have examined relationships between *structure* and *agency* where making choices can impact morbidities but can also transform structure from within.

Metzl and Hansen described how physicians now have access to research that demonstrates “how diseased or impoverished economic infrastructures can lead to

diseased or impoverished or imbalanced bodies or minds” (p. 4). As in the teachings of Minobimaadiziwin, cancer was understood by some participants to be the result of an imbalance in the physical, mental, emotional or spiritual aspects of the person’s being. Furthermore, this imbalance can be understood as being a direct result of those external structural forces that confound the person's economic, political and social context. However, Metzl and Hansen have gone a step further than identifying the sources of imbalance. They argue that current medical approaches to delivering health care do little to address the structural roots of these imbalanced states. Instead, they suggest that these social and economic forces that produce imbalances are not immutable and will require *structural intervention* by health care professionals who hold the power. These interventions might involve advocacy or creating change in health policy (Metzl & Hansen, 2014). Similarly, Gould et al. (2009) have, rather bluntly, implicated health professionals in the process and policy culminating in health disparities which originate from these structural forces. They also recommend that health professionals act as advocates for Anishinaabek and assist in any way they can to facilitate positive change. They state: “There is an opportunity and, we assert, responsibility to demonstrate that no citizen in a country with universal health care is ‘below our notice’” (Gould et al., 2009, p. 313).

I argue that this step up to advocacy in partnership with Indigenous peoples can involve the implementation of strategies to braid IH/TM with Western medicine as a means of closing the gaps in health between Indigenous peoples and their Canadian counterparts. This will undoubtedly require some degree of humility on the part of physicians in acknowledging that Western medicine has limitations and that Indigenous practitioners

have something of value to bring to the table. Comparably, Metzl and Hansen (2014) have put forth as one of their core structural competencies the development of structural humility. This understanding is fitting where health care professionals come to realize that in their interactions with Anishinaabek patients they are “at once speakers and listeners, leaders and collaborators, experts and benighted” (Metzl & Hansen, 2014, p. 12).

I contend that an understanding of *zhagwenmowin* [Translation: imposed shame] is also associated with the Seven Grandfathers teaching of humility and is therefore, also relevant to this discussion. As with all words or phrases in *Anishinaabemowin*, there is rarely ever a one-word, direct English translation. In addition to its connotation of shame, *zhagwenmowin* also means to be humble and show reverence to all of Creation and the Creator, that which is greater than ourselves. With this meaning, Anishinaabek would view other human beings as equals and speak to and treat one another with respectful regard as illustrated in the teachings of Minobimaadiziwin.

In my reading, I came across this story in an article which speaks to this thread of humility and how it weaves into knowledge and healing for Anishinaabek. This story is intended to illustrate the purpose of humility for those who work with Anishinaabe people and is told from the perspective of a Canadian physician. I have taken the liberty of shortening the original story for this rendering:

The sense of humility comes with understanding your limitations ... I saw a very Elderly Native lady; her daughters brought her in ... and they called me that night and asked would I come to the house and see her and I did

... everything seemed fine ... [so] I was pretty annoyed that they had done that ... when one of the daughters said to me: “Would you like a cup of tea?” I said, “Sure” ... it sort of diffused my little reprimand.

I went into the kitchen ... to have my tea, the daughters went back into the bedroom ... one of them said, “Well, she’s gone very peacefully” and I said, “What?” and ran into the bedroom. She was lying there as dead as a doornail and they said, “Thank you very much for coming when mother died ... we knew she was going to go and we really appreciate you being here.”

That injected in me a great sense of humility ... they know a lot that I don’t know, about their mother, but also just about death and dying and anyway I’ve held onto that sense of humility and that’s pretty much where I remain (Kelly & Brown, 2002, p. 1652).

As in the Metzl and Hansen (2014) understanding of structural humility and the physician’s account in Kelly and Brown (2002), I assert that the current health care system requires this humility to acknowledge what Indigenous healing can bring to cancer care. They may even come to the realization of where their limits lie, and consequently, where a referral to an IH/TM practitioner is necessary. However, I am not so naïve as to assume that everyone will support the braiding of IH/TM with Western medicine for cancer care. Instead, it is my hope that I can provide some insight into the value of these two methods of healing and what they can bring to Indigenous people when braided respectfully.

The value of Western medicine, IH/TM and braiding

Secondary research questions for this study concerned whether the inclusion of Indigenous healing brought the Anishinaabe person closer to Minobimaadiziwin and how this contributed to the overall cancer experience. Although both methods focus on healing, Western and Indigenous medicine are based in distinctly different ideologies. To assist with the understanding of the differences, I revisit Waldram (2000) and the distinctions he draws between curing and healing. I also employ the contrast Cohen (2003) provides between IH/TM and Western medicine. Elements of these dichotomies were reminiscent in the findings of the present study and also appear in the Minobimaadiziwin teachings. I believe that they can provide a useful frame of reference for examining the secondary research questions.

The findings of the present study concerning Western medicine suggest that participants highly valued the Western treatments for cancer, especially if they were successful. Participants were in agreement that Western medicine primarily focused on the physical aspect of their being. Both preventative and curative elements were mentioned to be of value. For example, many were encouraged by the gains made in the ability of Western medicine to prevent further progression and to cure some cancers. Western health professionals also highlighted that in terms of efficacy, their medicine measures up to the “gold standard” of clinical trials. Practitioners of Western medicine in this study acknowledged the small steps that the health care industry is making towards offering a more holistic approach. Likewise, Indigenous practitioners also acknowledged value in Western medicine where they encourage their clients to employ Western medicine in their cancer treatment, to the degree that these treatments were comfortable for the client.

Overall, however, it was felt that Western medicine places the physician in a role of authority and power which at times made it difficult for participants to relate to them.

Cohen's (2003) descriptions supported the present study's findings where he described Western medicine as placing the physician as the authority. He saw this method of healing as relying heavily on medication and the use of technology to investigate the etiology of illness. Cohen (2003) also stated that Western medicine focused on the curative aspects of healing and pathology and was based in an adversarial approach (i.e., "How can I destroy the disease?"). Waldram (2000) cited several medical anthropologists who hold that Western medicine places emphasis on curing or "a primarily biological process that emphasizes the removal of pathology or the repairing of physiological malfunctions, that is, disease" (p. 604). Similarly, Gracey and King (2009) have aptly noted that politicians, policy makers and community leaders need to hear the message that for improvements in Indigenous health "prevention is better than [a] cure." Moreover, that holistic health and community health are future visions for First Nations people (King, Smith & Gracey, 2009).

In light of the present study's findings that Western medicine is primarily a physical intervention and that Western medicine has made small gains towards a holistic approach, it would make sense that health care providers would welcome a deeper awareness of the holistic worldview of Indigenous peoples and how this can improve practice. The present study proposes that cultural safety training which includes a focus on structural competence is one way to achieve this aim. It is recognized that in order for this personal inquiry to occur, some humility is required. A starting point may be to learn

about the traditional healing or holistic programs available at Manitoulin community health organizations and what they can offer patients. This window of understanding may lead to confidence in making referrals to such programs, if patients express an interest. It may also enable meaningful dialogue between Western and Indigenous practitioners. It is not expected that the physician has to be an expert on IH/TM to be able to contribute to this discussion with other healers or patients. Shelly et al. (2009) suggested that physicians need only engage with non-judgemental interest and honesty (and, I argue, humility) regarding the limits of their knowledge about IH/TM to foster relationship development and empowerment.

The findings of the present study concerning IH/TM suggest that participants valued the ancestral connection of this method of healing to their current lives where it was seen as preventative in nature. Participants who utilized IH/TM believed it complemented their use of Western medicine. Specifically, IH/TM enabled them to realize their own *Minobimaadiziwin* as it supported their physical, mental, emotional and spiritual well-being. It was found, though not acknowledged by all participants, that IH/TM involves a spiritual component, often ignored in the Western medical paradigm. Similarly IH/TM practitioners who impart Anishinaabe teachings as a part of the healing process, found that they were able to help change the mindset of clients from a negative outlook on cancer to a positive outlook on life. King, Smith and Gracey (2009) have further noted that the passing on of traditional teachings and knowledge can be the basis for improvement of self-image and healthy identity where Elders play a pivotal role. In the present study many participants viewed the cancer as a “teacher” or an agent of change

where cancer was perceived as an obstacle to acknowledge and overcome for Minobimaadiziwin.

These findings correlated with what was found by Cohen (2003). IH/TM focuses on healing the person and community and was found to be based on a “teleological” approach (i.e., “What can the disease teach the patient? Is there a message or story in the disease?”). As Cohen (2003) suggested, IH/TM was observed to be preventative rather than curative and should be a part of daily life. In a similar way, Waldram’s (2000) work supports the notion that IH/TM has more to do with healing than curing. In his work, Waldram (2000) also noted the common understanding of healing that is, “a broader psychosocial process of repairing the affective, social, and spiritual dimensions of ill health or illness” (p. 604). However, Waldram cautioned that although it may appear that Western medicine is focused only on “curing” and IH/TM is focused only on “healing,” this is not always the case. For Waldram, disease and illness taken together describe sickness, with cancer being the specific example highlighted in this study. Focusing on either curing disease or healing illness raises the risk that this single-minded approach may not be addressing the sickness that is cancer. Thus, as has been mentioned throughout this discussion, a willingness to consider braiding of the two healing methods as a viable option for cancer care is necessary.

For those participants who braided the two forms of healing successfully, it was found that braiding allowed Anishinaabek to approach their cancer care with two-eyed seeing. That is, they were able to have the best of what Western medicine had to offer as well as the best care from their IH/TM practitioner. It was acknowledged that braiding might

very well be necessary due to the loss of much Anishinaabe *gikendaasowin* regarding IH/TM and the onslaught of “new diseases,” including cancer, with which Western medicine can be beneficial. Western health care professionals also acknowledged the benefits of braiding, especially in the palliative stage of cancer. They also realized that there are some things that Western medicine cannot offer. It is also recognized that health care institutions are facilitating the introduction of braiding by developing policy and infrastructure to facilitate meeting Anishinaabe cultural needs. This is a positive initial step in an initially rigid system that is adjusting to accommodate patient choice.

Improvements can continue, however. A system-based finding illustrated the stark contrast in ideology between how Western medicine is delivered, especially in tertiary health care settings where the focus is on small physical domains of the body, and the holistic way in which Anishinaabek view life. In light of this, some researchers have suggested the focus of care should shift from being disease-centred to a whole person-centred approach (Steinsbekk & Launso, 2005). I believe this is possible with braiding as a component of cancer care, thus addressing the whole person. In this type of approach, the patient can better view themselves as a stakeholder in health care decision-making, and the physician can further the relationship by showing respect for Anishinaabe culture and delivering culturally safe care.

Overall, Anishinaabek viewed IH/TM as involving more than physical healing and was holistic in nature. Minobimaadiziwin and IH/TM were seen as involving balance of the physical, mental, emotional and spiritual domains and addressing the “big picture” (Cohen, 2003; Shahid et al., 2010). The participants believed all four of these domains

must function effectively to achieve Minobimaadiziwin and to cope effectively with cancer. Furthermore, all of the Anishinaabek participants viewed Western medicine as valued physical intervention on their journey with cancer. Some participants recognized that Minobimaadiziwin could not be realized with Western medicine alone. It was shared that with the inclusion of IH/TM and recognition of the spiritual component of life, a person can approach Minobimaadiziwin despite the obstacle of cancer along their path. This is best facilitated through braiding the two types of healing. The caveat stands that Anishinaabe people have diverse spiritual beliefs and that the braiding of IH/TM with Western medicine for cancer care should only be implemented according to individual beliefs and should consider their comfort level with IH/TM.

Recommendation: A new pedagogy for cancer care

Through the process of *biskaabiiyang* or “returning to ourselves” (Geniusz, 2009, p. 9), Anishinaabek have an opportunity to take collective responsibility for sharing our teachings with future generations, thereby fostering pride in Anishinaabe ways of knowing and being, which includes a return to IH/TM. The present study is a meaningful contribution to evidence-based medicine and to *biskaabiiyang* in the area of cancer. I propose that this can be accomplished with a new pedagogy for cancer care which is founded on returning to ourselves and the teachings of Minobimaadiziwin. The “Path of Life” or Minobimaadiziwin teaching has a long history as an effective instructional aid in ceremony (Angel, 2002). Therefore, it is not a far stretch of the imagination to propose that this teaching can also be applied to a new culturally safe tool for understanding cancer. This, in turn, would create better understandings of this complex disease and its treatment. The present study employed Anishinaabe *gikendaasowin* as a framework for

the collective teaching story and is intended as a new pedagogy for cancer education. The story was created with the aim of “reinterpreting the private and individual experience of illness into a more potent and collective experience of solidarity and heightened social and self-awareness” (Scheper-Hughes & Lock, 1986, p. 139).

Most Anishinaabek participants expressed that there was a general lack of cancer education; hence, there is a need for this new pedagogy of cancer to reflect the specific learning needs of Anishinaabek. It was felt by many participants that this pedagogy should be delivered by Anishinaabek who have “walked with cancer.” Larsen (2009) and Pierret (2003) both addressed the quest for meaning in the illness experience. They found that the perception of cancer is a reflection of its representation through images, metaphor and discourse with others, which will form the basis of the illness experience. I assert that the way in which this new pedagogy is delivered will have an impact on how Anishinaabe people will seek treatment and how they will ultimately experience cancer.

For Anishinaabek in this study, participants also recognized that cancer could be accepted as a “teacher.” This could be interpreted as an acceptance of change in their lives. Some participants referred to this as a “waking up” and that changes were necessary to get back on the path of Minobimaadiziwin. Similar findings in Pelusi & Krebs (2009) work with Native American cancer survivors reflected the perception of cancer as a lesson or gift which related to their spiritual teachings. Participants recognized that popular cultural metaphors for cancer (i.e., waging a war on cancer; or fighting cancer) were in conflict with Anishinaabek beliefs. It was interesting to note that the Western metaphors for

fighting or battling cancer were seen as impediments to the process of acceptance, were incongruent with Anishinaabe understandings of the illness and also impeded healing.

An explanation of cancer provided by this physician demonstrates the principles of balance and Minobimaadiziwin:

[Cancer] comes primarily from an imbalance within the system that isn't attended to. Gradually, it progresses from being just an imbalance in any of the four aspects of a person's being to a sort of an inflammation, a disease, and then eventually a lack of immune response because of the disease or illness within the person. I think cancer cells are probably forming all the time within people, but if you're in a good state of health and balance, you can get rid of them. If you're not, they build up to the point where they become noticeable by either tests or symptoms or signs.

(WHP06)

This straightforward explanation provides an excellent example of a culturally safe method which links directly to cultural understandings of Minobimaadiziwin. To further its meaning for Anishinaabek, it could be translated into *Anishinaabemowin* and be supplemented with images to meet a variety of learning styles, including visual. The graphic representations would assist the Anishinaabe patient in coming to terms with cancer. Many have stated that a person must acknowledge and face cancer and providing a visual image could assist in this process. A community Elder also shared that the visual image would help in the spiritual domain. Here, the visual would provide a focus for the

prayers in ceremony and personal prayer. In effect, an Anishinaabe person diagnosed with cancer would ask for assistance from spirit helpers with this visual cue in mind.

The Minobimaadiziwin teaching presented as a graphic could also represent the cancer experience as relatively short in comparison with the length of life's overall path (Figure 8). With the cancer experience is viewed in this way, it would be easier for cancer not to be permitted the power take over one's life, as many participants have cautioned others against. Participants in the Pelusi and Krebs (2009) study also shared that cancer should be thought of as a journey, only part of life's greater journey and should not consume daily life. The new pedagogy is perhaps a new way of framing positive messages and possibilities for changing the perception of cancer with respect to Minobimaadiziwin.

Despite many cancer messages being delivered daily via the media and agencies such as the Canadian Cancer Society or the Canadian Breast Cancer Foundation, Anishinaabe people still harbour worst-case scenario thinking (i.e., cancer is a death sentence). In the present study, one participant stated that this is often a truth for Anishinaabek. As a consequence of their fear and "waiting too long" many Anishinaabek will have a late-stage diagnosis with poorer outcomes (CPAC, 2012). It was also suggested that many Anishinaabek "do not know how to read their body's signals." It can be inferred that Anishinaabek do not have a frame of reference for Minobimaadiziwin or they have forgotten its meaning. As a result, there appears to be an absence of understanding or detection of when they are unwell or out of balance.

Some health care providers in my study have encouraged Anishinaabek to use introspection in their self-care and self-management. This means learning to do a self-

scan and learning what is normal for their health (and what is not), to improve their reading of possible symptoms of illnesses like cancer. This may require direct teaching by health care workers. Kalbfleisch (2009) addressed the fact that patients should be empowered to become informed health consumers (i.e., learn to ask questions and ask for care that is appropriate to their cultural needs) and stressed that a successful therapeutic relationship is also contingent upon the input of the patient. Hence, the notion of personal responsibility is relevant, where the onus is on the patient to acknowledge that there is a health problem and to make this known to the health care professional. In order to receive help or clarification when required, Anishinaabek need to be able to ask for that help and this, too, may also require teaching. This teaching, I argue, can be facilitated through use of the new pedagogy for cancer.

The use of *Anishinaabemowin* may also facilitate the teaching process in a variety of ways and should be a central component of this new pedagogy. One participant shared the concept of *mn'ji-ii-ish* [Translation: a recurring feeling of being unwell that can manifest as a negative experience]. Using *Anishinaabemowin* may bridge a gap between Western preventative medicine and Indigenous knowledge. Anishinaabek can be taught how to work with this feeling of *mn'ji-ii-ish* and being out of balance so that *chi-akoziwin* [Translation: term used to describe cancer; a great sickness that has the potential to take someone's life] cannot manifest at later stages. Another *Anishinaabemowin* term essential for this new pedagogy is *kam na dap nan akoziwin* [Translation: taking illness in a good way], and it concerns acceptance – it was interpreted as acceptance of cancer, of change or of death. I have found that language has profound implications for understanding the participants' stories and for improving my own understanding of the philosophy,

ontology and epistemology of the Manitoulin Anishinaabek. This new pedagogy should be disseminated with the inclusion of as much *Anishinaabemowin* as possible. Otherwise, it would be an exercise in futility.

For Anishinaabek, acceptance is synonymous with learning lessons from the experience. This means taking the illness that we have been given in a good way, being able to learn from that experience and moving on to the next part of the Spirit Journey. These teachings became especially apparent in the palliative/Western Doorway care stage of the cancer experience. The spirit teachings and, overall, the Minobimaadiziwin teaching concerning taking care of our spirit and each other (Appendix 12) became a focus for many in the Western Doorway stage of cancer, regardless of the spiritual tradition.

Family and community were central to achieving Minobimaadiziwin. The spirit teachings also helped families accept cancer and death. Similarly, Pelusi and Krebs (2009) found that spirit teachings helped to facilitate coping. Moreover, these spiritual understandings of death and dying take precedence at the palliative stage, a sacred time of transition to the Spirit World (Baydala, Hampton, Kinunwa, Kinunwa, & Kinunwa, 2006). Many Anishinaabek have to learn about and come to rely upon IH/TM in the Western Doorway stage of cancer. The new pedagogy can assist Western and Indigenous practitioners teach individuals and families about the Spirit Journey and Minobimaadiziwin and assist clients with *kam na dap nan akoziwin* and the acceptance of death.

It was unanimously agreed that cancer support was under resourced on Manitoulin Island. A cancer support group specifically for, and led by, Anishinaabek would benefit the Manitoulin communities. It was felt that this community-based support could provide the

much needed discussion around issues that went beyond the medical aspects of cancer, including the personal. It was also felt that the social implications of this group would be of benefit for those not willing or ready to share their difficulties or concerns about cancer with family. Pierret (2003) stated that some self-help groups have become patients' associations with the power to speak to the media and other authorities rallying against issues like stigmatization. This supportive function can also benefit Anishinaabek in advocating for the proper support and resources at the political level. The cancer support groups serve another purpose based in relationality and responsibility. All of the Anishinaabek in this study expressed that they wanted to help others who were experiencing cancer through the sharing of their stories. Pelusi & Krebs (2005) also found that Native American survivors felt some responsibility to help others to connect to the proper support and resources. Thus, an Anishinaabek cancer support group can serve as another meaningful outlet for sharing this new pedagogy of *Minobimaadiziwin* for cancer care whilst providing the necessary support throughout this experience.

As other Indigenous scholars have suggested, King, Smith and Gracey (2009) pose a compelling argument for why Indigenous peoples should be empowered to create their own solutions to address the gaps in inequity and overall Indigenous health concerns. However, this should not release the political powers from responsibility for providing the necessary support for culturally appropriate solutions, services and support (King, Smith & Gracey, 2009). "True healing cannot occur until mainstream society also heals – together" (King, Smith and Gracey, 2009, p. 83). While the proposed new pedagogy would ideally be planned for Indigenous peoples, by Indigenous peoples as a means to better health outcomes and closing the health inequity gap in the area of cancer,

assistance from and partnership with the dominant society should not be removed from consideration.

Limitations

One limitation concerned the relatively short amount of time for data collection and its effect on the sample size of the study. The data collection phase of the study was from September 6, 2012 to March 6, 2013. This fact, coupled with the relatively small population of the participating communities that were sampled, may have had an impact on the overall sample of the study. Despite the fact that the call for participants included anyone with cancer, the male Anishinaabe cancer perspective is lacking. Several reasons for this have been speculated. One speculation was that men, in general, have difficulty sharing their experiences with cancer, especially if they were cancers of the reproductive organs or colon (Boehmer & Clark, 2001; Gray, Fitch, Phillips, Labrecque & Fergus, 2000; Maliski, Rivera, Connor, Lopez & Litwin, 2008; Oliffe & Thorne, 2007; Papadopolos & Lees, 2004), and this difficulty might be amplified if they were also survivors of sexual abuse. Males may have been unwilling to share with myself or Karen, the community-based research assistant. Finally, it was also speculated that females use health care services at a higher rate than males (Bertakis, Azari, Helms, Callahan & Robbins, 2000; Courtenay, 2000) and therefore men would not be diagnosed or may be diagnosed with late-stage cancer.

A second limitation concerned the quality of interpretation by the principal researcher, who is not fluent in *Anishinaabemowin*. The participants were encouraged to use *Anishinaabemowin* and many did throughout their interview, which added a layer of

complication to the data analysis. Due to unforeseen circumstances, Karen, a fluent speaker of *Anishinaabemowin*, was unable to participate in all of the interviews. The member-checking letters to participants were disseminated without the completed translations. Thus, the translation occurred after member-checking with individual participants. This may have had an impact on interpretation where some of the original intent of the participants' words may have been lost. To compensate for this, the translation of concepts was later presented to community advisory committee members as well as community Elders who were fluent in *Anishinaabemowin*.

A third limitation concerned the possible recall bias in the participants' account of the treatment experience (Friedman, Skilling, Udaltsova & Smith, 2005; Hassan, 2005). For instance, the Anishinaabek with cancer did not share any of the physical struggles in accessing treatment and specialist care in a facility far from their homes. One community nurse with personal recent experience with her husband's cancer stated that the complex issues she experienced in getting her spouse to and from treatment were not reflected in the findings. It may have been that the participants did not recall those details of the experience because they were too ill at the time. This level of detail may be possible from the caregiver's perspective and would assist in addressing the everyday realities of experiencing cancer on Manitoulin Island.

A final limitation observed is that this study is representative of only the Anishinaabek on Manitoulin Island, and the findings may not be transferable to other populations.

However, other Indigenous scholars (Gracey & King, 2009; Kovach, 2009) have argued that Indigenous people share a collective history, similar health status, determinants of

health, as well as similar teachings, all of which may afford some application of these findings to other Indigenous peoples.

Strengths

This study represents a true attempt at a two-eyed seeing approach. It involved the use of Western theory (i.e., Critical Medical Anthropology and Participatory Action Research) while employing an Indigenous research paradigm with Indigenous methodology.

Moreover, this study was truly participatory in that it engaged the community from inception to the final dissemination of the research products. The research also aimed to encourage participants to use their language of choice in an effort to break down any barriers in sharing their ideology and feelings. The Anishinaabe language also served to explain the findings in a meaningful, good way.

The use of the conversational method promoted a true, collaborative, dialogue reflective of relationality between the participants and the researcher. This methodology allowed for depth in the conversations which may not have been possible without the unique quality of a researcher-in-relation or insider-researcher relationship. I contend that the methodology in concert with the rapport established between the researcher and participants lead to a richer data set than might have been otherwise possible. One participant described her participation in this research process as therapeutic and, in her words, “a healing encounter.”

Finally, the knowledge translation took into account a variety of audiences, and the implications of each were addressed throughout the study. Making the research relevant to Anishinaabek communities was of paramount importance. It stands to reason that a

variety of deliverables would increase accessibility of this information for Anishinaabek. The findings were presented in a story format for this reason. The study and its research products were aimed at Anishinaabek health care providers, organizations, Western health care professionals, policy makers, the academic community and the Anishinaabek community.

Implications for policy and future research

It was found that in order to conduct health research that was in true partnership with Indigenous peoples, it was imperative to couch the research in the terminology and ideology that resonated with that population. Failing to consider the language of the peoples will further serve to marginalize and disempower Indigenous peoples. As mentioned earlier, I have found that *Anishinaabemowin* had profound implications for understanding the stories and life ways of the Anishinaabek. I would caution other researchers to use the language which best articulates the philosophies, ontologies and epistemologies of the Indigenous peoples when developing future research projects.

This study considered the input of Anishinaabe people with cancer and health professionals working from both Western and Indigenous perspectives. One perspective that was limited is that of the caregivers' experience with their loved one's cancer. Clipp and George (1992) examined the reliability of caregiver informants in clinical settings by comparing the patterns in responses to those with cancer. There was low agreement between some aspects of the subjective cancer experience including "pain, confidence in treatment, time spent thinking about illness and fear of the future" where caregivers saw their loved one's illness in more of a negative light (Clipp & George, 1992, p. 1078).

However, the researchers stated that they do not know who projected the truer perception of patient functioning. In all, these researchers suggest that it is important to interview both the caregiver and the loved one with cancer to provide a more accurate picture of the cancer experience and the impact on families (Clipp & George, 1992). With respect to the present study, it was recommended that the caregiver's perspective be included in future research.

Pelusi and Krebs (2009) shared an implication of the findings in their study which I feel is also directly applicable to the present study: "Health care providers should spend less time talking about the intricacies of cancer and its treatment and more time looking at, listening to, and trying to understand how cancer and its treatments affect the everyday lives of the people and families [they] treat" (p. 16). Taking the time to listen to stories and attempting to respond to the cultural needs is an example of how relationship development between health care providers and their patients can be enhanced. It is understood that time is a limited quantity in this interaction, but it would be worth the investment for this difficult to reach population. It is suggested that the investment of time in both relationship development and training health care professionals for future work with Indigenous peoples be a priority for policy development – especially where there is a high Indigenous population.

Finally, I believe there are future opportunities for education, training and policy development for health care in the area of cancer and Indigenous populations. Ongoing cultural safety training is required at all levels of the health care system. This training should involve a focus on the cultural significance of braiding in addition to the

development of structural competence. This cultural safety training should include partnerships between Western and Indigenous health care providers to foster the development of mutual understanding of Minobimaadiziwin for their patients. With a better understanding of the cultural understandings of cancer and holistic healing, there should be a shared responsibility in the roll-out of this new cancer pedagogy specific to Anishinaabek. I believe that the state of cancer education can be improved with the input of both Western and Indigenous health care providers, as well as the input of those who have “walked with cancer.” The current health care policies regarding braiding IH/TM with Western treatments for cancer also require further attention to creating seamless health care delivery. Linklater (2011) reminds those interested in pursuing methods for change that any new proposed approach, especially one from an unfamiliar paradigm, may be challenged and resisted. The fact that cancer care is currently dominated by evidence-based medicine and clinical trials means that it may prove challenging to secure funding for program development, training design and further research. Despite this, the work is necessary for ensuring quality cancer care for Anishinaabek.

Concluding thoughts

It seems fitting to conclude with an outline of the potential benefits to the Anishinaabe community, as the research began with their interests in mind. A key goal of this research was to bring awareness and recognition of Indigenous healing methods and, specifically, to the contributions of Indigenous medicine for treating cancer. There was a paucity of research regarding Indigenous healing and its relationship to Western medicine in the context of cancer. This research contributes to the evidence-based research concerning the potential benefits of pluralistic medicine in relation to Indigenous health and healing

and has the potential to inform policy and practice. This research also emphasizes the need for culturally safe health care and encourages health professionals to be open to the prospect of empowering Aboriginal patients to choose healing models that are specific to achieving their Minobimaadiziwin.

A further aim of this dissertation was to build capacity for health research in the participating Anishinaabe communities. This research addressed the issue that community choice was a central tenet of the Tri-Council Policy Statement Ethical Conduct for Research Involving Humans (TCPS2, 2010). A community-based research assistant and a community advisory committee were involved in all aspects of this research, and this experience added to the research repertoire in those participating communities. Finally, the research aimed to improve awareness of the alternatives to treating cancer for Anishinaabe patients. The findings which emerge from this research have already begun to enhance strategic planning for health organizations that deliver cancer care services for Anishinaabe people. One First Nation community employed the findings as a measuring stick for a funding application to hire a community social worker. It is anticipated that this social worker will improve case coordination and liaise with local and regional hospitals for discharge planning. Another First Nation community has proposed that the findings of this study be presented at the Anishinaabe and provincial levels of government to lobby for improvements in palliative care for Anishinaabek communities.

This adapted excerpt of *The Seven Grandfathers and the Little Boy* speaks to the overall purpose of this new pedagogy for cancer care to impart the importance of learning

Anishinaabe teachings and the value of Indigenous healing/Traditional medicine for Minobimaadiziwin.

With the old man's return, the people became better adjusted physically to live on Earth. The people had a sense of hope that gave them the strength to face life's daily tasks. No longer did diseases claim so many lives. With the knowledge of the Seven Grandfathers and the gradual use of medicines to treat illnesses, the people approached that delicate balance that lies in living in harmony with all of Creation. It only remained now for the people to follow the path of Minobimaadiziwin laid out before them.

(Benton-Banai, 1988, p. 66).

This dissertation provided a novel approach to the qualitative study of the cancer experience and the use of Indigenous healing. In essence, this study conveyed the story and voice of the participants through a culturally-relevant paradigm for Anishinaabek. At the outset of this research, there were few studies addressing this topic, none of which employed an Indigenous approach to methodology. In conducting this research, I have based the interpretation of results and the frame of the discussion on the Minobimaadiziwin teachings of the Three Fires Midewiwin Society. I am grateful for and humbled by the Anishinaabe *Gikendaasowin* shared with me over the past twenty years of my life.

References

- Aboriginal Nurses Association of Canada. (2009). Cultural competence and cultural safety in First Nations, Inuit and Métis Nursing Education. Retrieved from <http://www.anac.on.ca/Documents/Making%20It%20Happen%20Curriculum%20Project/FINALFRAMEWORK.pdf>
- Absolon, K., & Willett, C. (2004). Aboriginal research: Berry picking and hunting in the 21st century. *First Peoples Child and Family Review, 1*(1). Retrieved from <http://journals.sfu.ca/fpcfr/index.php/FPCFR/article/view/5/2>
- Absolon, K., & Willett, C. (2005). Putting ourselves forward: Location in Aboriginal research. In L. Brown & S. Strega (Eds.), *Research and resistance: Critical, Indigenous, & anti-oppressive approaches*. (pp. 97-126). Toronto, ON: Canadian Scholars' Press/Women's Press. Retrieved from http://occupyresearchcollective.files.wordpress.com/2012/06/research_as_resistance_critical_indigenous_and_anti_oppressive_approaches1.pdf
- Adelson, N. (2000). *'Being alive well': Health and the politics of Cree well-being*. Toronto, ON: University of Toronto Press.
- Allan, B. & Smylie, J. (2015). First Peoples, second class treatment: The role of racism in the health and well-being of Indigenous peoples in Canada. Retrieved from <http://www.wellesleyinstitute.com/wp-content/uploads/2015/02/Report-First-Peoples-Second-Class-Treatment-Final.pdf>
- American Cancer Society. (2014). *Cancer basics: What is cancer?* Retrieved from <http://www.cancer.org/cancer/cancerbasics/what-is-cancer>

- American Cancer Society. (2014). *Family cancer syndromes*. Retrieved from <http://www.cancer.org/cancer/cancercauses/geneticsandcancer/heredity-and-cancer>
- Angel, M. (2002). *Preserving the sacred: Historical perspectives on the Ojibwa Midewiwin*. Winnipeg, MB: The University of Manitoba Press.
- Badarudeen, S., & Sabharwal, S. (2010). Assessing readability of patient education materials: Current role in orthopaedics. *Clinical Orthopaedics and Related Research*, 468(10). DOI: 10.1007/s11999-010-1380-y
- Barkwell, D. (2005). Cancer pain: Voices of the Ojibway people. *Journal of Pain and Symptom Management*, 30(5), 454-464.
<http://dx.doi.org/10.1016/j.jpainsymman.2005.04.008>
- Barton, S. (2004). Narrative inquiry: Locating Aboriginal epistemology in relational methodology. *Journal of Advanced Nursing*, 45(5), 519-526.
- Battiste, M. (2000). *Reclaiming Indigenous voice and vision*. Vancouver, BC: UBC Press.
- Battiste, M., & Henderson, J. (2000). *Protecting Indigenous knowledge and Heritage: A global challenge*. Saskatoon, SK: Purich Publishing Ltd.
- Baydala, A., Hampton, M., Kinunwa, L., Kinunwa, G., & Kinunwa, L. (2006). Death, dying, grieving, and end of life care: Understanding personal meanings of Aboriginal friends. *The Humanistic Psychologist*, 34(2), 159-176.
DOI:10.1207/s15473333thp3402_4
- Benton-Banai, E. (1988). *The Mishomis book: The voice of the Ojibway*. Hayward, WI: Indian Country Communications.

- Bertakis, K., Azari, R., Helms, L., Callahan, E., & Robbins, J. (2000). Gender differences in the utilization of health care services. *Journal of Family Practice*, 49(2), 147-152.
- Bishop, R. (1996, June). Collaborative storytelling: Meeting Indigenous people's desires for self-determination. Proceedings from the World Indigenous People's Conference: Education. Albuquerque, NM.
- Boehmer, U., & Clark, J. (2001). Communication about prostate cancer between men and their wives. *Journal of Family Practice*, 50(3), 226-23.
- Bourgeault, I., Dingwall, R. & de Vries, R. (Eds.). (2010). *The SAGE handbook of qualitative methods in health research*. Thousand Oaks, CA: SAGE Publications Inc.
- Brady, M. (1995). Culture in treatment. Culture as treatment: A critical appraisal of developments in addictions programs for indigenous North Americans and Australians. *Social Science and Medicine*, 41(11), 1487-1498.
- Brody, E.M. (1981). Women in the middle and family help to older people. *The Gerontologist*, 21, 471-480.
- Broome, B. & Broome, R. (2007). Native Americans: Traditional healing. *Urologic Nursing*, 27 (2), 161-173.
- Browne, A., & Fiske, J. (2001). First Nations women's encounters with mainstream health care services. *Western Journal of Nursing Research*, 23(2), 126-147.
- Butow, P., Tattersal, M., & Goldstein, D. (1997). Communication with cancer patients in culturally diverse societies. *Annals of the New York Academy of Sciences*, 809, 317-329. DOI: 10.1111/j.1749-6632.1997.tb48095.x

- Buyx, A. (2008). Personal responsibility for health as a rationing criterion: Why we don't like it and why maybe we should. *Journal of Ethics*, 34 (12), 871-874.
DOI:10.1136/jme.2007.024059
- Campbell, V. (2011). The challenges of cancer pain assessment and management. *Ulster Medical Journal*, 80(2), 104-106.
<http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3229856/pdf/umj8002-104.pdf>
- Canadian Breast Cancer Foundation. (2015). *Know your breasts*. Retrieved from
<http://www.cbcf.org/ontario/AboutBreastHealth/BeBreastAware/Pages/Know-Your-Breasts.aspx>
- Canadian Partnership Against Cancer. (2011). *First Nations, Inuit and Métis action plan on cancer control*. Retrieved from <http://www.partnershipagainstcancer.ca/wp-content/uploads/First-Nations-Inuit-and-M%C3%A9tis-Action-Plan-on-Cancer-Control-June-2011.pdf>
- Canadian Partnership Against Cancer. (2012). "Walk a mile in my moccasins": *Foundations for action in First Nations cancer control*. Retrieved from
http://www.cancerview.ca/idc/groups/public/documents/webcontent/fnim_cancer_ctrl_on_res.pdf
- Cancer Care Ontario. (2002). *Aboriginal cancer care needs assessment: analysis of the findings*. Retrieved from
<http://www.cancercare.on.ca/common/pages/UserFile.aspx?fileId=13686>
- Cancer Care Ontario. (2002). *Report of the Aboriginal cancer care needs assessment: It's our responsibility*. Retrieved from
<http://www.cancercare.on.ca/common/pages/UserFile.aspx?fileId=13836>

- Cancer Care Ontario. (2012). *Aboriginal cancer strategy II*. Retrieved from <https://www.cancercare.on.ca/common/pages/UserFile.aspx?fileId=138007>
- Chiefs of Ontario. (2013). *A guide for First Nations in Ontario: Navigating the non-insured health benefits & Ontario health programs benefits*. Retrieved from <http://www.chiefs-of-ontario.org/sites/default/files/files/NIHB%20Guide%20Jan%202013.pdf>
- Clarke, V., & Holtslander, L. (2010). Finding a balanced approach: Incorporating medicine wheel teachings in the care of Aboriginal people at the end of life. *Journal of Palliative Care*, 26(1), 34-36.
- Clipp, L., & George, E. (1992). Patients with cancer and their spouse caregivers: Perceptions of the illness experience. *Cancer*, 69(4), 1074-1079.
DOI: 10.1002/1097-0142(19920215)69:4<1074::AID-CNCR2820690440>3.0.CO;2-L
- Cohen, K. (2003). *Honouring the medicine: The essential guide to Native American healing*. New York, NY: One World Ballantine Books.
- Conrad, P., & Barker, K. (2010). The social construction of illness: Key insights and policy implications. *Journal of Health and Social Behaviour*, 51(S), 67-79.
- Cote-Meek, S. (2011). *Decolonization and the helping professions* [PowerPoint Slides]. Ph.D. Program Guest Lecture IRNH 6105.
- Coulehan, J. (1980). Navajo Indian medicine: Implications for healing. *The Journal of Family Practice*, 10(1), 55-61.

- Courtenay, W. (2000). Constructions of masculinity and their influence on men's well-being: A theory of gender and health. *Social Science and Medicine*, 50(10), 1385-1401.
- Czyzewski, K. (2011). Colonialism as a broader social determinant of health. *International Indigenous Policy Journal*, 2(1). Retrieved from <http://ir.lib.uwo.ca/cgi/viewcontent.cgi?article=1016&context=iipi>
- Deloria Jr., V. (2004). Philosophy and the Tribal peoples. In A. Waters (Ed.), *American Indian Thought: Philosophical Essays*. (pp. 3-11). Malden, MA: Blackwell Publishing.
- Denzin, N., Lincoln, Y., & Tuhiwai Smith, L. (2008). *Handbook of critical and Indigenous methodologies*. Los Angeles, CA: Sage Publications, Inc.
- DeSouza, R. (2008). Wellness for all: The possibilities of cultural safety and cultural competence in New Zealand. *Journal of Research in Nursing*, 13(2), 125-135. DOI: 10.1177/1744987108088637
- Dumont, J., & National Native Addictions Partnership Foundation. (2014). Definition of culture. *Honouring Our Strengths: Indigenous Culture as Intervention in Addictions Treatment Project*. Muskoday, SK. Retrieved from <http://www.addictionresearchchair.ca/wp-content/uploads/2012/04/Definition-of-culture.pdf>
- Duran, E. (2006). *Healing the soul wound: Counselling with American Indians and other Native peoples*. New York, NY: Teachers College Press.

- Durey, A., Thompson, S., & Wood, M. (2012). Time to bring down the twin towers in poor Aboriginal hospital care: Addressing institutional racism and misunderstandings in communication. *Internal Medicine Journal*, 42(1), 17-22.
- Dyson, S. & Brown, B. (2006). *Social theory and applied health research*. New York: Open University Press.
- Ermine, W., Sinclair, R., & Jeffery, B. (2004). *The ethics of research involving Indigenous peoples: Report of the Indigenous peoples' health research centre*. Retrieved from http://iphrc.ca/assets/Documents/ethics_review_iphrc.pdf
- Evans, M., Hole, R., Berg, L., Hutchinson, P., & Sookraj, D. (2009). Common insights, differing methodologies: Toward a fusion of Indigenous methodologies, participatory action research, and white studies in an urban Aboriginal research agenda. *Qualitative Inquiry*, 15(5), 893-910.
- Farmer, P., Nizeye, B., Stulac, S., & Keshavjee, S. (2006). Structural violence and clinical medicine. *PLoS Medicine*, 3(10), 1686-1691. Retrieved from <http://journals.plos.org/plosmedicine/article?id=10.1371/journal.pmed.0030449>
- Fletcher, F., Baydala, L., Letendre, L., Ruttan, L., Worrell, S., Letendre, S., & Schramm, T. (2011). "No lone person:" The ethics consent process as an ethical dilemma in carrying out community-based participatory research with a First Nations community. *Pimatisiwin: A Journal of Aboriginal and Indigenous Community Health*, 9(2), 323-348. Retrieved from http://www.pimatisiwin.com/uploads/jan_20112/04.1FletcherBaydala.pdf
- Foucault, M. (1975). *The birth of the clinic: An archaeology of medical perception*. New York, NY: Vintage Books.

- Freidson, E. (1970). *Profession of medicine: A study of the sociology of applied knowledge*. New York, NY: Harper and Row.
- Friedman, G., Skilling, J., Udaltsova, N., Smith, L. (2005). Early symptoms of ovarian cancer: A case-control study without recall bias. *Family Practice*, 22(5), 548–553.
DOI: 10.1093/fampra/cmi044
- Geniusz, W. (2009). *Our knowledge is not primitive: Decolonizing botanical Anishinaabe teachings*. Syracuse, NY: Syracuse University Press.
- Gone, J. (2006). Research reservations: Response and responsibility in an American Indian community. *American Journal of Community Psychology*, 37, 333-340.
Retrieved from <http://gonetowar.com/wp-content/uploads/2013/11/reservations.pdf>
- Gould, J., Sinding, C., Mitchell, T., Gustafson, D., Peng, I., McGillicuddy, P., Fitch, M., Aronson, J., & Burhansstipanov, L. (2009). “Below their notice”: Exploring women’s subjective experiences of cancer system exclusion. *Journal of Cancer Education*, 24(4), 308-314.
- Gracey, M., & King, M. (2009). Indigenous health part 1: Determinants and disease patterns. *The Lancet*, 374, 65-75.
- Graveline, F. (1998). *Circle works: Transforming Eurocentric consciousness*. Halifax, NS: Fernwood Publishing.
- Gray, R., Fitch, M., Phillips, C., Labrecque, M., & Fergus, K. (2000). To tell or not to tell: Patterns of disclosure among men with prostate cancer. *Psycho-Oncology*, 9, 273-282.
- Guadagnolo, B., Cina, K., Helbig, P., Molloy, K., Reiner, M., Cook, E., & Petereit, D. (2009). Medical mistrust and less satisfaction with health care among Native

- Americans presenting for cancer treatment. *Journal of Health Care for the Poor and Underserved*, 20(1), 210-226. DOI: [10.1353/hpu.0.0108](https://doi.org/10.1353/hpu.0.0108)
- Gurley, D., Novins, D., Jones, M., Beals, J., Shore, J. & Manson, S. (2001). Comparative use of biomedical services and traditional healing options by American Indian veterans. *Psychiatric Services*, 52(1), 68-74.
- Hallowell, A. (1967 [1955]). *Culture and Experience*. New York, NY: Schocken Books.
- Hankard, M. (2013). Barriers to accessing traditional healer travel funding form off-reserve. *Indigenous Policy Journal*, 24(1). Retrieved from <http://www.indigenouspolicy.org/index.php/ipj/article/view/151/157>
- Hart, M. (2002). *Seeking mino-pimatisiwin: An Aboriginal approach to helping*. Halifax, NS: Fernwood Publishing.
- Hassan, E. (2005). Recall Bias can be a threat to retrospective and prospective research designs. *The Internet Journal of Epidemiology*, 3(2). Retrieved from <https://ispub.com/IJE/3/2/13060>
- Hatcher, A., Bartlett, C., Marshall, A., & Marshall, M. (2009). Two-eyed seeing in the classroom environment: Concepts, approaches, and challenges. *Canadian Journal of Science, Mathematics and Technology Education*, 9(3), 141-153. Retrieved from <http://www.integrativescience.ca/uploads/articles/Hatcher-et-al-2009-CJSMT-Two-Eyed-Seeing-classroom-concepts-approaches-challenges.pdf>
- Health Canada. (2014). *Your health benefits – A guide for First Nations to access non-insured health benefits*. Retrieved from http://www.hc-sc.gc.ca/fniah-spnia/alt_formats/pdf/pubs/nihb-ssna/yhb-vss/nihb-ssna-yhb-vss-eng.pdf

- Health Council of Canada. (2012). Empathy, dignity and respect: Creating cultural safety for Aboriginal people in urban health care. Ottawa, ON. Retrieved from http://www.naccho.org.au/download/aboriginal-health/Canda%20Aboriginal_Report-Cultural%20safety.pdf
- Hunter, L., Logan, J., Goulet, J., & Barton, S. (2006). Aboriginal healing: Regaining balance and culture. *Journal of Transcultural Nursing*, 17(1), 13-22. DOI: 10.1177/1043659605278937
- Indian and Northern Affairs Canada. (1996). *Report of the Royal Commission on Aboriginal Peoples*, 3. Retrieved from http://www.collectionscanada.gc.ca/webarchives/20071207000526/http://www.aainc.gc.ca/ch/rcap/sg/sia3a_e.html#Appendix%203A:%20Traditional%20Health%20and%20Healing
- International Symposium on the Social Determinants of Indigenous Health Adelaide. (2007). *Social determinants and indigenous health: The international experience and its policy implications*. Retrieved from http://www.who.int/social_determinants/resources/indigenous_health_adelaide_report_07.pdf
- Jacklin, K. & Kinoshameg, P. (2008). Developing a participatory aboriginal health research project: Only if it's going to mean something. *Journal of empirical research on human research ethics*, 3(2), 53-68.
- Jacklin, K. & Warry, W. (2004). The Indian health transfer policy in Canada: Toward self-determination or cost containment? In A. Castro & M. Singer (Eds.),

- Unhealthy health policy: A critical anthropological examination* (215-234).
Walnut Creek, CA: Altamira Press.
- Jacklin, K & Warry, W. (2011). Decolonizing First Nations Health. In J. Kulig & A. Williams (Eds.), *Rural Health: A Canadian Perspective* (373-234). University of British Columbia Press.
- Javid, S., Varghese, T., Morris, A., Porter, M., He, H., Buchwald, D., & Flum, D. (2014). Guideline-concordant cancer care and survival among American Indian/Alaskan Native patients. *Cancer*, 120(14), 2183-2190. DOI: 10.1002/cncr.28683
- Johnson, M., & Ruttan, R. (1991). *Traditional environmental knowledge of the Dene: A pilot Project*. Hay River, NWT: Dene Cultural Institute. Retrieved from <http://library.umac.mo/ebooks/b11695237.pdf#page=25>
- Kalbfleisch, P. (2009). Effective health communication in Native populations in North America. *Journal of Language and Social Psychology*, 28(2), 158-173.
- Kelly, L., & Brown, J. (2002). Listening to Native patients: Changes in physicians' understanding and behaviour. *Canadian Family Physician*, 48, 1645-1652.
- Kewayosh, A., Marrett, L., Aslam, U., Steiner, R., Moy Lum-Kwong, M., Imre, J., & Amartey, A. (2015). Improving health inequity for First Nations, Inuit and Métis People: Ontario's Aboriginal Cancer Strategy II. *Healthcare Quarterly*, 17(SP), 33-40. DOI:10.12927/hcq.2014.24007
- Kim, C. & Kwok, Y.S. (1998). Navajo use of native healers. *Archives of Internal Medicine*, 158(20), 2245-2249.
- King, M., Smith, A., & Gracey, M. (2009). Indigenous health part 2: The underlying causes of the health gap. *The Lancet*, 374, 76-85.

- Kirmayer, L., Gone, J., Moses, J. (2014). Rethinking historical trauma. *Transcultural Psychiatry*, 51(3), 299-319. DOI: 10.1177/1363461514536358
- Kovach, M. (2009). *Indigenous methodologies: Characteristics, conversations, and contexts*. Toronto, ON: University of Toronto Press.
- Kovach, M. (2010). Conversational method in Indigenous research. *First Peoples Child & Family Review*, 5(1), 40-48.
- Larsen, P. (2009). Illness behaviour. In P. Larsen & I. Lubkin (Eds.), *Chronic illness: Impact and Intervention, 7th Edition*. Burlington, MA: Jones & Bartlett Learning.
- Lavallee, L. (2009). Practical application of an Indigenous research framework and two qualitative Indigenous research methods: Sharing circles and Anishnaabe symbol-based reflection. *International Journal of Qualitative Methods*, 8(1). Retrieved from
http://www.ryerson.ca/asbr/projectsasbr_files/Indigenous%20Research%20Framework%20and%20Methods.pdf
- Linklater, R. (2011). *Decolonizing trauma work: Indigenous practitioners share stories and strategies*. Retrieved from
https://tspace.library.utoronto.ca/bitstream/1807/31696/3/Broadbridge_Legge_Linklater_Renee_L_201111_PhD_thesis.pdf
- Lipowski, E.E. (2008). Developing great research questions. *American Journal of Health-System Pharmacists*, 65(17), 1667-1670.
- Loppie-Reading, C., & Wien, F. (2009). *Health inequalities and social determinants of Aboriginal peoples' health*. Prince George, BC: National Collaborating Centre for

Aboriginal Health. Retrieved from http://www.nccah-ccnsa.ca/docs/social%20determinates/nccah-loppie-wien_report.pdf

Lucero, E. (2011). From tradition to evidence: Decolonization of the evidence-based practice system. *Journal of Psychoactive Drugs*, 43(4), 319-324. DOI: 10.1080/02791072.2011.628925

Lux, M. (2001). *Medicine that walks: Disease, Medicine and Canadian plains Native people, 1880-1940*. Toronto, ON: University of Toronto Press.

Maar, M., Lightfoot N., Sutherland, M., Strasser, R., & Wilson K. (2009). *Collaborative Aboriginal Cancer Research: Priorities and Strategies for the Future Based on the Results from the "Go to the People" Consultations*. Northern Ontario School of Medicine, Sudbury, Ontario.

Maar, M., Manitowabi, D., Gzik, D., McGregor, L., & Corbiere, C. (2011). Serious complications for patients, care providers and policy makers: Tackling the structural violence of First Nations people living with diabetes in Canada. *The International Indigenous Policy Journal*, 2(1). Retrieved from: <http://ir.lib.uwo.ca/iipj/vol2/iss1/6>

Maar, M. & Shawande, M. (2010). Traditional Anishinabe healing in a clinical setting: The development of an Aboriginal interdisciplinary approach to community-based Aboriginal mental health care. *Journal of Aboriginal Health*, January. Retrieved from http://www.naho.ca/jah/english/jah06_01/v6_I1_Traditional_Anishinabe_Healing.pdf

- Macaulay, A. (2009). Improving Aboriginal health: How can health care professionals contribute? *Canadian Family Physician*, 55(4), 334-336
<http://www.cfp.ca/content/55/4/334.full.pdf+html>
- Macaulay, A., Commanda, L., Freeman, W., Gibson, N., McCabe, M., Robbins, C., & Twohig, P. (1999). Participatory research maximizes community and lay involvement. *British Medical Journal*, 319(7212), 774-778.
- Maina, F. (2003). Indigenous “insider” academics: Educational research or advocacy? *The Canadian Journal of Native Studies*, 23(2), 207-226.
- Maliski, S., Rivera, S., Connor, S., Lopez, G., & Litwin, M. (2008). Renegotiating masculine identity after prostate cancer treatment. *Qualitative Health Research*, 18, 1609-1620.
- Manitowabi, D., & Shawande, M. (2011). The meaning of Anishinabe healing and wellbeing on Manitoulin Island. *Pimatisiwin: A Journal of Aboriginal and Indigenous Community Health*, 9(2), 441-458. Retrieved from
http://www.pimatisiwin.com/uploads/jan_20112/10ManitowabiShawande.pdf
- Manitowabi, D., Williamson, P. & Shawande, M. (2009). *Assessing the institutionalization of traditional Aboriginal medicine*. Retrieved from
<http://www.noojmowin-teg.ca/Newsletters%20and%20Reports/Noojmowin%20Teg%20Traditional%20Medicine%20Program%20Research%20Final%20Report%20July%2016%202009.pdf>
- Marbella, A., Harris, M., Diehr, S., Ignace, G. & Ignace, G. (1998). Use of Native American healers among Native American patients in an urban Native American health center. *Archives of Family Medicine*, 7, 182-185.

- Marrett, L., & Chaudhry, M. (2003). Cancer incidence and mortality in Ontario First Nations, 1968-1991 (Canada). *Cancer Causes and Control*, 14(3), 259-268.
- Marsden, D. (2004). Expanding knowledge through dreaming, wampum and visual arts. *Pimatisiwin: A Journal of Aboriginal and Indigenous Community Health*, 2(2). Retrieved from <http://www.pimatisiwin.com/uploads/1193385529.pdf>
- Martin-Hill, D. (2003). *Traditional medicine in contemporary contexts: Protecting and respecting indigenous knowledge and medicine*. NAHO. Retrieved from http://www.naho.ca/documents/naho/english/pdf/research_tradition.pdf
- Martin-Hill, D. (2009). Traditional medicine and restoration of wellness strategies. *Journal of Aboriginal Health*, 5(1), 26-42.
- Mehl-Madrona, L. (1999). Native American medicine in the treatment of chronic illness: Developing an integrated program and evaluating its effectiveness. *Alternative Therapies in Health and Medicine*, 5(1), 36-44.
- Mehl-Madrona, L. (2008). Narratives of exceptional survivors who work with Aboriginal healers. *The Journal of Alternative and Complementary Medicine*, 14(5): 497-504.
- Metzl, J. & Hansen, H. (2014). Structural competency: Theorizing a new medical engagement with stigma and inequality. *Social Science and Medicine*, 103, 126-133. DOI: [10.1016/j.socscimed.2013.06.032](https://doi.org/10.1016/j.socscimed.2013.06.032)
- Mikkonen, J., & Raphael, D. (2010). *Social determinants of health: The Canadian Facts*. Toronto, ON: York University School of Health Policy and Management. Retrieved from http://www.thecanadianfacts.org/the_canadian_facts.pdf

- Ministry of Health and Long-Term Care. (2012, November 30). *Northern health travel grant program*. Retrieved from <http://www.health.gov.on.ca/en/public/publications/ohip/northern.aspx>
- Minkler, M. (2000). Personal responsibility for health: Contexts and controversies. In D. Callahan (Ed.), *Promoting healthy behaviour*. (1-22). Georgetown University Press.
- Minore, B., Boone, M., Cromarty, H., Katt, M., Kinch, P., & Power, M. (2002). *It's just so different up here: Continuity of care for cancer patients in northwestern Ontario First Nation communities*. Centre for Rural and Northern Health Research. Retrieved from http://www.cranhr.ca/pdf/Its_Just_So_Different_Up_Here_2002.pdf
- Mitchell, J. (1998). Cross-cultural issues in the disclosure of cancer. *Cancer Practice*, 6(3), 153-160.
- National Aboriginal Health Organization. (2012, March). Integrating traditional medicines into Western medical treatment: Fact sheet. Retrieved from http://www.naho.ca/documents/naho/english/factSheets/2012_03_Fact-Sheet-traditional-medicine.pdf
- National Collaborating Centre for Aboriginal Health. (2011). *Looking for Aboriginal Health in Legislation and Policies, 1970-2008: The Policy Synthesis Project*. Retrieved from <http://www.nccah-ccnsa.ca/Publications/Lists/Publications/Attachments/28/Looking%20for%20Aboriginal%20Health%20in%20Legislation%20and%20Polcies%20%28English%20-%20Web%29.pdf>

- National Post. (2014). *Children's Aid Steps in After 11-year old Trades Chemo for Native Remedies*. Retrieved from <http://news.nationalpost.com/2014/05/14/girls-decision-to-drop-chemotherapy-in-favour-of-aboriginal-medicine-prompts-childrens-aid-intervention/>
- Nauman, E. (2007). Native American medicine and cardiovascular disease. *Cardiology in Review*, 15 (1), 35-41.
- Nelson, A. (2007). Seeing white: A critical exploration of occupational therapy with Indigenous Australian people. *Occupational Therapy International*, 14(4), 237-255.
- Noojmowin Teg Health Centre. (2003). *Guidelines for ethical Aboriginal research*. Retrieved from <http://www.noojmowin-teg.ca/Shared%20Documents/GEAR%20-%20FINAL.pdf>
- Oliffe, J., & Thorne, S. (2007). Men, masculinities, and prostate cancer: Australian and Canadian patient perspectives of communication with male physicians. *Qualitative Health Research*, 17(2), 149-161.
- Pace, J. (2013). *Meanings of memory: Understanding and dementia in First Nations communities on Manitoulin Island, Ontario* (Unpublished doctoral dissertation). McMaster University, Hamilton, ON.
- Papadopolos, I., & Lees, S. (2004). Cancer and communication: Similarities and differences of men with cancer for six different ethnic groups. *European Journal of Cancer Care*, 13, 154-162.
- Peltier, C. (2013). My Indigenous research paradigm: Staying true to my roots. In A. Corbiere, D. McGregor & C. Migwans (Eds.), *Anishinaabewin Niswi Deep Roots, New Growth 2012* (pp. 31-40). M'Chigeeng, ON: Ojibwe Cultural Foundation.

- Pelusi, J. & Krebs, L. (2005). Understanding cancer – understanding the stories of life and living. *Journal of Cancer Education*, 20(Suppl.), 12-16.
- Pidgeon, M., & Hardy Cox, D. (2002). Researching with Aboriginal peoples: Practices and principles. *Canadian Journal of Native Education*, 26(2), 96-106.
- Pierret, J. (2003). The illness experience: State of knowledge and perspectives for research. *Sociology of Health and Illness*, 25, 4-22.
- Puchala, C., Paul, S., Kennedy, C. & Mehl-Madrona, L. (2010). Using traditional spirituality to reduce domestic violence within Aboriginal communities. *The Journal of Alternative and Complementary Medicine*, 16(1), 89-96.
- Reading, C. (2013). *Understanding Racism*. Prince George, BC: National Collaborating Centre for Aboriginal Health. Retrieved from http://www.nccah-ccnsa.ca/Publications/Lists/Publications/Attachments/103/understanding_racism_EN_web.pdf
- Rheault, D. (1999). *Anishinaabe Mino-Bimaadiziwin: The way of a good life*. Peterborough, ON: Debwewin Press.
- Rose, D. (2011). Captive audience? Strategies for acquiring food in two Detroit neighborhoods. *Qualitative Health Research*, 21(5), 642-651. DOI: 10.1177/1049732310387159
- Saini, M. (2012). *A systematic review of Western and Aboriginal research designs: Assessing cross-validation to explore compatibility and convergence*. Prince George, BC: National Collaborating Centre for Aboriginal Health. Retrieved from [http://www.nccah-](http://www.nccah-ccnsa.ca/Publications/Lists/Publications/Attachments/103/understanding_racism_EN_web.pdf)

ccnsa.ca/Publications/Lists/Publications/Attachments/54/review_research_designs_web.pdf

- Scheper-Hughes, N., & Lock, M. (1986). Speaking “truth” to illness: Metaphors, reification, and a pedagogy for patients. *Medical Anthropology Quarterly*, 17(5), 137-140.
- Shahid, S., Blears, R., Bessarab, D., & Thompson, S. (2010). “If you don’t believe it, it won’t help you”: Use of bush medicine in treating cancer among Aboriginal people in Western Australia. *Journal of Ethnobiology and Ethnomedicine*, 6(18): 1-9.
- Shahid, S., Finn, L., Bessarab, D., & Thompson, S. (2011). ‘Nowhere to room ... nobody told them’: Logistical and cultural impediments to Aboriginal peoples’ participation in cancer treatment. *Australian Health Review*, 35, 235-241.
- Shahid, S., Finn, L., & Thompson, S. (2009). Barriers to participation of Aboriginal people in cancer care: Communication in the hospital setting. *Medical Journal of Australia*, 190(10), 574-579.
- Shelley, B., Sussman, A., Williams, R., Segal, A. & Crabtree, B. (2009). ‘They don’t ask me so I don’t tell them’: Patient-clinician communication about traditional, complementary, and alternative medicine. *Annals of Family Medicine*, 7(2), 139-147.
- Sibthorpe, B., Bailie, R., Brady, M., Ball, S., Sumner-Dodd, P., & Hall, W. (2002). The demise of a planned randomised controlled trial in an urban Aboriginal medical service. *The Medical Journal of Australia*, 176(6), 273-276.

- Simonds, V., Christopher, S., Sequist, T., Colditz, G., & Rudd, R. (2011). Exploring patient-provider interactions in a Native American community. *Journal of Health Care for the Poor and Underserved*, 22, 836-852.
- Singer, M. (1993). Knowledge for use: Anthropology and community-centred substance abuse research. *Social Science and Medicine*, 37(1), 15-25.
- Singer, M. (1994). Community-centred praxis: Toward an alternative non-dominative applied anthropology. *Human Organization*, 53(4), 336-344.
- Singer, M. & Baer, H. (1995). *Critical medical anthropology*. Amityville, NY: Baywood Publishing Company, Inc.
- Smith, H. (1932). Ethnobotany of the Ojibwe Indians. *Bulletin of the Public Museum of the City of Milwaukee*, 4(3), 327-525.
- Smye, V., & Browne, A. (2002). 'Cultural safety' and the analysis of public policy affecting aboriginal people. *Nurse Researcher*, 9(3), 42-56.
- Smye, V., Josewski, V., & Kendall, E. (2010). Cultural safety: An overview. Retrieved from <http://www.troubleshumeur.ca/documents/Publications/CULTURAL%20SAFETY%20AN%20OVERVIEW%20%28draft%20mar%202010%29.pdf>
- Spillman, B.C., & Pezzin, L.E. (2000). Potential and active family caregivers: Changing networks and the "sandwich generation". *The Milbank Quarterly*, 78, 347-374.
- Statistics Canada. (2012b). Sucker Creek 23, Ontario (Code 3551041) and Manitoulin, Ontario (Code 3551) (table). Census Profile. 2011 Census. Statistics Canada Catalogue no. 98-316-XWE. Ottawa. Released October 24, 2012. [358](http://www12.statcan.gc.ca/census-recensement/2011/dp-</p></div><div data-bbox=)

[e2=35&Data=Count&SearchText=Sheshegwaning&SearchType=Begins&SearchPR=01&B1=All&Custom=](http://www12.statcan.gc.ca/census-recensement/2011/dp-pd/prof/details/page.cfm?Lang=E&Geo1=CSD&Code1=3551040&Geo2=CD&Code2=3551&Data=Count&SearchText=Sheshegwaning&SearchType=Begins&SearchPR=01&B1=All&Custom=) (accessed November 28, 2014).

Statistics Canada. (2012f). Whitefish River (Part) 4, Ontario (Code 3551040) and Manitoulin, Ontario (Code 3551) (table). Census Profile. 2011 Census. Statistics Canada Catalogue no. 98-316-XWE. Ottawa. Released October 24, 2012.

<http://www12.statcan.gc.ca/census-recensement/2011/dp-pd/prof/details/page.cfm?Lang=E&Geo1=CSD&Code1=3551040&Geo2=CD&Code2=3551&Data=Count&SearchText=Whitefish%20River&SearchType=Begins&SearchPR=01&B1=All&Custom=&TABID=1> (accessed November 28, 2014).

Statistics Canada. (2012g). Wikwemikong Unceded, Ontario (Code 3551043) and Manitoulin, Ontario (Code 3551) (table). Census Profile. 2011 Census. Statistics Canada Catalogue no. 98-316-XWE. Ottawa. Released October 24, 2012.

<http://www12.statcan.gc.ca/census-recensement/2011/dp-pd/prof/details/page.cfm?Lang=E&Geo1=CSD&Code1=3551043&Geo2=CD&Code2=3551&Data=Count&SearchText=Wikwemikong&SearchType=Begins&SearchPR=01&B1=All&Custom=&TABID=1> (accessed November 28, 2014).

Statistics Canada. (2012h). Zhiibaahaasing 19A (Cockburn Island 19A), Ontario (Code 3551100) and Manitoulin, Ontario (Code 3551) (table). Census Profile. 2011 Census. Statistics Canada Catalogue no. 98-316-XWE. Ottawa. Released

October 24, 2012. <http://www12.statcan.gc.ca/census-recensement/2011/dp-pd/prof/details/page.cfm?Lang=E&Geo1=CSD&Code1=3551100&Geo2=CD&Code2=3551&Data=Count&SearchText=Zhiibaahaasing&SearchType=Begins&SearchPR=01&B1=All&Custom=&TABID=1> (accessed November 28, 2014).

- Statistics Canada. (2013a). Manitoulin, DIS, Ontario (Code 3551) (table). National Household Survey (NHS) Profile. 2011 Census. Statistics Canada Catalogue no. 99-004-XWE. Ottawa. Released June 26, 2013.
- <http://www12.statcan.gc.ca/nhs-enm/2011/dp-pd/prof/details/page.cfm?Lang=E&Geo1=CD&Code1=3551&Data=Count&SearchText=manitoulin&SearchType=Begins&SearchPR=35&A1=All&B1=All&Custom=&TABID=1> (accessed November 28, 2014).
- Steinsbekk, A., & Launso, L. (2005). Empowering the cancer patient or controlling the tumor? A qualitative study of how cancer patients experience consultations with complementary and alternative medicine practitioners and physicians, respectively. *Integrative Cancer Therapies, 4*(2), 195-200.
- Stevens, R. (1998). American Indian and Indigenous peoples' sovereignty and authority in cultural, historical and environmental studies: Developing cooperative research for resource management, repatriation and education. *Dissertation Abstracts International, 4201*.
- St. Pierre-Hansen, N., Kelly, L., Linkewich, B., Cromarty, H. & Walker, R. (2010). Translating research into practice: Developing cross-cultural First Nations palliative care. *Journal of Palliative Care, 26*(1), 41-46.
- Struthers, R. (2000). The lived experience of Ojibwa and Cree women healers. *Journal of Holistic Nursing, 18*(3), 261-279.
- Struthers, R. (2001, Spring). Conducting sacred research: An Indigenous experience. *Wicazo Sa Review, 16*(1): 125-133. Retrieved from

<http://nursing.ucla.edu/workfiles/CAIIRE/Articles/conducting%20sacred%20research.pdf>

- Struthers, R. (2003). The artistry and ability of traditional women healers. *Health Care for Women International, 24*(4), 340-354.
- Struthers, R., & Eschiti, V.S. (2004). The experience of Indigenous traditional healing and cancer. *Integrative Cancer Therapies, 3*(1), 13-23.
- Struthers, R., Eschiti, V.S., & Patchell, B. (2004). Traditional indigenous healing: Part I. *Complementary Therapies in Nursing and Midwifery, 10*, 141-149.
DOI:10.1016/j.ctnm.2004.05.001
- Struthers, R., Eschiti, V.S., & Patchell, B. (2005). Being healed by an indigenous traditional healer: sacred healing stories of Native Americans: Part II. *Complementary Therapies in Clinical Practice, 11*, 78-86.
DOI:10.1016/j.ctnm.2004.05.002
- Struthers, R., Eschiti, V.S., & Patchell, B. (2008). The experience of being an Anishinabe man healer: Ancient healing in a modern world. *Journal of Cultural Diversity, 15* (2), 70-75.
- Struthers, R., & Peden-McAlpine, C. (2005). Phenomenological research among Canadian and United States Indigenous populations: Oral traditions and quintessence of time. *Qualitative Health Research, 15*(9), 1264-1276.
- Sullivan, T., & Baranek, P. (2002). *First do no harm: Making sense of Canadian health reform*. Toronto, ON: UBC Press.
- TCPS2, Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, and Social Sciences and Humanities Research

- Council of Canada. (2010). *Tri-Council policy statement: Ethical conduct for research involving humans*. Retrieved from http://www.pre.ethics.gc.ca/pdf/eng/tcps2/TCPS_2_FINAL_Web.pdf
- Terblanche, M., & Burgess, L. (2010). Examining the readability of patient-informed consent forms. *Open Access Journal of Clinical Trials*, 2. DOI: 10.2147/OAJCT.S13608
- Tuhiwai Smith, L. (1999). *Decolonizing methodologies: Research and Indigenous peoples*. New York, NY: Zed Books Ltd.
- United Nations. (2008). *United Nations declaration on the rights of Indigenous peoples*. Retrieved from http://www.un.org/esa/socdev/unpfii/documents/DRIPS_en.pdf
- van Schaik, K., & Thompson, S. (2012). Indigenous beliefs about biomedical and bush medicine treatment efficacy for indigenous cancer patients: A review of the literature. *Internal Medicine Journal*, 42(2): 184-191.
- Waldram, J. (2000). The efficacy of traditional medicine: Current theoretical and methodological issues. *Medical Anthropology Quarterly*, 14(4), 603-625.
- Waldram, J., Herring, A., & Young, T. (2006). *Aboriginal health in Canada: Historical, cultural, and epidemiological perspectives, 2nd Edition*. Toronto, ON: University of Toronto Press.
- Walker, P. (2001). Journeys around the Medicine Wheel: A story of Indigenous research in a Western university. *The Australian Journal of Indigenous Education*, 29(2), 18-21.
- Walker, R., Cromarty, H., Linkewich, B., Semple, D., St. Pierre-Hansen, N., & Kelly, L. (2010). Achieving cultural integration in health services: Design of

comprehensive hospital model for Traditional healing, medicines, foods and supports. *Journal of Aboriginal Health, January*. Retrieved from http://www.naho.ca/documents/journal/jah06_01/06_01_06_Cultural_Integration_in_Health_Services.pdf

Warry, W. (1998). *Unfinished dreams: Community healing and the reality of Aboriginal self-government*. Toronto, ON: University of Toronto Press.

Weber-Pillwax, C. (2001). What is Indigenous research? *Canadian Journal of Native Education, 25*(2), 166-174.

Weber-Pillwax, C. (2004). Indigenous researchers and Indigenous research methods: Cultural influences or cultural determinants of research methods. *Pimatisiwin: A Journal of Aboriginal and Indigenous Community Health, 2*(1). Retrieved from <http://www.pimatisiwin.com/uploads/1470824524.pdf>

Wikwemikong Board of Education & Kenjgewin Teg Educational Institute. (1995). *Three Fires Confederacy historical research project: Elder interviews, Book 1*. Wikwemikong, ON.

Wilson, S. (2001). What is an Indigenous research methodology? *Canadian Journal of Native Education, 25*(2), 175-179.

Wilson, S. (2008). *Research is ceremony: Indigenous research methods*. Halifax, NS: Fernwood Publishing.

World Health Organization. (2000). *General guidelines for methodologies on research and evaluation of traditional medicine*. Retrieved from http://whqlibdoc.who.int/hq/2000/WHO_EDM_TRM_2000.1.pdf?ua=1

- Young, T. (1994). *The health of Native Americans: Towards a biocultural epidemiology*.
New York, NY: Oxford University Press.
- Young, T., & Choi, N. (1985). Cancer risks among residents of Manitoba Indian
reserves, 1970-1979. *Canadian Medical Association Journal*, *132*, 1269-1272.
- Young, T., & Frank, J. (1983). Cancer surveillance in a remote Indian population in
northwestern Ontario. *American Journal of Public Health*, *73*, 515-520.
- Zubek, E. (1994). Traditional Native healing: Alternative or adjunct to modern medicine?
Canadian Family Physician, *40* (11), 1923-1931.

Appendix 1: Laurentian University REB Ethics Approval



APPROVAL FOR CONDUCTING RESEARCH INVOLVING HUMAN SUBJECTS Research Ethics Board – Laurentian University

This letter confirms that the research project identified below has successfully passed the ethics review by the Laurentian University Research Ethics Board (REB). Your ethics approval date, other milestone dates, and any special conditions for your project are indicated below.

TYPE OF APPROVAL / New / Modifications to project X / Time extension X	
Name of Principal Investigator and school/department	Cindy Peltier
Title of Project	The Lived Experience of Anishinaabe People with Cancer: A Focus on Indigenous Healing, Non-Indigenous Medicine and Minobimaadiziwin
REB file number	2012-02-07
Date of original approval of project	March 12, 2012
Date of approval of project modifications or extension (if applicable)	July 5, 2012
Final/Interim report due on: <i>(You may request an extension at that time using this weblink)</i>	July 5, 2013
Conditions placed on project	Final report due on July 5, 2013

During the course of your research, no deviations from, or changes to, the protocol, recruitment or consent forms may be initiated without prior written approval from the REB. If you wish to modify your research project, please refer to the Research Ethics website to complete the appropriate [REB form](#).

All projects must submit a report to REB at least once per year. If involvement with human participants continues for longer than one year (e.g. you have not completed the objectives of the study and have not yet terminated contact with the participants, except for feedback of final results to participants), you must request an extension using the appropriate [REB form](#).

In all cases, please ensure that your research complies with [Tri-Council Policy Statement \(TCPS\)](#). Also please quote your REB file number on all future correspondence with the REB office.

Congratulations and best of luck in conducting your research.

Susan James, Acting chair
Laurentian University Research Ethics Board

Appendix 2: Health Sciences North REB Notification of Ethics Approval



Research Ethics Office
Children's Treatment Centre
41 Ramsey Lake Road
Sudbury, ON P3E 5J1
t: 705-523-7100, ext. 2409
email: reb@hnsudbury.ca

To: Cindy Peltier

Study Title: The Lived Experience of Anishinaabe People with Cancer: A Focus on Indigenous Healing, Non-Indigenous Medicine and Minobimaadiziwin

Sponsor: Training Scholarship HRSRH Volunteer Association
Indigenous Health Research Development Program

REB Review Type: Delegated

Date of Review: October 5, 2012

Notification of Approval for an Amendment

Documents Approved

Research Information and Participant Consent Form (Updated September 2012)
Research Information and Key Informant Consent Form (Updated September 2012)

Documents Acknowledged

Manitoulin Anishinaabek Research Review Committee Approval (March 27, 2012)
Mnaamodzawin Health Services Inc. Letter of Support (April 27, 2012)
Laurentian University REB Approval (July 5, 2012)
Funding Letter – Laurentian University (March 7, 2012)
Funding Letter – Indigenous Health Research Development Program (July 30, 2012)

Project Number: 869

The Research Ethics Board of Health Sciences North has reviewed the amendment request for the above research protocol.

The above Project Identification Number has been assigned to your project. Please use this number on all future correspondence.

Sincerely,

A handwritten signature in blue ink, appearing to read 'M. Shine'.

Dr. Martin Shine, Chair, Health Sciences North Research Ethics Board

The Health Sciences North Research Ethics Board operates in compliance with and is constituted in accordance with the requirements of TCPS 2 – 2nd Edition of the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans, the International Conference on Harmonization of Good Clinical Practices, Part C Division 5 of the Food and Drug Regulations of Health Canada and the provisions of the Ontario Personal Health Information Protection Act 2004 and its applicable Regulations. The HSN REB is registered with the U.S. Department of Health & Human Services under the IRB registration number IRB00003080.

**Appendix 3: Manitoulin Anishinaabek Research Review Committee Ethics
Approval**

Manitoulin Anishinaabek Research Review Committee

c/o Noojmowin Teg Health Centre
Attention: Lenore Mayers
Postal Bag 2002, Hwy 540
Little Current, ON P0P 1K0
Tel: (705) 368-2182 ext. 201
Fax: (705) 368-2229
melissa.biedermann@noojmowin-teg.ca

This is to certify that the research proposal entitled The Lived Experience of Anishinaabe People with Cancer: A Focus on Indigenous Healing, Non-Indigenous Medicine, and Minobimaadiziwin submitted by Cindy Peltier on March 12, 2012 has passed an ethics review by a subcommittee of the Manitoulin Anishinaabek Research Review Committee (MARRC).

Project Start Date: March 2012

Project Finish Date: April 2013

Conditions:

No conditions.

Please note:

This MARRC Ethics Certificate does not authorize a project to proceed. ***Projects must be approved by the respective First Nation community and/or organization.***

This certificate covers only the documents submitted, in the language in which they have been submitted. During the course of research, no deviations from, or changes to the protocol, recruitment or the consent process and form may be initiated without prior written clearance from the MARRC. If you wish to modify your research project please submit a letter outlining the proposed changes to the MARRC Secretary.

Within 6 months of completion of your research project, a report on the completed research project should be submitted to the MARRC secretary. The report shall include information on the following: the number of research participants, whether any problems were encountered during the course of the research as well as the main findings. Published articles would also be appreciated so that the MARRC can build a virtual resource library.

Congratulations and best of luck with your research!

Sincerely,



Lorrilee McGregor, Chairperson
MARRC

Date: March 27, 2012

Appendix 4: Community Research Agreement Form

A copy of the research proposal will be attached to this form.

The Lived Experience of Anishinaabe People with Cancer: A Focus on Indigenous
Healing, Western Medicine and Minobimaadiziwin

1.1 This research agreement establishes the basis of the relationship

*1.2 between **Cindy M. Peltier (Investigator), Dr. Kristen Jacklin, Dr. Nancy Lightfoot (Supervisors)***

*1.3 of **Laurentian University***

*1.4 and **Wikwemikong, _____ (UCCMM Community) and/or _____ Heath Centre***

In signing this document, the principal researcher and the representatives of the Health Centre acknowledge the following:

- (i) All research activities and reports or publications arising from research at the Centre will conform to the **research principles** outlined in the Guidelines for Ethical Aboriginal Research, and the **code of ethics** corresponding to the Tri-Council Policy Statement (TCPS2, 2010) and Laurentian University.
- (ii) All data collected shall be coded in a manner that guarantees the **anonymity and confidentiality** of the research participants; that is, data will be coded in a way that does not allow for identification of individual research participants. Except when agreed upon by the research participants (i.e., they may wish to have their contributions acknowledged by name, community and/or organization).
- (iii) Data from the study will be stored in a secure location. Digital recordings and interview notes will be labelled with pseudonyms. Transcripts and other raw data will only be seen by members of the research group.
- (iv) Upon completion of the study, within 5 years, data that are collected in the context of the research study shall be destroyed. This could include transcripts and digital recordings from interviews. The analysis and interpretation that arises from the raw data will remain the property of the researcher.
- (v) Authors of a publication (community reports, journal articles, presentations or products etcetera) will be listed in the order of the significance of their contribution to the writing of the publication and will include all, and only those individuals who have made a significant intellectual or scholarly contribution to the work reported, and without whose contribution the work would not be complete. Authors of a piece may include the researchers or _____ Health Centre staff persons, volunteers and Board members who have made contributions

to the writing of the publication. Members of the steering committee and other individuals instrumental to the project will be acknowledged in all publications.

- (vi) Results of community research shall be distributed as widely as possible within participating communities, and reasonable efforts shall be made to present results in non-technical language and Aboriginal languages where appropriate.
- (vii) Any reports or publications arising from the research shall be submitted to the Director of _____ Health Centre prior to distribution to communities and agencies or submission for publication. _____ Health Centre will review the proposed publications for adherence to this research agreement within 20 days.
- (viii) The _____ Health Centre shall be provided with copies of all reports/papers derived from the research project.
- (ix) The researcher shall report on an ongoing basis to the Executive Director or _____ Health Director and the Community Advisory Committee or designate on the development, planning, implementation and results of the research.
- (x) The data collected and stored may not be made accessible to other researchers and/or used for research purposes other than those agreed upon without the Health Centre's knowledge and consent and without informed consent of participants.

_____	_____
Signature of the Health/Executive Director	Date
_____	_____
Signature of the Principal Researcher	Date
_____	_____
Signature of a Community Advisory Committee Appointee	Date

(Adapted from Noojmowin Teg Health Centre, 2003)

Appendix 5: Research Information and Participant Consent Form



Cindy M. Peltier
School of Rural and Northern
Health
Laurentian University
705-859-1588
cm_peltier@laurentian.ca

Supervisor:
Dr. Kristen Jacklin
Northern Ontario School
of Medicine
Laurentian University
705-662-7277
kjacklin@nosm.ca

Supervisor:
Dr. Nancy Lightfoot
School of Rural and
Northern Health
Laurentian University
705-675-1151 ext. 3972
1-800-461-4030 ext. 3972
nlightfoot@laurentian.ca

Committee Member:
Dr. Susan James
School of Midwifery
Laurentian University
705-675-1151 ext. 3957
1-800-461-4030 ext. 3957
sjames@laurentian.ca

I, _____, agree to participate in the research, *The Lived Experience of Anishinaabe People with Cancer: A Focus on Indigenous Healing, Western Medicine and Minobimaadiziwin*, conducted by Cindy M. Peltier, a graduate student in the Interdisciplinary Ph.D. program in Rural and Northern Health, at Laurentian University. The project is under the co-supervision of Dr. Kristen Jacklin of the Northern Ontario School of Medicine and Dr. Nancy Lightfoot of the School of Rural and Northern Health.

What is the purpose of the research?

The purpose of the research is to understand how my life has been affected by cancer through the use of Indigenous healing *and* non-Indigenous medicine (Western medicine) or through the use of non-Indigenous (Western medicine) medicine *alone*. This holistic study will look at my health and the Anishinaabe concept of minobimaadiziwin - my mental, physical, emotional and spiritual well-being during cancer treatment.

What is my involvement in the research?

I understand that the research will consist of me agreeing to be interviewed for one interview that will be two to three hours in length. The time for the interview may be broken up if I get tired. During these interviews, I will be asked questions by the researcher or research assistant about how my life has been affected by cancer and its treatment. I have been invited to take part in this research because the researcher feels that my experience as a patient and community member can contribute much to her understanding and knowledge of local health practices regarding cancer and its treatment. I understand that my interview will be recorded via digital audio recorder. I may also choose to consent to sharing my story in written or video format for the purposes of creating a book or video about cancer and healing for Anishinaabe people.

Will my information be kept confidential?

I understand that the contents of this research will be used by the researcher only for the purposes of her PhD thesis research, including sharing with colleagues at academic conferences and in academic publications. I understand that my anonymity will be respected (real names will not be used, and no personal details will be disclosed that could reveal my real identity). My identity will be protected through the use of a pseudonym (a made-up name) when the researcher is analyzing the material, in writing publications and while presenting at conferences about the research. However, I may wish to have my contributions acknowledged and agree to being identified by name and community in order that I may leave a legacy with the recording of my story.

I understand that community-based research assistants are working under the supervision of the Cindy M. Peltier. The community-based research assistants will keep the information I share confidential and I have been informed that they are required to sign a Statement of Confidentiality.

Appendix 6: Research Information and Key Informant Consent Form



Cindy M. Peltier
School of Rural and Northern
Health
Laurentian University
705-859-1588
cm_peltier@laurentian.ca

Supervisor:
Dr. Kristen Jacklin
Northern Ontario School
of Medicine
Laurentian University
705-662-7277
kjacklin@nosm.ca

Supervisor:
Dr. Nancy Lightfoot
School of Rural and
Northern Health
Laurentian University
705-675-1151 ext. 3972
1-800-461-4030 ext. 3972
nlightfoot@laurentian.ca

Committee Member:
Dr. Susan James
School of Midwifery
Laurentian University
705-675-1151 ext. 3957
1-800-461-4030 ext. 3957
sjames@laurentian.ca

I, _____, agree to participate in the research, *The Lived Experience of Anishinaabe People with Cancer: A Focus on Indigenous Healing, Western Medicine and Minobimaadiziwin*, conducted by Cindy M. Peltier, a graduate student in the Interdisciplinary Ph.D. program in Rural and Northern Health, at Laurentian University. The project is under the co-supervision of Dr. Kristen Jacklin of the Northern Ontario School of Medicine and Dr. Nancy Lightfoot of the School of Rural and Northern Health.

What is the purpose of the research?

The purpose of the research is to understand how the lives of Anishinaabe people have been affected by cancer through the use of Indigenous healing *and* non-Indigenous medicine (Western medicine) or through the use of non-Indigenous (Western medicine) medicine *alone*. This holistic study will explore the Anishinaabe concept of minobimaadiziwin - the mental, physical, emotional and spiritual well-being of a person during cancer treatment.

What is my involvement in the research?

I understand that the research will consist of me agreeing to be interviewed for one interview that will be one to three hours in length depending on the extent of the information that I will share. The time for the interview may be broken up into smaller sessions, for my convenience. During these interviews, I will be asked questions by the researcher or research assistant about my role in the Anishinaabe patient's cancer experience and its treatment. I have been invited to take part in this research because the researcher feels that my experience as a healer or health professional can inform and contribute much to her understanding and knowledge of local health practices regarding cancer and its treatment. I understand that my interview will be recorded via digital audio recorder. I may also choose to consent to sharing my story in written or video format for the purposes of creating a book or video about cancer and healing for Anishinaabe people.

Will my information be kept confidential?

I understand that the contents of this research will be used by the researcher only for the purposes of her PhD thesis research, including sharing with colleagues at academic conferences and in academic publications. I understand that my anonymity will be respected (real names will not be used, and no personal details will be disclosed that could reveal my real identity). My identity will be protected through the use of a pseudonym (a made-up name) when the researcher is analyzing the material, in writing publications and while presenting at conferences about the research. However, I may wish to have my contributions acknowledged and agree to being identified by name, community and/or organization.

I understand that community-based research assistants are working under the supervision of the Cindy M. Peltier. The community-based research assistants will keep the information I share confidential and I have been informed that they are required to sign a Statement of Confidentiality.

What happens if I choose not to participate in the research?

My participation in this research is entirely voluntary. It is my choice whether to participate or not. If I feel uncomfortable about any questions that are asked of me, I can refuse to answer at

any time during the interview, or I can ask for the interview to stop. I am under no pressure to answer all of the questions, and I have been told by the researcher that I can stop at any time and I will still receive \$75.00 for my participation.

Where will my information be kept during the research project?

I understand that digital recordings of interviews and other data collected will be kept in a secure manner. Contents will be kept in a locked filing cabinet only accessible to the researcher at the researcher’s home office. During the research project, the data will only be available to the researcher and her research assistants. After 5 years, the digital recordings and other data collected will be destroyed.

What are the benefits to this research?

This research will bring awareness to the contributions of Indigenous medicine for treating cancer. It will contribute to evidence-based research concerning the potential benefits of making available a variety of treatment options for Aboriginal people and will have the potential to inform policy and practice. The research will emphasize the need for culturally safe and appropriate health care and will encourage health professionals to be open to the prospect of empowering Aboriginal patients to choose healing methods appropriate to them. For those participating communities, the research will build capacity for health research.

Who can I contact if I have concerns about this research project?

If I am concerned about any aspect of this research, I can talk to the researcher or her supervisors using the contact information provided above on this form. I can also contact Laurentian University about my rights as a research participant or about the conduct of the research project: Laurentian University Research Office or telephone 1-800-461-4030 ext. 3213.

There are two copies of the consent form, one of which I may keep.

I consent to participate in the research project entitled, “*The Lived Experience of Anishinaabe People with Cancer: A Focus on Indigenous Healing, Western Medicine and Minobimaadiziwin*”

Researcher’s signature

Date

Research participant’s signature

Date

I consent to have my contribution acknowledged and agree to be identified by name and community.

Research participant’s initials

I agree to share my information as a teaching story in written or video format for the purposes of creating a book or video about cancer and healing for Anishinaabe people.

Research participant’s initials

Documentation of Verbal Consent:

Tobacco was accepted by _____ on _____ at _____.
Research participant’s name Date Location

Appendix 7: Statement Respecting Confidentiality

I _____ hereby acknowledge and understand that during the course of carrying out my work as a community-based research assistant for the study entitled, *The Lived Experience of Anishinaabe People with Cancer: A Focus on Indigenous Healing, Western Medicine and Minobimaadiziwin*, under the supervision of Cindy M. Peltier, Principal Investigator, I will be dealing with information that is confidential and sensitive for the participating communities, health organizations and study participants.

I hereby agree to hold any information that I learn about communities, organizations and participants, due to my involvement in this study, confidential. I also accept that I will be ethically required not to disclose or release it to any person at any time.

Dated at _____ this _____ day of _____.

Signature

Witness

(Adapted from Nahndahweh Tchigehgamig Wikwemikong Health Centre, 2012)

Appendix 8: Questions for Anishinaabe People Diagnosed with Cancer

Part 1: Minobimaadiziwin

1. What is meant by Minobimaadiziwin (holistic well-being)? What does it mean to you?
2. Are you currently using any form of Indigenous (traditional) medicine)?
3. If yes, how does the use of Indigenous (traditional) healing help in achieving Minobimaadiziwin?
4. How does Western medicine (chemotherapy, radiation) help in achieving Minobimaadiziwin?

Part 2: Perspectives of Cancer

1. What do you think cancer is?
2. Why do you think people get cancer?
3. Where do you think cancer comes from?
4. How does cancer change an Anishinaabe (Aboriginal) person's life?
5. How does cancer affect Minobimaadiziwin (i.e. physical, mental, emotional, spiritual well-being)?

Part 3: Personal Cancer Experience

1. Describe your experiences with cancer diagnosis?
2. Describe your experiences with the treatment phase?
3. Have you had cancer before? What is your experience with the cancer recurring?
4. How has cancer affected your family?
5. How has cancer affected your community?

Part 4: Coping or Dealing with Cancer

1. How are you coping or dealing with cancer in all aspects of your life (i.e., physical, mental, emotional, spiritual)?
2. Do you have any lessons to share with others about how to cope with cancer?
3. Has it helped you grow as a person? If so, how has it helped you grow as a person?
4. What are some sources of strength in living with cancer?
5. What are some of the difficulties in living with cancer?
6. Have you had a change in attitude toward cancer?

Part 5: Health Care Seeking Behaviour and Treatment

1. Are you currently using (or do you plan to use) any forms of Western medicine in your cancer treatment?
2. Why did you choose to use Western medicine?
3. If you did not choose to use Western medicine, can you share the reasons why you did not?
4. Are you currently using (or do you plan to use) any forms of Indigenous healing (traditional medicine or care) in your cancer treatment?
5. Why did you choose to use Indigenous healing (traditional medicine)?
6. Where did you get information about Indigenous healing (traditional medicine)?

7. If you used or plan to use Indigenous healing, how did you locate and connect with an Indigenous (traditional) healer?
8. If you did not choose to use Indigenous (traditional) healing, can you share the reasons why you did not?

Part 6: “Braiding” of Health Care Treatment Plans

1. Have you had difficulty in blending Indigenous (traditional) and Western medical approaches to cancer care?
2. Have you talked about your cancer treatment plan with an Indigenous (traditional) healer?
3. Have you talked about Indigenous (traditional) healing with your doctor, nurse or other health professionals?

Part 7: Relationships with Health Care Provider(s)

1. Describe your relationship with your doctor(s).
2. Describe your relationship with your cancer care specialist(s).
3. Describe your relationship with the health care team in your community.
4. Describe your relationship with your Indigenous (traditional) healer.

Part 8: Healing Encounters

1. Can you share a specific example of a healing experience?
2. Share how this healing experience affected your health or Minobimaadiziwin.

Part 9: Supportive Care: Family Support

1. Has your family helped you deal with cancer? If not, why not? (Go on to the next section if the response is no).
2. Describe the role your family has played in your cancer care?
3. How has your family helped you in coping with cancer and its treatment?

Part 10: Services Received

1. What types of health services related to cancer are you currently receiving?
2. What types of supportive care, outside of health care services, do you think would make a difference for Anishinaabe people with cancer?

Part 11: Palliative Care

Palliative Care or End-of-life Care: Palliative care is an approach to care for people who are living with a life-threatening illness. The focus of care is on achieving comfort and ensuring respect for the person nearing death and maximizing quality of life for the patient, family and loved ones.

1. What role does Indigenous (traditional) healing play in achieving Minobimaadiziwin at the palliative stage?
2. What role does Western medicine play in achieving Minobimaadiziwin at the palliative stage?

Part 12: Access

1. In your experience, what do you see as common issues or barriers to accessing cancer treatment or services for Anishinaabe (Aboriginal) people from Manitoulin Island?
2. In your experience, what do you see as common issues or barriers to accessing Indigenous (traditional) healing for Anishinaabe people from Manitoulin Island?
3. In your experience, have you had any positive experiences in access to cancer care for Anishinaabe people from Manitoulin Island?

Part 13: Cancer Screening

1. Are you aware of Ontario's cancer screening program?
Yes No
2. Did you participate in colorectal, cervical or breast cancer screening?
Yes No
3. If yes, how did you learn about the cancer screening program?
4. If no, why didn't you participate in cancer screening?

Appendix 9: Questions for Western Perspective Key Informants

Part 1: Minobimaadiziwin

1. What is meant by Minobimaadiziwin (holistic well-being)? What does it mean to you?
2. How does the use of Indigenous healing (traditional medicine) help in achieving Minobimaadiziwin?
3. How does Western medicine help in achieving Minobimaadiziwin?

Part 2: Perspectives of Cancer

1. What do you think cancer is?
2. Why do you think people get cancer?
3. Where do you think cancer comes from?
4. How does cancer change an Anishinaabe (Aboriginal) person's life?
5. How does cancer affect Minobimaadiziwin (i.e., physical, mental, emotional, spiritual well-being)?

Part 3: Cancer Experiences of Clients

1. Describe some success stories or positive experiences you have had with the "cancer journey" (i.e., diagnosis, treatment phase, palliative or end-of-life stage)?
2. Describe some challenging experiences you have had with the "cancer journey."
3. At what stage, from the time of diagnosis to palliative care, do people have the most difficulty in dealing with cancer?
4. How does cancer affect the family of Anishinaabe (Aboriginal) people?
5. How does cancer affect the Anishinaabe (Aboriginal) community?

Part 4: Coping or Dealing with Cancer

1. Describe how you help Anishinaabe (Aboriginal) people cope or deal with cancer in all aspects of life (i.e., physical, mental, emotional, spiritual)?
2. Do you have any lessons to share with others about how to cope with cancer or how it has helped with personal growth of those you've helped?
3. What are some sources of strength you have observed in those living with cancer?
4. What are some challenges you have observed in those living with cancer?
5. Have any of the people you've helped had a change in attitude toward cancer?

Part 5: Health Care Seeking Behaviour and Treatment

1. Where do clients go to get information about Indigenous (traditional) healing?
2. Does the use of Indigenous (traditional) medicine or healing play a role in the lives of your clients?
3. Can you describe what types of Indigenous (traditional) healing clients use for cancer care?

Part 6: "Braiding" of Health Care Treatment Plans

1. How do you help the client integrate the care you provide with what they receive from an Indigenous (traditional) healer?

2. What are the challenges in talking to your clients about other approaches to health?
3. Do your clients talk about Indigenous (traditional) healing with you? If so, can you please describe?

Part 7: Supportive Care: Family Support

1. Describe the role family plays in cancer care?

Part 8: Services Received

1. What types of supportive care, outside of health care services, do you think would make a difference for Anishinaabe people with cancer?

Part 9: Palliative Care

1. What role does Indigenous (traditional) healing play in achieving Minobimaadziwin at the palliative stage?
2. What role does Western medicine play in achieving Minobimaadziwin at the palliative stage?

Part 10: Access

1. In your experience, what do you see as common issues or barriers to accessing cancer treatment or services for Anishinaabe (Aboriginal) people from Manitoulin Island?
2. In your experience, have you seen positive changes in access to cancer care for Anishinaabe people from Manitoulin Island?

Appendix 10: Questions for Indigenous Healing Perspective Key Informants

Part 1: Minobimaadiziwin

1. What is meant by Minobimaadiziwin (holistic well-being)? What does it mean to you?
2. How does the use of Indigenous healing (traditional medicine) help in achieving Minobimaadiziwin?
3. How does Western medicine help in achieving Minobimaadiziwin?

Part 2: Perspectives of Cancer

1. What do you think cancer is?
2. Why do you think people get cancer?
3. Where do you think cancer comes from?
4. How does cancer change an Anishinaabe (Aboriginal) person's life?
5. How does cancer affect Minobimaadiziwin (i.e., physical, mental, emotional, spiritual well-being)?

Part 3: Cancer Experiences of Clients

1. Describe some success stories or positive experiences you have had with the "cancer journey" (i.e., diagnosis, treatment phase, palliative or end-of-life stage)?
2. Describe some challenging experiences you have had with the "cancer journey."
3. At what stage, from the time of diagnosis to palliative care, do people have the most difficulty in dealing with cancer?
4. How does cancer affect the family of Anishinaabe (Aboriginal) people?
5. How does cancer affect the Anishinaabe (Aboriginal) community?

Part 4: Coping or Dealing with Cancer

1. Describe how you help Anishinaabe (Aboriginal) people cope or deal with cancer in all aspects of life (i.e., physical, mental, emotional, spiritual)?
2. Do you have any lessons to share with others about how to cope with cancer or how it has helped with personal growth of those you've helped?
3. What are some sources of strength you have observed in those living with cancer?
4. What are some challenges you have observed in those living with cancer?
5. Have any of the people you've helped had a change in attitude toward cancer?

Part 5: Health Care Seeking Behaviour and Treatment

1. Where do clients go to get information about Indigenous (traditional) healing?

Part 6: "Braiding" of Health Care Treatment Plans

1. Explain how you provide Indigenous (traditional) healing in a world dominated by Western medicine?
2. What are the challenges in talking to your clients about other approaches to health?
3. Do your clients talk about their cancer treatment plan with you? If so, can you please describe?

Part 7: Healing Encounters

1. Can you describe the care you provide for clients with cancer?
2. How does this affect the client's Minobimaadiziwin?

Part 8: Supportive Care: Family Support

1. Describe the role family plays in cancer care?

Part 9: Services Received

1. What types of supportive care, outside of health care services, do you think would make a difference for Anishinaabe people with cancer?

Part 10: Palliative Care

1. What role does Indigenous (traditional) healing play in achieving Minobimaadiziwin at the palliative stage?
2. What role does Western medicine play in achieving Minobimaadiziwin at the palliative stage?

Part 11: Access

1. In your experience, what do you see as common issues or barriers to accessing Indigenous (traditional) healing for Anishinaabe people from Manitoulin Island?
2. In your experience, have you seen positive changes in access to cancer care for Anishinaabe people from Manitoulin Island?

Appendix 11: Member-Checking Interview Summary Sample

April 2, 2013

Re: Your participation in my research project

Dear APDC05,

I hope you are feeling well when this package reaches you. I wanted to start by saying *chi miigwech* for agreeing to participate in my research project. The important information you have provided for my project will help others who are going through their own cancer experiences.

One of the things that I said I would do is to send you a written copy of what you told me when we had our visit in the fall. Enclosed in this package is a copy of my analysis of the interview for your review. Keep in mind that it may contain items that are repeated because these items fit into a number of my sub-themes.

In order to make sure that I have not misinterpreted anything that you have said or meant to say, I have shared with you some of the key points from your interview that I would like to include in my research paper. If any of the points that I have made are not what you would like me to share or you would like to change anything, please let me know.

If there is something you want to talk about or change, you can either call or email me at:

Phone: 705-859-1588 (home)

Email: cm_peltier@laurentian.ca

or

cindy.peltier@gmail.com

The time you have spent with me will not be forgotten and is very much appreciated. I will treat all of your information with the greatest of respect. *Chi miigwech*, APDC05 and I hope you are feeling better. Take care of yourself.

Sincerely,

Cindy M. Peltier
PhD Candidate, Laurentian University

Interview Summary:

APDC05 was pleased to participate in the study. She assured me during our review of the consent documentation that, for her, there were personal benefits to participating in this interview. APDC05 is a 68 year-old woman from XXXX who was diagnosed with colon cancer.

Minobimaadiziwin:

- APDC05 was very helpful in defining Minobimaadiziwin, she gave her personal views as well.
- “To me it means to try and take care of my life I guess, and a way of life. They say what goes around comes around. If you’re good to people good things will happen to you. And when I say good things, not just physical stuff or tangible stuff but spiritual. Like in my case, my health I think has come back because I believe very strongly in being positive. You know when I was teaching at Adult Ed somebody won at the bingo or won big money and the students were very negative and said “Oh she’s always winning there, what does she need money for?” And I tried to get them to turn it around and say ‘Good for her’, you know, good that she won the money, rather than putting people down. And that’s kind of been my policy, even if I go against the grain of the group that’s talking. And I’ll be put down, but that’s okay. You’ve got to commend people’s luck. Like I say, what goes around comes around. But that also extends to my family and those around me, I think anyway (laughing) ... And then my children, on the other hand, are getting the help I gave the students or the people I worked with. They’re getting emotional assistance, spiritual assistance; you know things like that, that I might have given to somebody a few years ago. And my son said “I believe strongly now when you say what goes around comes around.” And that circle that makes him go is not only for me but for anybody that’s in contact with me. So to me that’s Minobimaadiziwin, look upon your fellow man as you want to be looked at I guess, or helped.”
- APDC05 spoke about how one’s Minobimaadiziwin is affected by cancer. It is a curve or an obstacle in your path ... you can climb over the obstacle or something will help you get over it but you have to keep going. If you can’t, most accept that, even in death ... “that was how long their path was. There was nothing anybody could do about it. That’s what the Creator set out, however young the child is or however old the person is.”
- “... Minobimaadiziwin is everything really. And when we talk about Minobimaadiziwin, it’s kind of like a way or a road or a path that you follow. And as you follow this path you help your neighbour, love your friend, that kind of stuff. You eat well. You have to take good, fresh air; good breaths. Like you have to be outside; you can’t be inside all the time and not breathe the fresh air outside, open windows; this is all part of this Minobimaadiziwin. And when cancer gets in there it’s like a curve on the road or a big rock on the road. Sometimes you can climb over that rock or something will help you climb over that rock, or you can’t. But you still have to keep going. As Nishnawbek we talk about the path ahead. Even when somebody dies they say “Well that was how long their path was.” There was nothing anybody could

do about it. That's what the Creator set out, however young the child is or however old the person is. That was the length of their life. [*Anishinaabemowin* 38:30 part 1- *mi ekwabidinik bimaadziwin ... ekwabiising bimaadziwin*], so this Minobimaadiziwin, that was – regardless if you put them under life support, if you do everything you can, if your life is this long that's how far you're going to go. Now cancer jumps in there or falls in there and you have to keep going, you have to keep fighting, you have to keep trying to walk on that path. You can't just sit on the side of the road and say 'Well that's it, I got it' ..."

- “But you know, you can't just sit down and give up. It's like driving, your first driver's license, you can't get it and you say 'I'm never going to drive it, that's it, ever. I'll walk for the rest of my life'. No, you go back and you try it again. And that's the same thing with cancer, you keep walking, you keep going on that path. And then you don't give up all the positive things, good things that are happening in your life, thinking good about people, saying good things about people; I mean not always. I mean (laughing) there are a few that, you know, I have trouble with. But I was thinking about that last night, isn't that funny. In the Lord's Prayer it says – I can't remember now but, oh “Forgive us our trespasses and we forgive those who trespass against us.” Well forgive me as I forgive others. Well if I don't forgive anybody I don't expect the Creator to forgive me, you know. If I'm not nice to you I don't expect anybody else to be nice to me, or my family. Because what you do – I'm looking for the English word ...”
- “...[*Anishinaabemowin Shkweseh* 42:00 part 1], when you get hot water it splashes back, or splashes ahead. You do something bad; it splashes on to your family. I think everybody's in, but also the good stuff. So because something bad happens to you doesn't mean you try and look bad on somebody else, or I guess jealousy might be a good word, envy. If somebody that's healthy you don't say 'What the hell's wrong with them?' you know, 'I've been so good with myself and look at them, they're drunkster' you know. 'They don't take care of themselves and look at them walking around healthy.' You can't do that. What you do to yourself you do to the rest of the family. So when this cancer hits, you keep on going and you continue with the Minobimaadiziwin where you still take your medicine, where you still eat the fruit and berries and fish, living the good life, or living the good way I guess is better way; not the good life but a good way. I mean sometimes we don't have the money to live the good life but we can live the good way.”
“You can have cancer but you still continue the good way. Like I said, you still eat what you're supposed to eat. [*Anishinaabemowin Kamganagomak* 44:00 part 1] I was going to say looking good but looking well at everybody around you. I guess you don't become bitter. In some cases it would turn people bitter, angry; 'Why me', you know, and unfortunately, we shouldn't.”
- When I asked APDC05 how she was coping mentally she spoke about those things I would have attributed to spirituality. She commented that “emotions, mental, spiritual, they're kind of all one.”
- “As Nishnawbek we always kind of thought about three of them while we were talking, you know, your physical and then your spiritual, emotional and the other stuff all kind of goes in one. I guess it's again, Minobimaadiziwin, it's like trying

to tear it apart and see how it works, you know. But you can't because your way of life is you're thinking about how you're living but also, when you're this way of life, it's how you eat, how you speak to the Creator, how you thank the Creator, how you look upon your fellow man or your fellow person. It's all just that one way of life and it's hard to break it apart."

- "And it's the same thing with cancer. It's almost like you got to deal with it. And you can deal with it. You can fight it. And if it's a fight that you know you're not going to win, then at least you put up a good fight. If that is the length of your life [*Anishinaabemowin ekwabiising bimaadziwin ... 10:36 part 2*], then there's nothing you can do. Even if there's a miracle drug, that's the length of the life the Creator gave you. Think back and say you had a good life, you know. That's why you got to make every day work...
- But you've got to greet every day. You've got to be happy for every day. Like every night before I go to bed I say okay, what have I done. Okay, I cut out some material, thank you, I needed that done. Hey, I didn't do anything today, boy that was a nice rest. You know, why sit there and say 'Oh my God, I was just lazy today, did nothing'? No, I had a good rest.
I might have even watched a couple of programs on TV, you know. So what if I didn't do the laundry today? It's going to be there tomorrow. You know, it'll be done. That whole idea of don't worry, you know. What's meant to be will be. And I think once you accept that I think things will be okay."
- "You know there's some things that we really want so badly and we pray, we try to give thanks, we try everything, everything and it doesn't happen. But that's for a reason. Like my heart attack was for a reason. As for reason, the Creator sent you down here for a reason and he has something in mind for you. Regardless of how hard you fight to get there, he'll get you there... But the Creator has something in mind for you. Regardless of where you want to go, your path leads to that certain spot. And if your path is going to be littered with cancer or have cancer in there, then that's your path. You try and fix it. You do everything you can to take care of yourself, but it's there."
- APDC05 spoke about how healing encounters throughout her life have influenced her Minobimaadiziwin.
- "I know that there's something after we pass. And I know, those that have passed, I'm going to see them and there's a place where everybody is that is gone. So I'm not going to say I'm not afraid to die because I am afraid to die, or I should say I don't want to die. I have too much that I need to do, you know. But this Minobimaadiziwin, you try and live it the best you can ... Yeah, so you would try and take care of yourself as well as you can for as long as you can. And that's made all aspects, spiritually. I think if you're healthy spiritually you can meet anything or anyone head on. If you're weak spiritually or emotionally then the least little thing's going to trip you up and it's going to take you a while to get up. But if you're strong and you make yourself strong by this Minobimaadiziwin, like I said before, how you treat people is how people treat you, or you treat people the way you want them to treat you. And they will.

- I could have had a miserable stay in the hospital. I could have had a miserable doctor, but I haven't. And even the miserable principal I had, I was able to get over that. That was his problem, not mine. I didn't do anything ...”
- APDC05 talked about how we can be barriers to our own health by not accessing services or allowing things to become barriers.
- “...But I think because I personally want to take control of my life, of my health, of my Minobimaadiziwin, I want to take care of that, I will tear down barriers if I see any. Or somebody might see as a barrier and I will only see it as ‘Well let me call somebody else. Let me talk to your manager’, you know.”

Appendix 12: Minobimaadiziwin Teachings

The Path of Life/Seven Stages/Miikaans Teaching

The Seven Stages teaching, in Anishinaabe we call it *Miikaans*, little roads. That's what it's called in Anishinaabe, that's the name of the teaching, the *Miikaans*, because there are seven little roads in life that can take you out of life before your time. But the whole teaching, it begins with the spirit path teaching which is a very simple, absolute concept, and I mentioned that before where we're spirits and physical form. Basically the human spirit came from the Creator, it came into this life, it journeys through this life and it's going to go back to the Creator; that's the spirit path.

So the spirit is immortal, it's good, it's even perfect. That's at the core of every human being. So what happens then, before you come here you have a conversation with the Creator about why you come here; every human who is here has had that conversation. The ones who didn't decide to come here are still conversing or they've taken a break from that conversation with the Creator and they're still there. But we believe every human who is here decided to come here in this life journey, so the Creator and you talked about some elements of this existence.

And when you came here you had to enter a human form while you were still in your mother, the perfect human spirit in the perfect human form, we say. Then you live for a while inside your mother with all of this knowledge of why you're coming here. And then you are born and the shock of your birth made you forget a lot of that conversation, but you remember some things. That's why we say children are born with knowledge, because they have that conversation, bits of it, still in their memory.

So when you were born ideally you were in a perfect human and physical form the instant you were born. There's none of those anxieties or, you know, jealousies or anything with you, you're perfect. So right at the beginning the Creator gives you a teaching on perfection that you're perfect and then that's what he says to you now, he says 'I created you perfect, now start your journey and find out about yourself.'

That's what he says, because he gives two gifts in the beginning, well, many gifts but two of the main ones everybody gets is, the first one is *Zaagidwin* or love. That's if you go through this life using love as your guiding principle things will manifest for you "in a good way"; that's where you get that kindness and everything from that. And then the other thing you get is free will. Even though you and the Creator talked about

you coming here to do something, he gives you the freedom to choose how you're going to do it, because you are an autonomous being like him. None of us are servants to the Creator. He creates us to be his equal, his peer. So there's going to be seven changes in your life, from birth, you're born. The first physiological change is puberty, major one. The next physiological change is when you grow tall, stop growing tall between 25 and 29.

And then after that it becomes an internal thing and that's why it's a good idea to look at your family history, what people got. Maybe people developed what they call mental illness nowadays, maybe people developed, you know, cancer, heart disease, you know. Families will appear to have an ailment. But what that does, there's a point in your life where your internal chemistry shifts and it changes, so what you would do is you would change, you would modify your diet to address those changes because like your body will need those medicines to show your strength. So it becomes internal.

And then there is, let's see, puberty, growing tall, internal change, and then it becomes another kind of internal change but then it becomes a kind of like an awareness. And what they talk about, it goes hand in hand but the mental aspect of how you regard yourself. There comes a point and I'm not going to say in the middle part, but there comes a point in that development there where you absolve your parents of their responsibilities. Anything your parents couldn't get you, that's where you can get it, in fact, so that's sort of like you can do this and some of the modern therapy calls that reclaiming of the inner child or reclaiming, you know.

But it's actually you're an adult now, if you want something from your child you can get it. And in my healing ceremony I was told to buy cars, hey, because I didn't have cars when I was a little boy, so the healer told me, she said go buy some cars and play cars. She said it'll do you a wonder of good, and she was right. So that's where you get to that point basically where you're making an admission mentally that you're an adult, you can look after yourself basically.

And then you come to another change and the change is actually more of an awareness that you're doing what you and the Creator talked about you coming here to do. You have this sense that you're fulfilling your purpose and you get that feeling everything you do is natural to you, so it feels good. And then what you do is you start noticing, you start to notice the variety and the way that you can fulfil your purpose; you start to know variations. In fact, that's where you learn that you're very adaptable and you don't have to have things in a set way.

And I guess, in a sense you're learning gets more of a spiritual energy and then a doing kind of thing, your energy manifests. So it's like, you know, if someone drummed with the hand drum all their life, there would come a point where they realise they don't need the hand drum because it's their voice is the spirit of the song that comes from them and that's what their gift is. So it become like a realization.

And then there's a physical form for that and once you realize everything in your who you are, they say that's when externally you get white hair, your hair turns pure white, then you become the pure human being. You know everything about yourself and you have total confidence in anything about you, and that's when they say you become the Elder, right. And young people see your white hair as they can come to you for your wisdom and your knowledge.

But each one of those seven changes, it's like, you know, it's like seven lives within one big life, so between each little life there's kind of like a gap. So at one time ritualistically we used to have a ritual to help us bridge those gaps and you know in puberty there's the berry fast and the vision quest.

There was another one when you stop growing tall that they did there, and in each one of these changes inside you there was a ritual that helped you bridge that gap. And that's some of what I tend to wonder about, maybe we get cancer, maybe we get some of these illnesses because we're not remembering these rituals, because the ritual helps you, guide you, Minobimaadiziwin.

Because what you do at each change in your life, you let go of one life and look forward to a new one, literally look forward to it. And in the old days old people would tell you what they look forward to. They'd say, oh, we're going to, and they would give you a good positive thing that's coming your way. They'd say watch out for it, it will happen to you this time, and then so you'd be in this new life with expectation, a good anticipation.

So it was like that seven times, that ritual would help you look forward to the new thing coming at you. So that was the seven stages and in each stage nowadays has a name, like the Good Life is the first one, Fast Life is the second one, Wandering and Wondering is the next one and then Getting Ready and then Doing and then Knowledge Gathering and then Pure. But each one of those has a physiological change because you change physiologically, your perception about life changes.

So it's an intellectual evolution, your mind and your thinking change so you move. And they say at each one of these gaps - it took me a long time

to learn how to say this - you have an existentialist moment. Why am I here? And we even say that every time you have that question, Why am I here? That's actually a spiritual moment. That's your spirit trying to connect to you to remember why you came here to this place, so then that's when you get philosophy and you start to wonder, and you put everything that happened to you in your life and you put things together and then you go, oh, I know what I'm going to do next. And then you do it because your spirit asks you to wonder about that.

So that's a holistic happening at each one of these changes. Now they call it *Miikaans* because at each one of these changes there's an opportunity where you could leave life before your time. And the only one we really talk about or give it a definition is at puberty. That's where the person has to understand what selfishness is and the parents are called the first teacher, because parents teach their children how to share.

So when parents are teaching their children that's such a natural process, every parent teaches their child to share. When they get to that first change the child knows how to share, and actually has a good idea of how to moderate. So if they didn't get that teaching they could become so selfish here, they could have everything and that would take them out of life, maybe overeat a lot of candy, or do a lot of risk taking behaviour and they would die.

Or the other thing they could do is they could get the person stuck in a trap sort of thing, making the same mistake over and over again. And that's the only concept of how we have, we call that 'living hell' where life becomes unbearable because you're just doing the same mistake repetitively.

So each one of those little roads can do that for you and each person is going to be an individual thing, you know. In my family it was addiction, alcohol addiction; that's where you eventually, when I realize that there was more to life than drinking for me, I was away from that and I moved to the Wondering and Wandering life. But each one, it'll be different how the individual...

So the Seven Stages teachings, when we use it as a counselling technique it's told idealistically. The person's given the ideal life, to listen to, and then after a while then they're given the little roads, which is very negative, you know, when you can make a mistake and you could go before your time. And there are explained consequences to that; it just involves getting back to the Creator. If you leave before your time basically you need to walk in limbo for that number of days, they say, but at the same time your loved ones could petition the Creator to take you back.

And the Creator, because he loves you, will take you back, so the people you leave behind, just like in the healing, you know, it's a group effort kind of thing. The more support you have, the more things can go positively, so that's some of our philosophy. And then this last part, when you leave life the instant your spirit leaves your body that's when you're perfect one more time, but you're perfectly you. You've gained the perfection of who you are, so that's the other side of that perfection teaching.

We need to become perfectly us, and then when you leave this creation there's four nights when you're still here and that gives your family and acquaintances the opportunity to honour your life and send you to the Spirit World "in a good way", do everything they can for you to have a smooth transition. And in the next four nights those are when you're on your own.

So when people are in palliative care, they get to this part of the teaching. And that was the misunderstanding I had the first time I gave this teaching, was I would be encouraging this person to go to the Spirit World was my theory. But in fact, these last four nights the teaching about that encouraged the person to live. It gives them, you know, the freedom to choose to have well, Minobimaadiziwin, even if they're terminally ill.

So the first night they just walk towards the Western focus on the path which is still focusing on your life purpose. So if you focus on your life purpose all your life, then when you get here it'll be easy for you. And then you come to a place where two animals are they will ask you how you treated every living thing, and then that's where you remember what your parents taught you, 'I treated every living thing with respect. I only took what I needed and I shared the rest'. Is what you say to those animals and when that's the sincere and honest truth they just let you go by.

But we say that's the final place where if there's anything still on your spirit, you get a final cleansing, so that's where they say like, you know, if there was an abuser and he hadn't resolved his behaviour before he died. Those two cats would show him how his victims felt; they would give him that, you know, experience of how he made his victims feel. And when he realized the remorse, he realised what they had felt, then they let him go by. It's not viewed as a punishment, it's viewed as there's something still has to be cleaned off of his spirit, and they clean it off so that now he can go clean, fully clean.

So then the third night what happens is he comes to a fork in the road and that's where your loved ones would have given you the tobacco for your spirit journey. So you put your tobacco down in the fork of the road and

then the right road shines. So in your lifetime if you're ever stuck with a decision, it's either way you don't know what to do. They say that's when you use your tobacco. It'll show you which way to choose.

And then last one is where you come over the hill, you come down, there's a valley with a river through of rapids and you wonder how you can get across. But your loved ones had given you megis shell, so you take that megis shell and you put it down and the river goes flat and this log comes. So the megis shell represents life. The Creator blew life into life into us with that, so even there, to get to the Spirit World, you still have to have a good outlook for life. You still have to have Minobimaadiziwin. So you put that shell down and then you can go across and that's when all your ancestors come over the hill and they meet you and they you know, put new clothes on you and then there's a big celebration. So it's as much a spirit journey as it is a physical journey, as it is a mental journey, yeah, the way your thinking changes. (John Rice, Wasauksing)

Medicine Wheel/Stages of Life Teaching

With the springtime is birth, its new life, it's a new beginning, everything is brand new in the East according to Anishinaabe people and the teachings that we have. And its springtime and so there's new life coming, the spirit comes through that doorway and when you decided to come into the world, your spirit came through that doorway. And so now you're going to be one years old, two years old, three years... So by the time you're nine years old, I said you're getting "little buttons" and your body's already starting to change and you're getting ready and I said you're starting to have breasts. You know, your body's changing. So I said you're moving into a night time because your body's changing, physically change. And so the Grandmother is getting ready to come and visit you, to come and be with you and that's a big power time.

So I said your hormones are going to start to do a number. So we're moving into the South, into summer of our lives. It's your youth and it's a very, very powerful time, so enjoy it. Be happy and it's an incredible, beautiful, beautiful time your youth and lots of things happening and you have incredible energy. And just like the earth, the greenness of the earth, you know how the earth puts on a beautiful shawl ... A green shawl in the summertime, when everything is in bloom. There's movement, the birds are singing, the fish, the flowers, the medicines are in full bloom, everything is green and so it's a very powerful time. And that's the way you are. I try to tell them that they are like that. I said that you're in your most powerful time, in your youth. You're learning about relationships, how you are connected to the land, your relationship to the land, your relationship to your Dodems, the birds, the water life, the four leggeds, the flyers, all of that. Everything in Creation that you're connected to ...your

relationship to your loved ones, your family, your brothers and sisters, your aunts and uncles. All of that, you're surrounded by that, so how do you relate, because they are your relatives. So how do you relate to them? How do you relate to the earth? Because that's your mother ... What kind of relationship do you have with the earth?

And you move into the next phase. We're celebrating, now you're a young woman, you're a young man and you're moving into the Western part. The Western part of the wheel and the sun goes down in the West and for us as Anishinaabe people, our doorway ... when we leave this world it is in the west. So we learn about that, we learn those teachings about being responsible and in the fall time we learn about death and how in the fall everything dies. Everything goes back to the earth. The leaves fall, the Earth has done her most beautiful dance and so the leaves begin to fall and there is that sense of death, things die, everything dies. And so that's where I talk to them about death ... We're all going to die and that is inevitable, nobody lives on forever, but the one that lives on forever is your soul. That's the one that goes back to where we came from. We know where we come from and we know where we're going. We're going to go back to the spiritual realm, to the Creator. We came from the Creator and we go back to the Creator when we're done our work here. And so I talk to them about responsibility and that when you're in the West, you look to the East. So now you're responsible for that new life that's coming into the world. Now you're going to be a mom, you're going to be a dad, you're going to be parents and you're going to bring forth life. You're going to open that door so that that new spirit will come into the world and how are you going to look after those children that are going to come into the world, who are choosing you to be their mom and their dad. And so there's a responsibility there and you have to work and so we talk about work. And you've got to put food on the table, you've got to pay the bills, you've got to look after your children. And don't just look after the body and the mind and I said look after the spirit too. Acknowledge that new spirit that has come into the world to be with you. They've chosen you to be their mom and their dad. So look after that spirit. So there's a whole parenting teaching there that goes on.

And then we move over to the North and to old age and I say that's where I am. I'm moving into my old age and I said I'm not old yet, but my body feels old. But when I'm starting to move into the North, I'm looking to the South. I'm looking to the youth where I want to pass that knowledge on to the young people. So that's why my work is important because it will help you to move into your adulthood, your adult life and to be responsible and to have respect for it. So I said this is my time of giving back now. All the years that I've spent gathering this knowledge, now I can give it back, its reciprocity ... giving back. And I give it back to the people. I give it back to the young people, so that they might have

something that will help them along the way because there was always somebody there to help me when I was struggling, when I was growing, there was always somebody there. And so I said now I'm giving it back. So those are the four R's ... Respect, Relationship, Responsibility and Reciprocity, giving back. Those Four Directions, the Four Winds, those Grandmothers and those Grandfathers, they give us those teachings and they give us a way to help us through life. They give us direction and it's all in there; in our ceremonies and our teachings and our stories and our songs. The drum is the one that wakes us up and encourages us and tells us to come into tune, into harmony and balance and work on centering ourselves, feeling good about who we are and to be happy.

And so when we get to that place, when it's time for us to go through that doorway, we can dance out and we're not afraid. We're happy to go home. Back to where we came from originally and that we've left good teachings, we've left good stories, so that you might have something to nourish you as you go through life. And so we tell the ones that are being left behind, know that your loved one has gone on and that he's not suffering ... he's not suffering anymore. The body is the one that was a burden. (Edna Manitowabi, Wikwemikong)

Cedar Bath Teaching

I think one of the things that people need to keep in mind is the medicine [cedar bath] when people finally do pass. Wash down with cedar and boil a couple of handfuls of cedar for an hour in a big pot until it gets real dark, then scoop out one cup and put that aside, pour the rest in the bathtub and then mix it with the bathwater. You don't need to wash with soap or shampoos. You just sit in that water and soak. Just wash your face and everything, your hair and wet it down and just use the wash cloth and you're just washing that death off of you because that death can make you depressed. After you get done, after you dry off, you drink that one cup and it like cleans your insides and it cleans all that death off you so you don't feel all these issues. What happens is it intensifies the issues - if you have unresolved issues in your life. For loved ones who end up passing [people are] going to the funeral home and they take a big jug of cedar water that's all done up. They take a basin and they usually give them a sponge bath, wash them down and that prepares them for their spirit journey. That's part of the grieving process for the people if they want to take part in that and they see that. That's part of that healing process where everybody does their cedar bath but you try and do that at the same time. I tell people sometimes, even if you're not related to the person but you go and support the family, and just by shaking their hands where they've touched the body and everything, then they're getting that death on you also, so you should try and have that cedar bath also. (IHP08)

Preparation for Spirit Journey Teachings

The [other] teaching we have is when they put moccasins on the person, they cut in the ball of the foot. Later on, they cut a hole in those moccasins and paint a line down the middle with pipe stone dust, red pipe stone dust. They put it on there and make a line so they can find that path that our people have always walked to the Spirit World. (IHP08)

We have a four-day feast because it takes four days because you had the funeral. We had a funeral on Monday. We don't count Monday night, because he's starting to leave, but Tuesday night, Wednesday night, Thursday night and then Friday night he gets there. And that's when he has a reunion with his people that have gone on before him. We offer food, send food up there [Spirit plate], because they have a big meal up there. When he arrives up there, he has a reunion with his people that have gone on before him. (IHP02)

Our people used to be prepared. They would even prepare what they were going to wear; they'd have a box all set, the dress and everything that they're going to wear; everything would be set. Wilfred Peltier [a Wikwemikong author] wrote in his book, when somebody dies in our community, there's no one that really takes charge. People just seem to come out and somebody does this, somebody does that, or makes the pies and somebody makes the rough box and the grave gets dug, all that. So many little things and then they'll say anybody who has a small child, less than one, should not be a pall-bearer and a pregnant woman should not view the body. They forget those teachings, I think people forget that and so you have to give them reminders. (WHP05)

Colours of Life Teaching and Baa maa pii ka waabmin

We put up all the colours the colours of life - yellow was all the background, and then we put red, then the blue and then the green. The yellow represents the sunlight and moonlight. Red represents the blood of all animals, birds, everything in this life; every kind of animal or fish that's got blood. Blue represents the sky and the water and the green represents all the plant life, the trees - so those are all colours of life and they say those are the original colours. We got cedar trees and we cut them down and we put them in a big flower pot and put rocks in there. We put two on each side of the casket and then we put a nice colourful blanket draping over the casket. We lit a fire and kept that fire going and we just did a ceremony and family talking a circle. The last day of the wake with the family, all the kids and grandkids, we all got our bedrolls and all slept at the base of the casket. In *Anishinaabemowin* there is no way you can say goodbye, something that means forever. So when people are done and we're finished we say *baa maa pii ka waabmin* [Translation:

another time later, I will see you again], which is I'll see you later.
(IHP08)

Reunion with Ancestors and Spirits as a Resource

If they're going to leave, they acknowledge that Anishinaabe medicine and healing so then they go to "the happy hunting grounds." They meet their ancestors and say yes, I have learned this while I have been here in the physical realm. So when they reach the spiritual realm they're acknowledged for that. Our ancestors are happy when they see that the people were taking their own medicines. Usually they tell us at the end, when they start doing those visits, they start travelling towards the end, they will tell us this, "Oh, they are all standing up there. They're dancing and they're happy." So they share those stories with us, so that's, it's positive to hear. We have to believe the people – "Oh, they're just hallucinating from the narcotics." And it's the actual visits from the spirits, so we hear those stories. (IHP04)

Even though we're grieving here there's a great celebration that you are walking towards on the other side. And so that kind of takes care of that fear. You're always thinking you're alone and you're going through this but those ones are always with you no matter what. Yeah, they move on to a different realm but they're still here with you. They still check up on you. They want to make sure that you're doing okay here. (IHP06B)

One of the beauties of our ways is that transformation. When that spirit leaves there're things we can do for that spirit. There's work to do and you can still help that spirit make its way to where it needs to go through the fires that we light, or the medicines we burn, through the food that we put in the offerings we make, the prayers we send, the tobacco we offer. All of these things give us an opportunity to continue to help that person that we've known in this world and they've become a spirit but we can still help them. We can still connect to them. We can still see them in our dreams. They can still visit us. Our way comforts families and the spirit and keeps us connected. So it's not over, there's a whole new experience now through your dreams, through your spirit, through those things you feel. You feel their presence, you know they're there. So our way looks at that in a holistic way. (IHP06A)