

Journey to wellness: Identifying culturally relevant supportive services for First Nations peoples
in Northeastern Ontario during their cancer journey

By:

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Abstract

This thesis is intended to identify culturally relevant supportive services for First Nations in Northeastern Ontario, as perceived by service providers, in order to improve access to cancer care services and the follow-through of treatment at the time of diagnosis and during treatment. The author interviewed thirteen front line health care providers who provide direct services to First Nations communities. The participants within the research study discussed the importance of relationships First Nations peoples have with family members and their community as well as to the land and water. The need for supportive services that incorporate family and community, as well as land and water based healing practices are integral in ensuring the psychosocial needs of First Nations cancer patients are being addressed in a culturally relevant and safe fashion and that these services are significant for the patient, family, and community. The results of this research will be useful in broadening the understanding of the needs of service providers in First Nations communities who are working with First Nations patients during their cancer journey.

Keywords: psychosocial, cancer, First Nations, Northeastern Ontario, coping.

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Situating Self

Journey to the Centre

Boozhoo, Kwe kwe, Aanii Ozhaawashko-giizhegkwe ndishnikaaz (Hello, my name is Blue Sky Woman). I have been on a path back to the centre of the circle for many years to reclaim what has been lost from my soul. As I situate myself in the research I am about to embark upon, I will be going through the process of walking back to the centre of the circle. When I am done I will be at the centre and ready to begin my journey. As Dr. Sheila Cote-Meek (2014) writes “one can enter the circle or Medicine Wheel at any point” (p.12). I have chosen to walk back to the centre of the circle before starting so I can have a clear view of all the directions and all my relations. Grace Ouellette (2002) describes “The Circle of Life, or Medicine wheel” as a worldview or a set of guiding principles for understanding the purpose of the circle. She explains that “within this circle, there are four main directions, four elements, four races, four colours, four seasons and four main teachings. The concept of the Circle of Life is also known as Pimaatisiwin” (p.48). In my traditional area which is the community of Temagami First Nation, located on Bear Island in the heart of the Lake Temagami we refer to this as ‘MinoBimaadziwin’ which means living the good life. Living a good life on this Earth is what I hope to assist my people with while they are on their cancer journey. I use the term ‘my people’ to acknowledge that I am part of the Anishinaabe people. The use of the term ‘my’ is not to imply ownership but is rather a term used in everyday language to refer to one’s sense of belonging to a group of people

When I reflect upon what has drawn me towards the topic of holistic and culturally appropriate care for First Nations people with cancer, I often find myself thinking about the day my family moved from Edmonton, Alberta to Northern Ontario. I was only seven years old at

this time but the memory plays in my mind like an 8mm vintage camcorder. It was a beautiful sunny summer day and I remember looking out the back of our station wagon feeling the loss of something greater than just moving. At the time, I didn't know what that loss was. I have now come to realize that the loss was learning about my culture which is where my heart and identity lay. The significance of this move to Northern Ontario was that I was moving away from grandparents, aunties, uncles and cousins who all shared my Anishinaabe identity and cultural beliefs. As a child leaving Edmonton, I was going to a place where I knew no one. Over the years that followed, it was a struggle and still continues to be a struggle to relearn my culture. The struggle was not only an internal struggle but also external one. I will first speak about this internal struggle and then speak to the external struggle.

I am of both Anishinaabe and French descent. I purposefully choose not to be called mixed-raced or bi-cultural as this is an extension of the colonized "terminology [which] is really about boundary maintenance and a means of demarcating the racial divide" (Goodyer & Okitikpi, 2007, p.86). I have only recently come to understand that the dichotomy of racial divide was part of my internal struggle of self-acceptance. For many years, I felt the pull from two worlds; Western and Anishinaabe, and if I identified with one, I was somehow rejecting the other part of myself. I often experience a struggle of being viewed by others as both the oppressor and the oppressed. Bonita Lawrence explores this concept in her book "Real" Indians and Others: Mixed-blood Urban Native Peoples and Indigenous Nationhood (2004)

"...white-looking...individuals described the difficulty of negotiating a sense of Native identity ...when Native people also made it clear they didn't belong. Many...described multiple experiences of everyday rejection from Native people..." (p.183).

My external struggle of the loss that I felt was related to being in an environment where I no longer felt a strong sense of self. I also experienced a tremendous disconnect with my grandmother who was the traditional knowledge keeper in my Anishinaabe family. When she passed away several years after our move to Ontario, the feelings of loss were exacerbated and I felt all that could have been in terms of cultural understanding was gone. I not only mourned the loss of my grandmother, but for many years I mourned the loss of my connection with the Anishinaabe culture because I felt that my only real claim to being Aboriginal was through my grandmother and mother. As I grew up, I felt that I was not an authentic 'Indian' because those were the messages I had received from Aboriginal and non-Aboriginal people. Some of this was based on societal perceptions of what an Aboriginal person should look like, for example, dark skinned (Lawrence, 2004, p.182). I was non-Status as defined by the Indian Act, which is imposed by the Federal government of Canada, and fair-skinned and therefore did not fit the mold. Bonita Lawrence (2004) confirms this in her research on how Native people were perceived,

For Native people, appearance has been one of the obvious ways in which boundaries have been maintained between members of Indigenous societies and a hostile colonizing society. And yet a crucial way in which the cultural distinctiveness-and the nationhood-of indigenous societies has been to reduce cultural identity to race, therefore reducing Nativeness to appearance, with its implicit connection to 'purity' of blood... (p. 228)

Presently, I am employed as a social worker in the field of oncology as an Aboriginal Navigator. In this role I have observed that when many First Nations peoples return home while undergoing cancer treatment they do not always appear to have adequate support. This prompted me to want to understand why.

In all honesty, working in the field of oncology was never something I thought I would be doing. My grandmother passed away from cancer and I thought cancer was something I never wanted to know about. But now I understand that I am right where I am supposed to be. The Creator opened this door and now a flood of opportunities to learn about my culture have come my way. This reminds me that as I approach the centre of the medicine wheel, I find that these new opportunities also come with a renewed sense of responsibility and passion to help better the lives of Aboriginal peoples.

For as long as I can remember, I have held a paradigm for social justice and equality - it is what led me to the field of social work. I continuously advocate and push back against dominant ideologies on behalf of those who have lost their voices and/or are also marginalized. I recently learned from my mother that the women from Temagami-Anishinaabe, which is where my people's traditional territory is, are known for being strong, vocal women who push back against systems of oppression. This brings a smile to my face because I see similar qualities in many of the women in my family and it also explains why I, like my sisters, find myself in the role of advocate or aide in some way.

As I stand in the center of my circle, I see all of my relations and in particular, my grandmother and her journey with cancer. I remember the difficulties, struggles, and the lack of cultural consideration from institutionalized dominant ways of doing where often times the whole person is not attended to. I hope my research will assist in developing culturally relevant care programming for Aboriginal peoples while on the cancer journey. I have come to understand my journey is a calling to bring forward better ways for approaching cancer care for Aboriginal peoples that are wholistic and based on understandings of the Aboriginal culture. It is my hope that my research on healing and self-care during the cancer journey will assist

Aboriginal peoples to use the traditional circle as a tool to be themselves during what is often a difficult and challenging time. I end with a poem on the Circle of Life:

The Circle of Life

The Creator made the Earth round
She made the Grass and the Trees
the Birds, Fish and Animals
to follow the purpose of Her Creation.
and She made the four races of Mankind
black, white, yellow, brown
and placed them in the East, North, West and South
and asked them to form circles
so that we should understand
the Wisdom and Meaning of Life.
because Life as the Creator meant it
is a circle: from the Creator
to the Creator, the Circle of Life
(Elle Han'sa, 1989, p.53)

Chapter 1: Introduction

It has been well documented that First Nations people have higher rates of chronic illness and experience challenges in accessing appropriate health care resources that may impact their lives in a positive manner (Allen & Smylie, 2015). This is especially evident in the area of cancer care where there has been a growing recognition of the lack of Indigenous psychosocial services when Indigenous patients are receiving cancer treatment (Shahid et al., 2011). This is also true in Northeastern Ontario where there is a need to assist First Nation service providers with resources that are culturally relevant to provide support to First Nation patients diagnosed with cancer and families in their community (Cancer Care Ontario, 2012).

A cancer diagnoses can affect different aspects of a person's life including the psychological and social aspects of their lives ("Psychosocial," n.d). Stanton (2006) explained that the "earliest phase of diagnosis and treatment of life-threatening disease certainly is recognized as psychologically taxing for affected individuals... [that encompass the] physical, psychological and interpersonal (hereafter referred to as psychosocial)" (p. 5132). For example, many cancer patients will experience side effects of undergoing treatment such as loss of hair, weight loss, physical changes to the body as well as difficulty concentrating and/or forgetfulness. Coping with a diagnosis of cancer, while dealing with the side effects of treatment, can be challenging and, at times, traumatic for a person (Grassi & Riba, 2012).

Psychosocial services are services that are put in place to assist patients with mitigating the psychosocial issues of cancer. These services may include patient education sessions regarding cancer treatment and effects, counselling for emotional support, suggestions for coping, relaxation, and assistance with grief work (Stanton, 2006). Psychosocial services are an integral aspect of supporting patients during their cancer journey. Figure 1 titled, The Cancer

Journey, provides a diagram that shows steps in a cancer journey and provides a good visual of the potential points in the journey that a person may require psychosocial services.

Figure 1. The Cancer Journey

(Source: Cancer Care Ontario, 2013, para 2.)



The purpose of this thesis research is to identify which culturally relevant supportive services are required for First Nations in Northeastern Ontario during the diagnosis and treatment steps of the cancer journey, as perceived by frontline service providers within the participating First Nations communities. As an outcome, outside of this research project, the hope is that the results will enable the development of a psychosocial tool kit that frontline service providers can draw upon to provide services to patients during diagnosis and treatment of cancer in the participating First Nations. The results of this research will be presented to the Aboriginal Patient Navigators at Cancer Care Ontario as well as the participating First Nations. It is hoped that these presentations will bring about a discussion on what should be included in a toolkit that can support service providers caring for cancer patients. The focus on this research project are community health care centres located on local First Nations. Local First Nations were selected

because they had already indicated an interest and therefore this would assist with participation for the completion of this Masters thesis.

There are few research projects, to my knowledge, after the extensive literature review that I did, that examine the cancer care journey from the perspective of First Nations people during their cancer journey.

A Note about Terminology

Before moving to the next chapter it is important to clarify terminology. First Nations, Inuit, Metis, Aboriginal, and Indigenous are used throughout this thesis when identifying groups of people(s) or are described in the literature as such. I acknowledge that each term describes a different group of Indigenous peoples in Canada. In this project, the research will be carried out specifically with First Nations peoples and for the most part I will be using this term. First Nations in this context refers to people who are recognized as members of a First Nations community as defined by the Indian Act (Allen, & Smylie, 2015). At times, I will also be using the term Anishinaabe to describe peoples from a particular geographical region, primarily in Northern Ontario. Other terms that will be used are Aboriginal and Indigenous. These terms are used as inclusive terms of all First peoples of lands in Canada and other lands internationally. This is not meant to say that all Aboriginal and Indigenous peoples are the same but rather highlights the fact that they have faced similar issues of colonial rule.

Chapter 2: Literature Review

This literature search was carried out using Pro Quest, EBSCO, OVID, Psych Info, CINAHL, sociological abstracts, PubMed, ERIC, and Google Scholar. The broad question that the literature search focussed on centered on identifying what culturally relevant supportive services have been identified in the literature for First Nations peoples during the diagnosis and treatment steps of the cancer journey. The key words searched included cancer, Aboriginal, Indigenous, First Nation(s), psychological, psychosocial, supportive care, experiences, barriers, environment, tool kit, programming, worldview, health disparities, health care, cancer, oncology, traditional, community health services, and environment. Grey literature such as news articles and magazines were also searched with the same key words using Google. The review of literature that follows is grouped under the following six topic areas that emerged during the search: colonization and health, relationship between culture and health, land based traditions and health, barriers to accessing health, support services for First Nations, and the Northeastern Ontario context.

Colonization and Health

I start this section with a brief discussion on colonization. This is important because the history of colonization has deeply affected First Nations culture and health. Further, part of the reason for the increasing rates of cancer amongst First Nations peoples lies in the impact of longstanding historical issues related to colonization which has contributed to the negative effects of health among First Nation peoples (Health Council of Canada, 2012). Kelm's (1998) defined colonization as,

...a process that...includes geographic incursion, sociocultural dislocation, the establishment of external political control and economic dispossession, the provision of

low-level social services and finally, the creation of ideological formulation around race and skin colour which position the colonizer at a higher evolutionary level than the colonized. (p xviii)

This definition points out several dimensions of colonization that include geographical and socio-cultural displacement as well as the control over a people, which Loppie Reading and Wien (2009) asserted has resulted in poorer levels of services and a hierarchy that puts First Nation peoples at the bottom. Several authors have also examined the link between colonization, racism and acts of social exclusion relative to the impact on First Nations health. Cote-Meek (2014) traced how social inequalities are related to colonial practices and have resulted in Aboriginal peoples being affected by a number of social and health issues. She drew links between colonization, cultural loss, and the decrease of health among First Nations peoples. Poudrier and Mac-Lean (2009) also discussed how First Nation health is linked to colonization and neo-colonialism through the federal government's racist and discriminatory agenda to assimilate First Nations peoples. Loppie Reading and Wien (2009) further noted that the impact of colonial imposition has resulted in health inequalities in First Nations peoples in Canada. "Colonialism impacts the health of Aboriginal peoples by producing social, political and economic inequalities that 'trickle down' through the construction of unfavorable intermediate and proximal determinates [of health]" (p. 21).

Czyzewski (2011) discussed how colonialism continues today, and that "there are and have been direct effects of colonialism or colonial policies on Indigenous health, for example, the introduction of contagious diseases like smallpox...or the gamut of negative experiences within the residential schooling system" (p. 3). Colonial policies such as assimilation policies, which saw the erection of the residential school systems, is one of several examples of how

colonization has and continues to contribute to poorer health among First Nations peoples. The residual effects of residential school systems has also left many First Nations peoples and communities with a “loss of language and cultural fluency...[along with] cultural trauma and lack of social cohesion that translated into diminished resiliency, lessened fortitude to overcome addictions, and higher rates of family violence” (de Leeuw, Greenwood & Cameron, 2009, p. 284). The negative effects of colonization has left many First Nations peoples at a disadvantage within greater society, leaving what could only be described as wounds as they attempt to rebuild and come out from under the colonial power. Wounds or soul wound is a concept from Duran & Duran (1995), which they describe:

If one accepts the terms, soul, psyche, myth, dream, and culture as part of the same continuum that makes people’s experiences of being in the world their particular reality, then one can begin to understand the soul wound. The notion of soul wound is one which is at the core of much of the suffering that Indigenous peoples have undergone for several centuries. This needs to be understood in a historical context... (p. 24)

Finally, the process of colonization inflicted by western colonial imposition through policies and government agency has left many First Nations people with feelings of suspicion that any good intention is really a no good intention. This is discussed further under barriers to access to health care.

Relationship Between Culture and Health

The increased prevalence of cancer among First Nations peoples is associated with a number of factors which affect the overall health of First Nations. Reading (2009) explained that physical health of many First Nations peoples is directly connected to their mental, emotional, and spiritual aspects of being, which is affected by the environment, including family,

community, and the political and socioeconomic environment. Loppie Reading and Wien (2009) pointed out that the same environmental influences, which Reading (2009) illustrated, have an impact on people's life choices (such as physical activity, nutrition, and smoking) and opportunities to achieve optimal health. In addition, they noted that "...living in conditions of low income has been linked to increased illness and disability, which in turn represents a social determinant, which in turn is linked to diminished opportunities to engage in gainful employment thereby aggravating poverty" (Loppie Reading & Wien, 2009, p. 7). Poverty has also been linked to "anxiety, insecurity, low self-esteem, and feelings of hopelessness... The accumulation of these psychosocial stressors often leads to poor mental health and increased vulnerability to [health conditions]" (Loppie Reading & Wien, 2008, p. 9). Cancer Care Ontario (2012) further explains that "This systemic social and economic inequality promotes health inequality. Aboriginal Ontarians have higher rates of sickness, hospitalizations, and exposure to harmful risks..." (p. 28). In other words, poverty impacts ones over all wellbeing.

According to Cancer Care Ontario's Aboriginal Cancer Strategy II (2012), cancer is on the rise for status First Nations peoples compared to their non-Aboriginal counterparts; "Since 1991, incidence rates for colorectal, lung, breast and prostate cancer have been increasing amongst Status First Nations. Status First Nations in Ontario have shown to have poorer survival for cancers of the breast, colon/rectum, prostate and lung than Ontarians from the general population" (Cancer Care Ontario, 2012, p. 32). Furthermore, Aboriginal peoples' cancer is often diagnosed at a later stage. For example, "Only 34% of First Nations women were diagnosed at stage I [breast cancer] when tumours are smaller and more receptive to treatment, compared to 44% of non-First Nations women" (Cancer Care Ontario, 2010, p. 3). Stage II, III and IV breast

cancer are diagnosed at approximately 66% for First Nations women versus 55% for non-First Nations women (Cancer Care Ontario, 2010).

Land Based Tradition and Health

Land based traditions and health was the third topic area that emerged in the literature. Many First Nations peoples incorporate land based cultural practices related to health and healing as part of their overall health care. Based on my own observations in my current work as an Aboriginal Navigator in a Cancer center, First Nations peoples often refer to ‘wholistic’ care, which is often depicted through the concept of the medicine wheel. Many First Nations people engage in their own cultural healing practices, which may include ceremony, prayer, and use of traditional medicines, which often take place out on the land. Lewis Mehl-Madrona (2008) provided preliminary results indicating that cancer patients who used a traditional (Aboriginal) healer experienced marked improvements in their spiritual well-being. It is important to note that traditional healers often will use plant medicines and/or ceremony and traditional knowledge as part of their traditional doctoring.

Wilson (2003) noted that “First Nations peoples contend that the relationship they have with the land shapes the cultural, spiritual, emotional, physical, and social lives of individuals and communities” (p. 1). Taiaiake Alfred (2009) called on a revitalization of culture and healing of health, self-sufficiency, and autonomy by going back to land based practices. He argued that this is the only way to restore a wholistic way of living and to eliminate diseases, especially preventable diseases. Both Taiaiake Alfred (2009) and Wilson (2003) explained that land, or going back to the land, is significant to First Nations peoples’ health. If there is a perception that the land is not suitable to sustain health and it is sick with pollutants, it is reasonable to think that First Nations peoples will not want to use culturally relevant healing practices that are based on

the land in areas where the land is viewed as contaminated. This could mean that ceremonies such as the sweat lodge or the gathering and use of traditional medicines in particular geographical areas may be avoided if people think that their physical health may be jeopardized by the environment. Therefore, incorporating traditional based healing practices to heal the psychosocial (emotional and mental) aspects of a person may be hindered where communities are surrounded by industries that may be contributing to contaminating the land.

A good example of this is the recent train derailment in Gogama, Ontario, just south of Timmins, on February 15, 2015. The oil spill was claimed as a disaster and will without a doubt affect the land, plants, and animals all around it. Little attention is being paid to the devastating effects this may have on the Mattagami First Nation people who derive their livelihood from the lands nearby (Chiefs of Ontario Indians, 2015). In other areas, such as the Ring of Fire in Northwestern Ontario, mining has the potential to seriously affect the lands that many First Nations communities use (Chong, 2014). Surrounding First Nations have continued to speak out about the effects of building a road and a mine in the area: “If the Ontario plan for the Ring of Fire is implemented it will bring limited economic benefits for First Nations, its social and environmental impacts would be devastating” (Moonias, 2012). There is no doubt that First Nations will be directly impacted by the Ring of Fire development. They want to know what the environmental impact will be on their community, their people, and their health. Little has been said in regards to health and the environment at this point. There appears to be a gap in the literature on the perceptions of First Nations peoples relative to how industry and development may affect their ability to practice their traditional healing practices vis-à-vis the perceived negative health effects that may contribute to cancer along with how First Nations peoples cope with a cancer diagnosis.

Barriers to Accessing Health Care

Issues relating to accessing appropriate and timely health care for First Nations peoples are complex in nature. There are multiple factors operating that affect each other such as issues relating to socioeconomic status and practical issues such as transportation, orientating self within a new community where services are accessed, distance away from home and family, filling out forms for reimbursement, competence among health care providers in mainstream agencies, and communication challenges (Shahid, Durey, Bessarab, Aoun, & Thompson, 2013). In the review of literature that I conducted, socioeconomic status and practical issues were often referred to as a barrier for First Nations peoples in accessing health care. In this section, I will describe socioeconomic status, lack of access to adequate health, water security, and marginalization as being significant barriers to health care.

Socioeconomic status. Thompson, Shahid, Bessarab, & Davison (2011) indicated that practical issues such as finances to attend cancer treatment, transportation costs, and ongoing family responsibilities often cause delay in or failure to follow through with treatment. The implications for patients not attending or delaying treatment can have dire consequences on their prognosis. Oftentimes First Nations peoples have to travel great distances for treatment, which means leaving their communities and families to take up temporary residence in a hotel or lodge away from their home. The cost associated with this creates a significant financial burden on someone who may already be having financial issues. For instance, it is well documented that the income rate of many First Nations peoples is below the national average. The “unemployment rate for First Nation people living on-reserve was 25% approximately three times the rate then non-Aboriginal Canadians. [The] average household income [was]... \$15,958 compared 36,000” (Assembly of First Nations, 2011).

The Non-Insured Health Benefit (NHIB) plan was developed through the First Nations and Inuit Health Branch of the federal government and is designed to assist with financial costs associated with health care. Unfortunately, the NHIB is wrought with problems that affect First Nations access to health care. This health benefit plan “provides coverage for a limited range of medically necessary goods and services...includ[ing] prescription drugs, dental care, vision care, medical supplies and equipment, short term crisis counselling, and medical transportation” (Loyer & Small Legs, 2014, p. 1). Despite the intent of the plan, the NHIB is often a source of frustration due to the frequent increased burden placed on individuals and families because the process is so onerous (Allen & Smylie, 2015). The result is that the NHIB becomes a barrier to accessing health services. Allen and Smylie (2015) noted that in Canada, it is difficult to navigate the approval process because the approved medications and treatments continually change thereby “limiting access due to onerous process changing...” (p. 3). Loyer and Small Legs (2014) also asserted that the NIHB branch requires a preapproval process where practitioners are required to submit for pre-approval for either services, medical supplies or equipment. The authors argued that the process creates “Confusion among clients over access and coverage...” (p. 2). Both the practitioners and clients often have difficulty in dealing with NIHB as it is a confusing and time consuming process, which often leads to practitioners not wanting to dealing with NIHB (Loyer & Small Legs, 2014). Until recently, NIHB would not cover the cost of transportation for women in rural and remote areas to have a mammogram for breast cancer screening. The costs of travel, especially for First Nations women who live a significant distance away from a site where mammograms are conducted, can place an unnecessary financial burden on an individual and may dissuade them from accessing this preventive service. More recently, Cancer Care Ontario has been able to negotiate with NIHB to

cover the cost of transportation for women who require mammograms as part of their health care treatment (2015). These difficulties with accessing appropriate health care services have created structural barriers for First Nations peoples accessing NIHB for cancer related services. Although screening is not cancer treatment per say, the effects of not screening or taking preventative measures to reduce the incidence of cancer means that women who do not have access to cancer screening are at greater risk for developing cancer in what would be considered an otherwise preventable diagnosis.

Lack of access to adequate health care. Another related issue that affects access to health care services is the lack of understanding within primary health care teams about the lived realities of First Nations peoples (Poudrier & Mac-Lean, 2009; Shihid, Finn, & Thompson, 2009). A good example is the lack of access to adequate health care in many northern First Nations. In 2014, it was reported that the community of Attawapiskat had been without a hospital for several months due to a 1200 litre oil leak in the hospital building (CBC News Sudbury, 2014). It would be hard to fathom people in a community like Sudbury or Toronto being without a hospital for that length of time. Primary health care providers may not feel the immediate impact of the distances one has to travel or of the pre-approval process through NIHB for travel that patients such as the ones in Attawapiskat have to go through to access essential health services. If services were offered closer to home, then patients would have greater access to care they need.

Water Security. Another example of the experiences and realities First Nations peoples face is the chronic issue of water security. There were 126 First Nations communities under a drinking water advisory in 2016 (Health Canada, 2016). “Twenty nine of these [First Nation] communities have been under a water advisory for over five years, fourteen for ten years, and

three for over fifteen years...” (Lui, 2015, p. 6). Drinking water advisories range from a boil water advisory to a do not consume advisory. These boil water advisories range from improper maintenance, system break down and high chlorine levels to unacceptable heavy metals in the water such as uranium (Lui, 2015). The effects of water insecurity in many First Nations communities has had devastating consequences. The United Nations has compared First Nations living conditions to those of a third world country (United Nations Association in Canada, 2007, p. 11). In 2007 it was suggested by the United Nations that the lack of government policies to address First Nations drinking problems is a shining example of the federal government’s lack of commitment to First Nations peoples (United Nations Association in Canada, 2007, p. 11). It is fair to conclude that this would not happen in the greater Canadian context without a major outcry by the public and would likely result in a search for persons or organizations responsible and in some cases, provincial or federal probes such as in the case of Walkerton, Ontario in 2000 (CBC NEWS, 2010). The point here is that if people are most concerned with meeting the daily basic needs of life, it would be reasonable to assume that they will not be as occupied in attending to their health care needs. People may not be thinking about cancer screening, which is an early detection method to finding cancer, if they are more focused on tending to their everyday needs, such as access to clean water. In addition, “elevated levels of arsenic [in the water] has been linked to atherosclerosis and vascular disease...cancer, cardiovascular problems and the likelihood of developing diabetes” (Assembly of First Nations Environmental Stewardship Unit, 2009, p. 19). There are considerable health concerns that arise from a lack of proper sanitation and clean water. Stastna (2011) said that the inability to conduct daily routines such as bathing and household cleaning has significant consequences, “the combination of improper sanitation and bad water quality can lead to a number of health problems, including

skin rashes and infections, diarrhea and other gastrointestinal illnesses. It also means infections take longer to heal and infectious diseases spread more easily” (p. 13). This context would make it difficult for anyone undergoing cancer treatment when their immune systems are often suppressed (Breastcancer.org, 2016).

Marginalization and Racism. Access to health care is compounded by ongoing issues of marginalization and racism. Many First Nations peoples feel that the health care system marginalizes them and makes them feel invisible, which points to lack of understanding by primary health care workers as well as systemic barriers that exist (Czyzewski, 2011; Poudrier & Mac-Lean, 2009). Much of the literature that I reviewed identified themes such racism, marginalization and invisibility as systemic issues of structural violence that lead to barriers for First Nations peoples when accessing care (Bourassa, McKay-McNabb, & Hampton, 2005; Brown et al., 2011; Health Council of Canada, 2012; Kurtz, Nyberg, Van Den Tillaart, & Mills, 2008; Sherwood, 2009; Thompson et al., 2011; Treloar et al. , 2013). Kurtz et al., (2008), in their article *Silencing of Voice: An act of Structural Violence*, provided an example from one participant’s experience with structural violence that demonstrates common experiences that First Nations peoples face when accessing health care. Kurtz et al., (2008) said that this particular person had suffered a stroke and described their experience with a doctor “[I] have not drunk for many years... [even if you tell them] ‘oh, I’ve been sober for 10, 12, 15 years,’ [they will ask] ‘Are you sure? Are you sure you put your own pants on this morning?’ That’s what he said to me” (p. 57). The result is that many First Nations people do not want to access services out of fear and lack of trust of mainstream service providers (Maar et al., 2013; Petereit, Rogers, Burhansstipanov, Kaur, & Govern, 2005; Poudrier & Mac-Lean, 2008). Consequently, First Nations people often delay seeking or do not access health care services, which can have a

devastating effect on their life and health. This is of particular concern in the area of cancer related services where we know that cancer is on the rise for First Nations, Inuit, and Métis people and that early diagnosis is important for successful outcomes of treatment (Cancer Care Ontario, 2012, p. 29). Providing access to meaningful and appropriate health care services that may include attention to culture and tradition is viewed as a way to increase access.

Supportive Services for First Nations

Typically, the treatment of cancer varies depending on the site, stage, and type of tumor with which an individual presents. Treatment can range between surgery, chemotherapy, and radiation. The length of time that a patient is treated for cancer is determined by best practices for that particular type of cancer and the stage of the cancer (Cancer Care Ontario, 2010). While the cancer journey begins with prevention then screening, diagnosis, treatment(s), recovery/survivorship/end of life care, Cancer Care Ontario situates psychosocial care in the diagnoses, treatment and recovery/survivorship/end of life stages of the cancer journey (see figure 1). This study follows suit and focuses on the psychosocial care aspect of the cancer journey at the time of diagnosis through to recovery/survivorship or end of life.

The literature that I reviewed explicitly established the urgent need for supportive services for Indigenous peoples within the health care setting (Browne et al., 2013; Burhansstipanov, 1998; Burhansstipanov, Gilbert, LaMarce, & Krebs, 2001; Howard et al., 2014; O'Brien et al., 2013; Poudrier & Mac-Lean, 2009; Purden, 2005; Shahid et al., 2009; Shahid, Finn, Bessarab, Thompson, 2011; Schanche Hodge, Itty, Cadogan, Martinez, 2011; Thompson et al., 2011; Treloar et al., 2013; Whop et al., 2012). While some of the literature pointed to having services within the hospital setting (Joshnstone, & Kanitsaki, 2006; Kurtz et al., 2008; Shahid et al., 2011) without consideration for community-based services, other

literature pointed to the need for setting up community-based supportive services (DeCourtney, Branch & Morgan, 2010; Howard, et al., 2014; Taiaiake Alfred, 2009). The reasons provided for hospital-based services was not extensively explored in the literature that I reviewed with regards to the benefits of having services solely provided in hospital because the research focused on examining community-based services (Joshnstone & Kanitsaki, 2006; Kurtz et al., 2008; Shahid et al., 2011). Shahid et al., (2009) made the argument that the onus for shifting how health care is delivered for Indigenous peoples should be coming from the primary care teams “for ensuring optimal care (including psychosocial care and cultural safety...)” (p. 577). It appeared somewhat counterproductive to place First Nations supportive services only within a hospital setting when there are clearly barriers within the hospital system that prevent First Nations peoples from accessing care. These have been discussed previously with regards to NIHB services and the structural barriers that existed in the previous section.

Support services also need to be available at the community level to enable people to easily access psychosocial services. A good example of a cancer screening program currently established within First Nations community is the partnership between the Northeast Cancer Centre in Sudbury and the local First Nations health access centres pilot project, Under/Never Screened (Health Sciences North, 2015). The goal of this project is to work within First Nations communities to increase access to breast and colorectal screening. “According to the report, breast screening rates increased from 21.8% to 34.6%, representing an absolute increase of 12.8% and colorectal screening rates increased from 22.1% to 30.5% representing an absolute increase of 8.4%” (Health Sciences North, 2015).

There is research calling for cultural safety, cultural competence and culturally relevant services in the delivery of health care services for First Nations peoples (Bourque Bearskin,

2011; Burhansstipanov, 1998; Burhansstipano, Gilbert, LaMarce, & Krebs, 2001; Burhansstipanov et al., 2010; Clark & Holtslander, 2010; Harun, Harrison, & Young, 2012; Marr et al., 2013; McGrath & Phillip, 2009; Mokuau, Braumm, & Daiggelis, 2012; Muircroft McKimm, William, & MacLeod, 2010; O' Brien et al, 2013; Poudrier & Mac-Lean, 2009; Shahid et al., 2009; Shahid et al., 2011; Shahid et al., 2013; Thompson et al., 2011; Withrow, Amartey, & Marrett, 2014; Zehbe, Maar, Nahwegahbow, Berst, & Pintar, 2012). Allan and Smylie (2015) suggested that not enough has been done to shift the foundation of the health care system. They noted that,

Race-based policies, experiences and anticipation of racist treatment by health care providers also act as barriers to accessing needed health services... [these]...common experiences that participants actively strategized around how to manage negative responses from health care providers...[and] in some cases keep people from accessing health care at all...Racism in the Canadian health care system can be fatal; a fact devastatingly illustrated by the death of Brian Sinclair. (p. 9)

The death of Brian Sinclair resulted in a high profile case about how some Aboriginal people have been neglected in the health care system. Brian Sinclair was a First Nations man from Winnipeg who was a double amputee. Mr. Sinclair attended the Winnipeg Emergency Department for a blocked catheter and waited for 34 hours in the Emergency Department. When Mr. Sinclair was discovered in the Emergency Department, he had already passed away and rigor mortis had set in (CBCNews, 2014, para 9). Although the example provided is not specific to cancer, cancer patients enter into the health care system at several different entry points and may find themselves confronted with similar racist treatment by health care providers. It is important

to highlight that the hospital system as a whole presents systemic barriers that prevent First Nations people from accessing health care.

Recently, there have been changes to the hospital setting such as the introduction of Aboriginal Navigators at each of the regional cancer centres throughout Ontario through the Aboriginal Cancer Strategy II. These positions were created with the goal to “guide FNIM [First Nations, Inuit and Metis] patients through the process and help them make... decisions...” (Cancer Care Ontario, 2012, p. 24). These positions do assist Aboriginal people with addressing issues that may arise while attending cancer treatment. Fundamental changes in attitudes and perceptions about First Nations peoples within the hospital system will take time and it would be difficult to assume that one position such as the Aboriginal Navigator in a cancer centre could shift this on their own. Services throughout the cancer continuum (see Figure 1) would better ensure that there are culturally appropriate services that address the needs of First Nations peoples. Generally, while work has started in the hospital setting in terms of bringing about a change in attitudes about Aboriginal peoples, there remains much work to be done and multiple interventions are needed to implement real changes.

On the other end of the spectrum is the issue of lack of community-based services to support First Nations peoples during their cancer journey. It makes sense to have supportive services within the community. First Nations peoples often return home after their cancer treatment and, at times, may only attend a cancer centre periodically for appointments or treatment. Howard et al. (2014) supported the notion of community-based services and found that “rural [Aboriginal] cancer survivors were adamant that culturally appropriate activities and counseling, accessible from their community and open to family members, were essential to putting their cancer journey into perspective” (p. 377). Along with having supportive services

closer to home, Burhansstipanov et al. (2001) and Whop et al. (2012) both reported that supportive services are linked to better survival rates and quality of life. Mokuau, Braunm and Daniggelis (2012) further explained that family supports often showed that people have better outcomes. Being proximally closer to family members enables the family to help care for the patient and/or provide emotional support for the patient. While family support cannot be provided by external groups, it is important that the role of the family in providing support to a cancer patient is conveyed to families so that they are aware of their important role. Overall, these studies are important in outlining critical components to providing supportive services to patients during cancer care.

There are two research articles in the literature that I reviewed, published in the United States, on the success of having community-based Aboriginal Navigators (Braum et al., 2012; Burhansstipanov et al., 2012). These Navigators worked within the community to bring relevant cancer information and education to the community through workshops and also assisted with cancer screening programs. Burhansstipanov et al. (2012) found that adherence to treatment increased along with reduced wait times for accessing treatment.

Although patient navigator roles can vary depending on where the navigator is positioned within the system, their ultimate goal is to reduce systemic barriers to services, to provide supportive services to the patients including seamless coordination of services from hospital to community and back again, and to provide culturally competent services.

When supportive services are offered closer to home, they are more accessible to patients thus ensuring that patients have access to services. Schanche Hodge et al. (2011) explained that, “cancer survivors and family members lack effective self-management techniques for common symptoms, such as pain, depression, and fatigue” (p. 187). Supportive care services in the

community could easily incorporate “cultural values into the design, delivery and evaluation of services” (Shahid et al., 2013, p. 9). Incorporating traditional cultural practices and values can have a profound effect on patients and can be an important part of the recovery process including pain management and depression (Poudrier & Mac-Lean, 2009). Poudrier and Mac-Lean (2009) further noted that a patient who they interviewed who was recovering from breast cancer stated that the connection to traditional values and family were an important source of strength. The patient was quoted as saying that ‘the sweat lodge was...a safe place for healing – a place free of racism” (p. 311). Poudrier and Mac-Lean (2009) explained that multi-dimensional support is needed for Aboriginal cancer patients that include support groups, nurse navigators, and a hospital environment that is inclusive to Aboriginal peoples' experiences including attention to their culture and traditions.

In summary, this section of the literature review has shown that there is still a need for supportive services such as support groups, cultural safety, cultural competency, and culturally relevant programming, which will address First Nations peoples' unique experiences when accessing health care. Poudrier and Mac-Lean (2009) and Thompson et al. (2011) indicated that these groups are best placed within the community.

Northeastern Ontario Context

The literature search that I carried out revealed very little on the psychosocial needs of First Nations peoples living in Northern Ontario during their cancer journey. While the literature was scant, it did reveal two different studies pertaining to cervical cancer (Maar et al., 2013) and Human Papilloma Virus screening (Zehbe et al., 2012). Both of these studies highlighted the barriers First Nations peoples face in participating in health care services, which include structural barriers such as the need for transportation, confidentiality, and lack of trust with

health care providers. In addition, Maar et al. (2013) explained that due to longstanding implications from colonial practices, the lack of trust runs deep. Many Aboriginal women have suffered sexual abuse in residential schools and are more reluctant to seek services for a cervical examination due to the intrusive nature of the examination. They may also have issues with a male healthcare provider performing the exam (Maar et al., 2013). This further supports the importance of providing culturally relevant services that address First Nations' needs. It is important to note that Cancer Care Ontario released the Aboriginal Cancer Care Strategy II which is intended to address the gaps for services for First Nations, Inuit, and Metis peoples. As previously mentioned, the Northeast Cancer Centre has undertaken a project called the Under/Never Screened to assist First Nations communities and Aboriginal health authorities with increasing cancer screening for the breast, colorectal, and cervical screening (Health Sciences North, 2015).

Due to the minimal literature specifically documenting Aboriginal peoples' needs in Northern Ontario during their cancer journey, the literature review was expanded to the Canadian context. This literature supported the need for services to address the gap in psychosocial services for First Nations peoples within a general Canadian context. The report from the Canadian Partnership Against Cancer (2012) stated that "providing emotional and informational support for First Nations throughout their cancer journey can help to improve patient experiences as they interact with the cancer care system," (p. 40). As noted earlier in this literature review, Poudrier and Mac-Lean (2009) also clearly asserted that supportive services for First Nations are needed. Additionally, one article that I found described the barriers to psychosocial supportive care services for First Nations peoples post treatment: "First Nations RCS [rural cancer survivors] were adamant that culturally appropriate activities and counseling, accessible from

their community and open to family members, were essential to putting their cancer journey into perspective” (Howard et al., 2014, p. 311).

Summary

In summary, this literature review revealed several research studies in the area of health and cancer for Indigenous peoples. While literature specific to the Northern Ontario context was minimal, there was literature available in the general Canadian context. This literature also was limited in regards to understanding the psychosocial needs of Aboriginal peoples during the cancer journey. What the available literature did outline was how the social determinants of health and structural barriers, such as the lack of cultural sensitivity, relevance of approaches, and cultural safety, have created an environment where First Nations peoples do not feel comfortable accessing health care services. This was highlighted in several articles (Maar et al., 2013; Poudrier & Mac-Lean, 2009). The literature also confirmed the importance of programs such as the Aboriginal Navigators (Braum et al., 2012; Burhansstipanov et al., 2012) and the Under/Never Screened pilot project (Health Sciences North, 2015), both of which have led to increased access for health care services for First Nations peoples. Despite these findings, research that specifically explored the psychosocial needs for First Nations peoples undergoing cancer treatments is lacking and therefore supports the need for further research in this area.

Chapter 3: Theoretical Framework

The theoretical framework that informed this research project was a decolonizing Indigenous research methodology rooted in the Anishinaabe teachings of the Medicine Wheel.

Decolonizing Indigenous Research Approach

Using a decolonizing perspective is key because of the longstanding history of colonization and the continue marginalization of Indigenous peoples, Margaret Kovach (2010) has argued. A decolonizing pedagogy seeks to question dominant discourses and the ways in which dominant discourses have subordinated and positioned Indigenous knowledges. Decolonizing research can be viewed as both “counter-hegemonic and self-determining” (Cote-Meek, 2014, p. 35). Specifically, a decolonizing Indigenous research methodology is the process of bringing Indigenous knowledges to the forefront or to the centre of the research. This ensures that the realities, perceptions and ways of viewing the world of Indigenous peoples are represented (Chilisa, 2012). Centering Indigenous knowledges in the context of decolonization is important because far too often First Nations peoples have been researched on and not researched with (Tuhiwai Smith, 2012). Research that has been conducted on First Nations peoples has far too often reflected the perspective of the researcher and not the community (Tuhiwai Smith, 2012). Tuhiwai Smith (2012) further discussed this concept and explained that research is one of the “dirtiest” words for many Indigenous communities because of the historical implications with which research came. She explained that, “Indigenous peoples were researched, their knowledges expropriated and taken up and owned by the West, while simultaneously dismissing and marginalizing Indigenous peoples as a group” (p. 56).

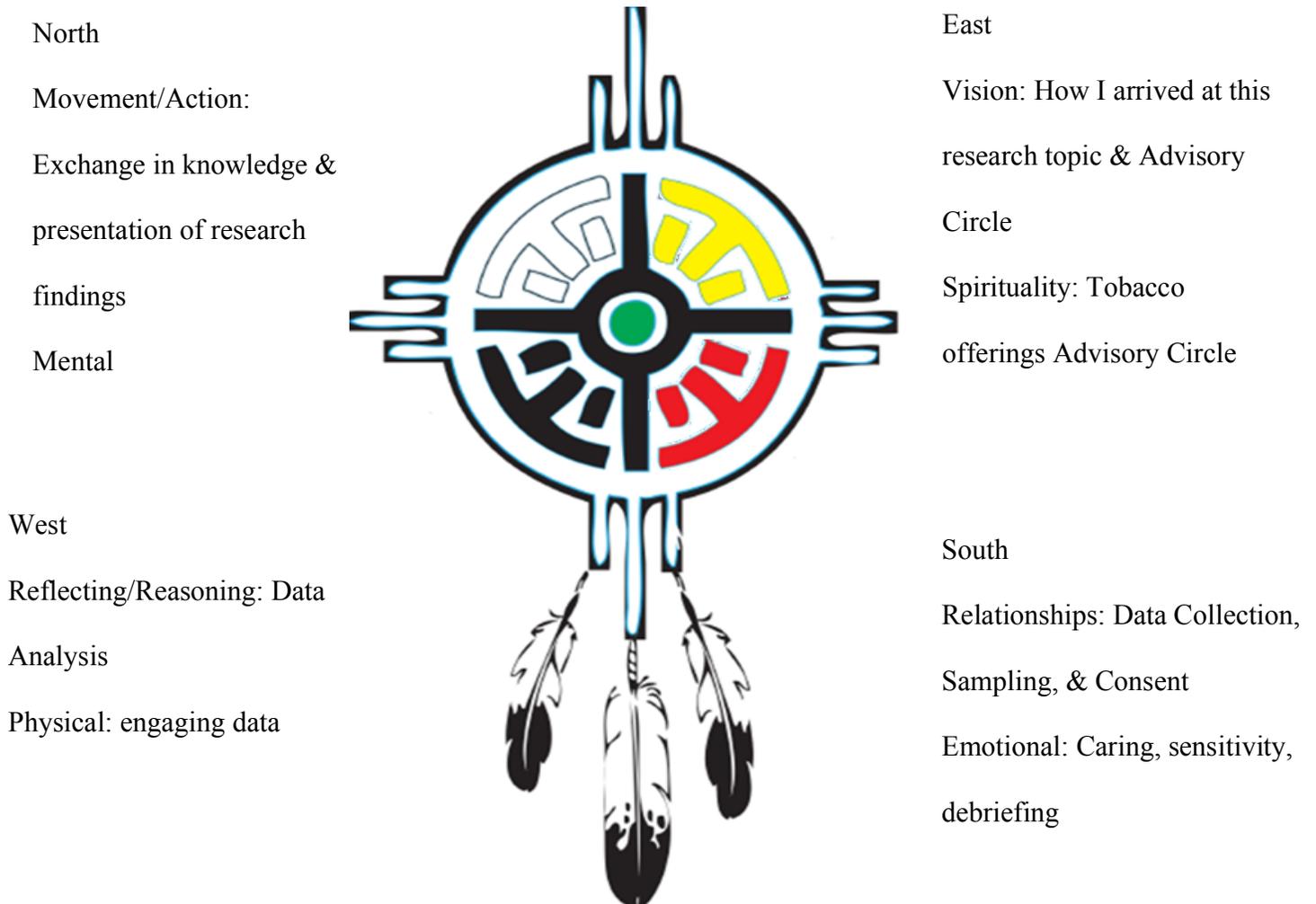
In defining an Indigenous research methodology, it is important to understand the underlying values and principles that inform it. Lavallee (2009) noted that an Indigenous

epistemology, also referred to as a worldview, will shape and direct an Indigenous research project. Kovach (2010) also noted that Indigenous methodologies are based in the underlying values: “Indigenous methodologies are a paradigmatic approach based upon an Indigenous philosophical positioning or epistemology” (p. 1). According to Kovach (2010), Indigenous knowledges have specific ways of viewing the world that originate from traditional ways of passing knowledge from one generation to the next. Indigenous research methodologies are therefore born out of Indigenous knowledges, cultural beliefs, and traditional practices and may vary across communities.

In approaching research from a decolonizing perspective it is important that the research “be framed within Aboriginal epistemologies” (Cote-Meek, 2014, p. 14). Researchers must be conscious of Indigenous knowledges and use such knowledge to frame and approach research. Wilson (2008), Tuhiwai Smith (2012), Kovach (2010) and Battiste (2013) also supported the notion of using Indigenous knowledges when approaching Indigenous research methodologies.

In order to ensure a decolonizing Indigenous methodology this research was framed within the Indigenous knowledges, cultural beliefs, and traditional practices of the Anishinaabe. My understandings have been informed by people of the Temagami-Anishinaabe territory, and the teachings that were passed down within my own family through my Anishinaabe grandmother, Lucienne Cote-Meek. I understand that these teachings may be slightly different from those teachings in other communities in Northeastern Ontario. There are similarities as they also identify as Anishinaabe. Figure 2 provides a diagram of the Medicine Wheel that assisted with conceptualizing my approach.

Figure 2. Medicine Wheel Representation of the Process Used to Conduct Research



The Anishinaabe teachings of the Medicine wheel (in my traditional territory) is often used to express the cultural and traditional understandings of the world around us, both what is seen and unseen. It is important to note that the teachings of the Medicine Wheel take a lifetime to learn, and I am still at the infancy stage of learning about the teachings of the Medicine Wheel. I received Anishinaabe teachings, understanding of cultural values, traditions and way of living from both my grandmother and mother. As I have learned more about my Anishinaabe teachings I have found that I already understood a lot but did not have the language to express it because for me these teaching have always been part of the way of life that is expressed within

my Anishinaabe family. For the purposes of this research, I present a brief overview of the Medicine Wheel teachings that guided this research.

The Medicine Wheel is considered a sacred symbol depicting the circle of life (Hart, 1996). It encompasses all of who we are as peoples and is represented within this sacred symbol. The Medicine Wheel is usually divided into four quadrants representing the four directions of east, south, west and north. Each direction is represented by a colour and has a set of teachings. In the Anishinaabe territory, the east direction is represented by the colour red (although there is some variance in this and sometimes it is represented by the colour yellow), south by the colour yellow, west by the colour black, and north by the colour white. Each of these directions also represents the four races of mankind. Each race is unique and has equally important qualities and roles (Hart, 1996; Hart, 2002; Nabigon, 2006). The Four sacred medicines Tobacco, Cedar, Sage, and Sweetgrass are represented in each of the four directions. The Medicine Wheel is considered wholistic and also depicts four states of being. The four states of being include spiritual, emotional, physical and mental states. We need to care for each state in order to maintain balance within ourselves. If one of the states of being is not maintained then we will struggle with other aspects of our being (Hart, 1996). For this reason, the teachings of the Medicine Wheel often center around concepts of interconnectedness, interdependence, and interrelatedness within one's being as well as in relation to one another and the world around us including the land, plants, elements, animals, the sky, and the cosmos (Hart 1996; Hart 2002; Nabigon, 2006). All four directions of the Medicine Wheel are interrelated and interconnected.

Chapter 4: Design and Methods

The methodology for this research project is purposefully framed within an Indigenous worldview, specifically the Anishinaabe Medicine Wheel. Framing this project within the Medicine Wheel has ensured that the research reflected the worldview of First Nations peoples. In this section, I will be discussing the Methods of my research.

Qualitative Methods

The intent of this research was to identify which culturally relevant supportive services First Nations in Northeastern Ontario require to improve supportive services during cancer diagnosis and treatment, as perceived by service providers in those communities. The hope is that the results may later inform the development of a community-based toolkit that will contain information for service providers in order to provide culturally-based and relevant services.

This research utilized qualitative methods because qualitative methods seek “to understand human experiences from the perspective of those who experience them” (Yegidis, Weinbach, & Myers, 2012, p. 21). The use of qualitative methods is appropriate and complementary within an Indigenous framework because as Faulkner and Faulkner (2014) pointed out, these methods seek to generate a wider scope of peoples’ experiences through observations and interactions with the researcher. In the sections that follow, I will use the Medicine Wheel to indicate how I addressed recruitment of participants, ethics, data collection, and data analysis. I conclude with outlining key assumptions and limitations.

How the Medicine Wheel Informs My Methods

I start in the Eastern direction where Tobacco is the medicine that resides along with the colour red, which represents the Anishinaabe people (see Figure 2 of Medicine Wheel-

Conducting Research). The gifts of the eastern direction center around vision and spirituality (Hart, 1996; Hart, 2002).

The vision for this research came to me during my work as the Aboriginal Navigator at the Northeast Cancer Centre where I recognized gaps in supportive services for Aboriginal patients undergoing cancer treatment. During my work, I also dealt with the lack of supportive services when Aboriginal patients returned to their homes and communities. As well, part of the vision for this research included undertaking this research in what Aboriginal peoples refer to as "a good way". I interpreted this to mean that the research would be conducted in a way that is respectful, meaningful, and inclusive of the community.

In order to ensure I worked in a culturally relevant manner, I believed it was important to have a Community Advisory Circle (CAC) made up of First Nations peoples with first-hand knowledge of working with these specific communities. Members of this advisory circle were also chosen because of their experience with undertaking research in a culturally sensitive and appropriate manner. This is also an important step in building relations with people from the community. My CAC consisted of two people who I invited to assist me with community and cultural protocols with respect to this research. One advisor is the Medicine Lodge Keeper at Health Sciences North, and the other advisor is a member of Wikwemikong Unceded Indian Reserve, who has also undertaken research in the area of cancer and traditional medicine. Both of these individuals agreed to be members of my CAC. I met with both advisors before beginning the recruitment process to establish a protocol about how to approach each community. One of the advisors had initially advised me to correspond via email but, I received very few responses. I met with the advisors to follow-up regarding the difficulties I was experiencing. One of the advisors assisted me by sending correspondence via email to several

communities with whom she was in contact, informing members of who I was and asking that my information be passed on to those they thought would be good participants for the project for recruitment. Following this, I received several emails regarding the project. One community asked that I provide a presentation regarding the project to the staff and another community asked for specific details regarding the project. Having a member of my CAC assist with recruitment proved to be beneficial in getting the information about my research project out to the community.

I also met with my CAC before I proceeded with the data analysis aspect of this research. I discussed with them what my initial general findings were. I received some feedback about one of the advisor's own experience with the process of data analysis. The other advisor provided feedback regarding her experiences of providing services to Indigenous people in the hospital. Following both these conversations, I felt that I was on the right track with my initial data analysis. I felt more comfortable going deeper into the analysis, looking more closely at what each participant had spoken about within each transcription.

The teachings of the eastern direction also focus on spirituality. According to Gerald Taiaiake Alfred (2009) “the transmission of Indigenous culture, spiritual teachings and knowledge of land are all important forms of healing for First Nations peoples” (p. 183). The spiritual aspect of decolonization in this research was reflected in my understanding and recognition that we are all interconnected and interrelated, including the researcher and the participants. Spirituality was represented in my research in many ways including offerings of Tobacco to the CAC and to the research participants. The giving of Tobacco represents a spiritual contract between the Creator, those accepting to assist in the research, and myself. The spiritual contract meant that I undertook to ensure the research was conducted in a good way,

with good intentions, and that I give back to the community (Baskin, 2005). The offering of Tobacco is also a sign of respect within my cultural teachings. During the research process, I conducted a total of 13 interviews. Nine participants were offered tobacco before the face-to face interview began. Three interviews occurred over the phone and I was unable to give tobacco. Also, I was unable to give tobacco to one of the face-to-face interview participants because I was initially going to that community to interview one participant. However, two other participants came forward to be interviewed and as a result I was short one tobacco offering. For those participants, I burnt tobacco and said a prayer of thanks on my own in honour of their participation.

The Southern direction of the Medicine Wheel is where Cedar medicine is represented and the colour yellow (Hart 1996; Hart, 2002). The gifts of this direction centre on relationships and responsibility. This direction also represents the emotional aspect of being.

Building respectful trusting relationships with the First Nation communities I worked with was critical to ensuring my research would be meaningful to the community. In addition to forming a CAC, I also ensured that I nurtured those relationships in a respectful and good way that honoured the knowledge that they carry and share. Cancer is a very emotional topic, and through my own work, I knew to be extremely sensitive and caring in talking about it with those in the community. I ensured that anyone participating in the research had an alternate person with whom to debrief and/or seek support. It was also my responsibility to adhere to any community protocols as I was responsible for the effect the research may have on the lives of the people who participated in this research (University of Manitoba, n.d, p. 14). I approached the Executive Directors of the Health Centres in each of the communities first to discuss with them

the research project and requested permission to move forward. I also inquired to see if there were any additional requirements I needed to move forward with the project.

Recruitment of Participants

My intent was to recruit service providers who worked in a health centre in a First Nations community in Northeastern Ontario using purposive and snowball sampling. Snowball sampling allowed for recruiting potential participants through word of mouth and gaining appropriate participants through identifying who works closely with cancer patients (Yegidis et al., 2012). With the assistance of my CAC (described earlier), I was able to recruit 13 participants; one participant was not working in a health centre but was a retired front line service provider and was at the time providing healing circles for people who had undergone cancer treatment and therefore was included in the research. Of the 13 participants, 10 participants were First Nations and 3 participants were non-First Nations. Participation was based on experience working within a health centre. All 13 participants were included in this study because participation was based on experience working in a health care centre within a First Nation community. Further, all participants were people who felt that they had enough experience to provide information about their experiences working with First Nations peoples during cancer diagnosis and treatment. I did not ask for specific years of experience in the area of cancer supports by participants because I was aware of the high turnaround of employees in many First Nation health centres in the area. Level of competence to participate was determined by the individual themselves and not me as a researcher.

I initiated the recruitment process by a distributing an ‘Invitation Letter to Participate’ (see Appendix B) to each First Nation health centre along the northern routes of highways 11, 69, along the north shore of Lake Huron, and highway 17 east. The highway 11 and 69 corridor

is how First Nations communities along these stretches of highways identify their geographical location. These geographical areas were chosen as there are several First Nations communities within each of the areas, thereby ensuring a wider reach of potential participants. An email was sent to each Executive Director informing them of my research project, requesting permission to contact their staff, and asking if they could post my Invitation Letter to Participate within their health centre. Email addresses for the Executive Directors were obtained through the health centre website. As per my earlier discussion on my CAC, where Executive Directors did not respond to my initial attempts through email, I then followed-up with a telephone call.

Once a potential participant was identified, I contacted the potential participant to explain the research and obtain consent to proceed with an interview. Each potential participant was asked if they could provide a referral for other qualified participants. When they made a referral for a participant, I asked that they contact the potential participant for permission to release their names to me first. Once permission was granted, contact was made. Only two participants identified other potential participants for me. All other participants heard about the project either through me directly or through word of mouth. Interviews were scheduled as soon as participants agreed to participate.

Data Collection

Ten face-to-face and three individual telephone interviews were conducted using a semi-structured Interview Guide (see Appendix A) over a three month period, August to October, 2015. The 10 face-to-face interviews were conducted at a place of the participant's choosing. All 13 interviews were audio recorded with consent of the participant and lasted between 30-90 minutes in length. The length of time for the interviews varied depending on the amount of information each participant shared.

It should be noted that three participants did initially express that they felt intimidated by the audio recorder. I did verify consent with them before proceeding, and they were still in agreement. In these cases, after the interview was completed, I checked back in and asked about their level of comfort during the interview knowing that the interview was audio recorded. They all indicated that once they started the interview, they forgot about the recorder.

Shortly after each interview, the audio recordings were transcribed and saved on an encrypted USB stick. A backup copy of the transcriptions was stored on a password-protected file on my computer in my home office. The transcripts used non-identifying pseudonyms to protect the identity of the participants. All audio-recordings will be erased once my thesis is accepted.

All transcriptions were completed by mid-December, 2015. I reviewed all transcriptions for accuracy. One of the transcriptions had minor errors in spelling and was sent back to the transcriber for corrections. Once I felt confident of the accuracy of the transcriptions, I sent each of the participants their transcripts for review. One participant made changes to their transcription; they saved it and sent the new version back to me through email. It was unclear what was changed as I did not compare the first transcription with the new revised transcription. I simply deleted the previous transcription and replaced it with the new version that the participant was agreeing/consenting to share.

Consent

Informed prior consent was obtained from each participant before the interview. The research topic, the format, and the requirements of participation were explained to each participant before each interview was scheduled. Three interviews happened spontaneously. I had been in the community for another interview, or I had completed a presentation regarding the

research project, and they expressed their interest in participating. At this time, the format and requirements were explained to them. Participants were made aware that their participation was strictly voluntary and that they had the option to withdraw their consent at any time. Each participant was asked to sign consent for the audio recording (see Appendix C for the Consent form)

Ethics

The research was submitted to Laurentian University Research Ethics Board (REB) for approval in June, 2015, with the request for an expedited review. I also completed, with certification, the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans second edition (TCPS 2).

Community protocols were considered. This was done by showing respect for any protocols and was accomplished by seeking the advice from the CAC on the best way to approach people in the communities. In addition, I recognized that the stories/knowledge participants shared with me are considered sacred gifts. Respect is also the foundation to building relationships and trust (Wilson, 2008).

Data Analysis

The Western direction is where Sage medicine is represented and the colour black depicts direction (Hart, 1996; Hart, 2002). This direction represents the physical aspect of being and the gifts of the direction focus on reflection and reasoning.

Data analysis can be seen both in the reflection and reasoning teachings of the Medicine Wheel teaching. Transcriptions were coded and initially interpreted; this required thought, understanding, and reflection as well as reasoning. With the physical aspect of being, this can be viewed as the process of engaging with the data.

In keeping with an Aboriginal epistemology, I chose to use Braun and Clarke's (2006) model of thematic analysis because it complemented the four quadrants of the Medicine Wheel. Therefore, once the data had been transcribed and verified by the participants, I went through the series of six phases outlined by Braun & Clarke (2006) (see Figure 3). In addition to using Braun & Clarke's (2006) phases I also used the Medicine Wheel as a framework during the identification of the themes.

Figure 3. Thematic Analysis Table

Phase	Description of the process
1. Familiarising yourself with your data:	Transcribing data (if necessary), reading and re-reading the data, noting down initial ideas.
2. Generating initial codes:	Coding interesting features of the data in a systematic fashion across the entire data set, collating data relevant to each code.
3. Searching for themes:	Collating codes into potential themes, gathering all data relevant to each potential theme.
4. Reviewing themes:	Checking in the themes work in relation to the coded extracts (level 1) and the entire data set (level 2), generating a thematic 'map' of the analysis and [checking with Academic committee and community committee].
5. Defining and naming themes:	Ongoing analysis to refine the specifics of each theme, and the overall story the analysis tell; generating clear definitions and names for each theme.
6. Producing the report:	The final opportunity for analysis. Selection of vivid, compelling extract examples, final analysis of selected extracts, relating back of the analysis to the research question and literature, producing a scholarly report of the analysis.

(Braun & Clarke, 2006, p. 36)

As the data was coded and placed into themes, an overall picture of what the needs are for First Nations peoples during cancer diagnosis and treatment, as perceived by the service providers that participated in this research became clearer. The data was coded and then placed into themes, which produced an overall picture of what the needs are for First Nations peoples during cancer diagnosis and treatment, as perceived by the service providers that participated in this research. The themes that emerged during the analysis were then grouped within the Medicine Wheel quadrants to ensure the analysis remained consistent with the Indigenous research methodology described earlier. This also ensured cultural relevance of the data analysis. Once this was complete, I met individually with my CAC and then my thesis committee to share, discuss and seek feedback on the thematic analysis. Part of this feedback process ensured accuracy in interpretation and validity. It is important to also acknowledge my own positionality as a woman with Anishnaabe ancestry and my own personal lens of the Medicine Wheel did influence how I understood the data. Therefore, I cannot say that this research is without bias.

Coding

Coding was started once all the transcripts were read three times to check for errors and to become familiar with the content. During the readings, I also wrote down a few key ideas about what the participants were saying. I then engaged with the data by reading each transcript and highlighting key words or concepts that were repeated amongst other participants. I also continued to make notes on each transcript of items or themes that stood out. I then went through each transcript again and wrote out, on a separate sheet paper, all the codes that fit together within a theme. I repeated this for each theme. The process of coding took several months as I went back and forth examining the transcripts for themes. I also went back to a member of my CAC (only one member as the other member was unavailable) and discussed the themes that

emerged in my analysis. Through our conversation, I reflected back on what she was saying in view of the goal of working from a decolonizing lens. I subsequently changed some theme names to better reflect Anishinaabe worldviews.

Data was anonymized within the research study and as such participants are identified with the following coded indicators: PAR to indicate Participant followed by a number that has been assigned. For example, participant one will be identified as PAR1 and so forth. The number assigned to the participant is arbitrary.

Participants

A total of 13 interviews were conducted with service providers in five First Nations and one First Nations Health Access Centre which services eight First Nations: 11 women and two men. Each of the participants had varied work related roles in the area of health service delivery in the First Nation community. Each participant agreed to participate because they had experience providing services to clients diagnosed with cancer and were comfortable speaking about the topic. The varied jobs are reflective of the many roles that service providers take on in First Nation communities. I have deliberately not described participants' backgrounds in detail in order to ensure confidentiality and anonymity of participants.

In addition, two of the participants self-declared that they were cancer survivors and thus brought their own unique experiences to the study. There was no way to control for cancer survivors participation within the study as this was not a question or deterrent for participation. The two participants that disclosed their personal experiences brought a richness to what they understood as to what the needs are of patients who are undergoing cancer treatment and receiving services. There were several other participants who had been personally touched by cancer either through a family member, friend or community member and they also recounted

their experiences in providing support. These perspective(s) added to a broader understanding of the experiences of those who are affected by a diagnosis of cancer and are included in the analysis.

Finally, I will move to the north direction where the Sweetgrass medicine is located along with the colour white (Hart 1996; Hart, 2002). This direction represents the mental aspect of our being and the teachings are of movement and action. Movement and action can be viewed as the reciprocal exchange of knowledge that is done through the interview process (Kovach, 2009). Sharing the results and information of the research also represents the reciprocal exchange of knowledge (Kovach, 2009).

Once the data had been gathered, the participants received a copy of their transcripts. They were asked if there were any additions, deletions, or edits they wished to make to their transcripts. This helped each participant further add to their own understanding of the data to the analysis. I also discussed the data with my CAC to enhance the validity and cultural accuracy of the research. No identifiers were shared with the CAC. This process is seen as reciprocity and is about giving and receiving. To me, this is part of the process of continuing to build good and trustful relationships and ensures that I am sharing information. Kovach (2009) notes the importance of actively engaging with the participants in the project through active listening and honouring their stories.

Knowledge translation and dissemination to the community also happens in this direction. Once my thesis is defended, I will present the findings to the community through community presentations. I also have plans to present to the Northeast Cancer Centre and the Aboriginal Navigator Steering Committee to ensure the dissemination of the results.

All four directions of the Medicine Wheel are interrelated and interconnected. To summarize, the Eastern direction is where the medicine Tobacco resides along with the colour red, which represents the Anishinaabe people. The gifts of the eastern direction center around vision and spirituality. The Southern direction of the Medicine Wheel is where the medicine Cedar is represented and the colour yellow (Hart 1996; Hart, 2002). The gifts of this direction centre on relationships and responsibility and represent the emotional aspect of being. The Western direction is where medicine Sage is represented and the colour black is depicted in this direction (Hart, 1996; Hart, 2002). This direction represents the physical aspect of being and the gifts of the direction focus on reflection and reasoning. Finally, the North direction is where the medicine Sweetgrass is located along with the colour white (Hart 1996; Hart, 2002). This direction represents the mental aspect of our being and the teachings are of movement and action. All four directions are interrelated. It is impossible to consider one without the other as they are interconnected. My topic centres on cancer. Cancer can be viewed as an attack on the whole person: spiritually, emotionally, physically, and mentally. My hope is that using the Medicine Wheel methodology ensured a wholistic approach to my research and that the results will later inform the development of a community-based toolkit that will contain information for service providers who provide care to First Nations patients during cancer diagnosis, and treatment.

Reflexivity

Reflexivity is defined as the “awareness of the influence the researcher has on the people or topic being studied, while simultaneously recognizing how the research experience is affecting the researcher” (Probst, 2015, p. 37). My role as an Aboriginal Navigator within the Oncology system has provided me with a good understanding of the realities that Aboriginal

patients face when diagnosed, and with the treatment of cancer. This has provided me with a unique perspective in undertaking to conduct this research. After each interview, I reflected on the process and what was being shared with me at the time. There were times during the interviews that the participants would report something I had not seen or heard of before. In those cases, I would explore further with the participant(s) to ensure that I was gathering their ideas appropriately and to attempt to avoid influencing their thoughts with my own biases on the topic. Specifically, I checked with the participant by seeking clarification to what they had said. I kept a journal throughout the process of the research project to record what was happening and to record thoughts regarding the interviews.

My own experience working in Oncology was of benefit during all aspects of this research, including data collection and analysis. I found that I was able to easily understand what participants were discussing during the interviews, especially around aspects of cancer care. My experience also helped me during the data analysis as I had some initial understanding of some of the gaps in services.

In order to ensure accuracy of transcripts I sent transcripts back to each participant for their review, comments, and approval. This ensured that what was transcribed accurately reflected what the participant had intended and mitigated any bias in the way the transcriptions were done.

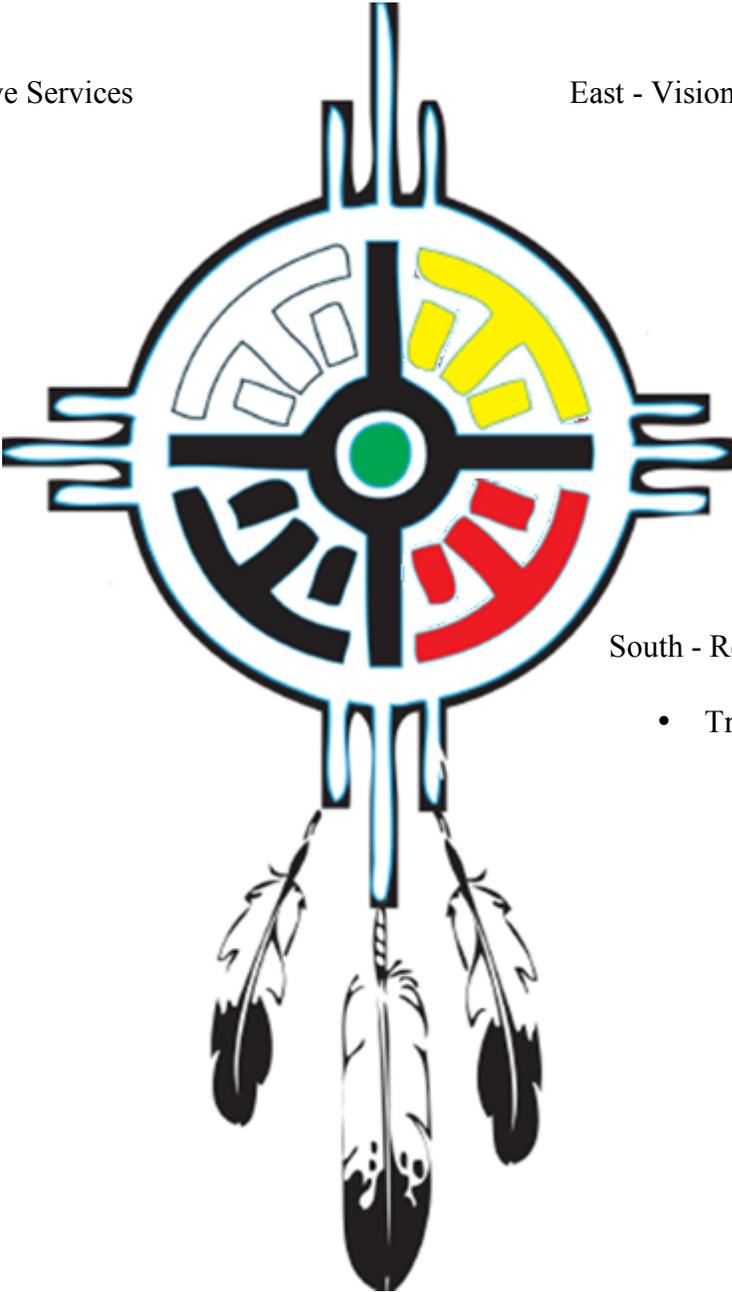
Chapter 5: Findings

In this chapter, the findings from the data analysis are presented through four main thematic areas that emerged from the data analysis, which include Anishinaabe ways of living, Relationships, Environment, and Supportive Services. The sub-theme, Trust, was also added under Relationships. After consulting with my thesis committee and reflecting on how this research was conceptualized within the Medicine Wheel, it made sense to place the four main themes within the four quadrants of the Medicine Wheel (See Figure 4 Medicine Wheel - Themes). These main themes are presented in each of the four directions. The teachings of the eastern direction center on Vision and the theme Anishinaabe ways of living is located there. In the South direction, the teaching is centered on Relationship and the theme Relationships is located there. The teachings of the West direction center on Reflection and Reasoning and this is where I have located the theme, Environment. Finally, the teachings of the North direction center on Action and the theme, Supportive Services, is placed here. Each of these themes were placed within specific quadrants that are reflective of the teaching within the Medicine Wheel. In the section that follows, each theme will be explained in greater detail.

Figure 4. Medicine Wheel - Themes Emerging from Finding

North - Action: Supportive Services

East - Vision: Anishinaabe ways of living



West - Reflection/

Reasoning: Environment

South - Relationship: Relationships

- Trust

East - Anishinaabe Ways of Living

During most of the interviews, the participants discussed the theme of Anishinaabe ways of living. The significance of this theme among the participants draws on the importance of Anishinaabe culture, ways of knowing, and interacting with the world around them. Through this Anishinaabe lens, the participants identified several things that point to the way in which one should live in order to be healthy and/or maintain health. These were often related to Anishinaabe ways of living such as living off the land and using Anishinaabe medicines and cultural practices as way to maintain health. Most of the participants identified that changes to Anishinaabe ways of living have impacted the peoples' health in a negative way. For example, one participant related how physical activity was tied to living off the land and that lack of activity and living off the land has resulted in two significant illnesses, diabetes and cancer:

And, years ago, there was no diabetes, no cancer, because people were living off the land, and, they were more active back then and everything must have worked in our bodies better back then...[we are] more sedentary [now] (PAR5)

PAR7 also spoke of the changes to the ways of living off the land and how it has impacted health. PAR7 linked these changes to a negative impact on the younger generation.

A lot of times, they very rarely see the doctor anyway, because of lot of them come from the bush. The older people. The younger people they are there [health centre] steady. I think that's for pills though.

What PAR7 explained is that the older generation very rarely saw a doctor because they used the medicine from the land to heal themselves whereas the younger generations often use the health centre, which the participant felt was to access pills or prescription drugs.

These quotes illustrated how participants linked the erosion of the Anishinaabe land based knowledge and one's ability to heal one's self from ailments. PAR7 went on to say:

They [western practitioners] didn't really want to; they didn't understand their [Aboriginal peoples] ways...their medicine. They had a hard time with that. Sometimes they would use their own medicines from the bush. And the animals, I still have my medicine. I still use my medicine that I find in the bush. I used that on my kids when they were growing up. Yeah, I used to do that a lot. I didn't realize that. I didn't go running to the doctor for a little ailment. We would just go for a walk in the bush and we would find the medicine.

The quote also illustrated PAR7's perception about the lack of understanding from doctors or other non-Indigenous people(s) about what Indigenous peoples were doing when it came to their own Anishinaabe ways of life and healing practices. The participant explained how she herself used her Anishinaabe knowledge to maintain health.

Effectively, PAR5 and PAR7 revealed the link between health and Anishinaabe ways of life that included living off the land and using time-honoured practices to maintain a healthy life. Another participant encapsulated the essence of what these two participants were conveying within the theme:

So it's our bodies, we're made from the earth, so in order to fix your body you have to go back to the earth and replenish yourself with those things that you are missing at wherever time. Let's say I'm sick. I have a cold. Well, you need to go back and get something because you're missing something. That's why you have a cold. Your immune system is down. So you go back out there [to the land] and you grab what you need, but instead we are taking this, that... we don't even know what's in them, we don't even

know where they are coming from, they are so processed and refined for our bodies, our bodies are not meant to take in, to me you are not supposed to take in those things. So we're not living off of the land. (PAR9)

Seven participants also discussed the impact of colonization on Anishinaabe ways of living and two participants expressed the importance of returning to Anishinaabe ways of living as a way to heal colonial trauma and make one's self healthy again. In the excerpt that follows, PAR1 articulated her understanding of the impact that colonization has had on the life of First Nations peoples. Referring specifically to residential schools, she poignantly described the impact as 'spiritual rape' where a person is stripped of their whole core of being:

PAR1: I think since colonization, the residential schools... I just think we have to start healing and loving ourselves again. That we're worth it. We're worth that healthy lifestyle and start living that way... Traditionally, tobacco was for ceremonies and all that but, it's just a form of coping too eh? Pacifying things.

INTERVIEWER: ...you talked a little bit about the residential schools, and the impact, do you think that has an impact on peoples' mental health and the way they cope?

PAR1: Oh yeah, yeah for sure. You know our whole, who we are – It's taken away our identity, our pride, our self-worth, everything, and it is just stripped. I call it spiritual rape. Taking everything, your core belongings, and say[s] no, it's no good... So, yeah for sure. Not just that, like, the Indian Act, and us living on reservations and our lifestyle has changed and, there's lots of factors. CAS and lots of addictions. Where did those come from? Well, probably from all that multigenerational stuff. You know.

INTERVIEWER: The impact of colonization and the impact of the residential schools and that kind of intergenerational trauma that you are speaking about, do you think it has any kind of links to cancer?

PAR1: We used to take care of ourselves, historically, right. And we used to treat common ailments and, heal and take care of ourselves...

In the latter part of the above quote, PAR1 also pointed out how the impact of colonization affects First Nations people ability to take care of themselves in the way that they had previously done.

In the next quote, PAR7 conveyed the importance of returning to Anishinaabe ways of living as a way to heal from the impact of colonization and to make one's self healthy again:

When I was sick I noticed that, as soon as I was out on the water I felt a whole lot better, or if I'd go in the bush, I didn't have to hunt, I didn't have to catch anything, just being in the bush, that was energizing. Just being there...People really like doing that, some of the old timers really like doing that. (PAR7).

What PAR7 explained is this deep connection to the land and water and the healing power it can provide. This is viewed as an important part of Anishinaabe ways of living. PAR7 also spoke about how she saw this connection between Anishinaabe ways of living as a way to heal during an experience she had at youth camp.

PAR7: Everybody becomes open, that spirit, that energy connects. I don't know how to explain that.

INTERVIEWER: Yeah, well, it's that whole idea that everything is interconnected and interrelated with everything, but you can actually feel that and...kind of transcends itself.

PAR7: Yes. Very, very, powerful.

INTERVIEWER: Yes. So, that in itself is healing?

PAR7: You could see it in their face, in their smiles, and hear it in their laughter. When I saw there at the camp this summer, my God, it was so awesome to hear that. And it felt, it made me, the person feel good.... Listening to them, the fresh air, the kids laughing and having a great time. Adults were just... comfortable, relaxed. That's one of the best things our community does, as a healing. I don't think we've ever identified that as that, but that's very powerful...It works good. I feel good when I come out of the bush...That connection of power.

In summary, in this theme the participants highlighted the importance of Anishinaabe ways of living on their overall sense of health and wellbeing. Participants are acutely aware of the losses they have experienced as a result of colonial practices like the residential schools.

South - Relationships

The importance of relationships emerged as another significant theme throughout the interviews. Participants discussed the following concepts: supports from community and family, difficult family relationships, poor coping and issues of trust with health care providers.

Twelve participants explicitly indicated that family and community supports were important during cancer treatment. Although one participant did not indicate that family and community supports were important, the participant did speak about their own cancer treatment and the supports through the community and family received. In the quote that follows, PAR4 discussed the importance of family involvement in assisting the cancer patient with coping with their diagnosis:

Yeah, and that's how they seem to...cope once they are diagnosed...it's much easier for them to cope because then the family is all involved. They have a really good support system with family.

PAR5 also stressed the importance of family and community supports.

...when somebody's sick, well everybody, go out and visit...It's part of the community, they want to help each other, so much...

PAR5 pointed out that even though there is support at the Cancer Centre for patients, it is important for family and community to support the patient.

PAR10 illustrated how she perceives cancer patients' need for their family support and how the community also tries support the family and the patient.

I think people lean on their families or I have also heard, here regionally, people keep it a secret until they are ready. So, they start to get a plan and get things in order for themselves and then they tell their families. But, I think that's a big thing is the family support, family being there and getting together and the community supporting the families. I think is also really important for the patient knowing that the community is trying to help their family to be with them (PAR10).

Similar to PAR10's notion that the diagnosis of cancer is kept a secret until they are ready to disclose, PAR4 also discussed how people keep things to themselves and do not always disclose what they are going through:

They don't like to talk about it...when they first come in, they don't want to, they don't want tell anybody...

PAR4 explained how the community will go about supporting the families and the patients during the treatment process by ensuring they have some of the basics needed during

cancer treatment like transportation. In addition, in the quote that follows, PAR4 shows that the community also provides a kind of wraparound support to ensure that the patient has sufficient resources.

With our Health Unit, you know everybody here, that's involved in our clinic, [Staff] goes out of their way. There's a lot of support for them [community members]...support them by medical transportation and... they may not have additional monies... like, if they, want to take a day or afternoon just to go and do a little bit of shopping. So what we will do, is we will do a lot of fundraising for them to get that additional support, just try to make it easier for them.

It is important to note that this notion of wraparound support may not be consistent in all communities. Each of these participants demonstrated the complexities of providing services needed for the family throughout the cancer treatment process. Family and community are an integral part of the process for the First Nations patients.

Three participants also indicated that when patients are facing a life threatening illness, it can be scary.

Ah, Scared...she [was] really...really, really...scared about going and staying there for the week (PAR5).

The three participants also stated that having the family/community support can help patients get through fears. In the next two statements, both participants described how family and community support help patients while they are going through cancer treatment.

...it's much easier for them to cope because when the family is all involved, they have a really good support system with family (PAR4).

Okay, I have a friend, she, is from xxx (removed identifier) here, but she lives, in xxx (removed identifier) and she came to me one day and she just sits down in my office and she says, I have cancer, and I said, “What!” You know...she says, “yeah”, I have to go for surgery and all she asked for was prayers. ..I am going to give you some tobacco and I want you to pray for me on this day because that’s when I go under the knife (PAR12).

While the participants pointed to family and community as important for patients going through cancer treatment, many of the participants also recognized that families may experience challenges. Some of these challenges may include general coping, drug and alcohol addictions, and/or other family dynamics. These challenges can create barriers for families to be in a position to offer the kinds of supports that patients need during cancer treatment. PAR1 noted, ...there are always issues within the family, right. That come out with all the [a cancer diagnosis]. There’s anger...You know. The cancer patient [is] not always, [or] were not always good people and have done things.

PAR1 highlighted the different kinds of dynamics that can come into play and the complexities that families face when trying to provide support to the cancer patient.

PAR7 also noted, “That depends on how much alcohol they can get a hold of (laughing)”. This participant discussed what she thought could happen when a cancer patient is first diagnosed with cancer. Although the comment was made in an off handed way PAR 7 went on to discuss how families cope with a family members diagnoses:

They struggle as well when there’s issues...sometimes they react outward, like, they act out... [as] if they are children...they turn to addictions....for some it’s easier than others. Again, PAR7 supported the notion that the complexities of families and how poor coping skills can further be exacerbated by a cancer diagnoses.

Seven participants directly linked these struggles with the effects of colonization. The following four quotes from PAR12, PAR1 and PAR7 all reflected different aspects that relate to the effects of colonization. PAR12 talked about individuals struggling with their identity and healing, PAR1 talked about some being part of the ‘walking wounded’ (a term often used to describe people who are impacted by historical trauma; similar to the concept of soul wounded) and PAR7 referenced the 60’s scoop, a period in time when high numbers of First Nations children were taken from their homes and fostered or adopted out of their communities.

I think, you know, it all depends, on where they are and when it comes to their own individual healing with their own individual self-identity, we still struggle with the past...(PAR12)

...I think we need to take care of the families, the individuals... We need to start taking care of the whole family because it ripples out. It affects you. I don’t think they know how to cope or deal with it, it’s just like suicide. Nobody wants to...It’s happened, but nobody wants to talk about it because they have so much going on in their own life, you know, they’re just numb. The walking wounded themselves.’ (PAR1)

We’ve had, I don’t know what you’d call 60’s scoop, we’ve had children taken and they were placed in care, and my family was one of those families that pretty much lost their culture because, my oldest sister was taken away. She was put into a residential school. That has funny impacts on families. (PAR7)

Yeah you see those effects that come down the line, the generations’ different coping, poor coping to not-so-good. (PAR 7)

Another aspect to consider when examining the theme of relationship is the relationship between the Anishinaabe people and western health care services. The relationship with western

health care service providers is an important aspect to explore because they have an impact on how a patient may adhere to treatment and can affect the type of experience they will have. The patient, family, and community will be affected by the experience with the health care institution. There were only two participants who discussed a strict adherence to a westernized model of health care service, and no discussion with regards to Anishinaabe approaches to health care.

All but two participants identified that Anishinaabe healers were an integral part of the health care team. This is significant as Anishinaabe healers are not on-site at the Cancer Centre but their involvement within some of the Anishinaabe communities is still strong. In the quote that follows, PAR11 discussed how people have started to shift their own thoughts on western medicine and Anishinaabe medicines and have accepted that someone can do both, but that they may need some reinforcement.

...I think it [‘s] all on the individual now. If we were doing this a couple of years ago, then, yeah, it would be just like, no. Tradition is tradition. And if you go and use that western medicine, we are going to disown you. And, that’s how a lot of the stuff was like. The real people, that really go live the traditional way – are really faithful – into it and they have all the beliefs...but now...younger people [are] getting back into it. As much as they do the traditional parts for the healing, they have enough to know that...if it’s not working, now I am going to go to the western because then there’s all these teams of people that are there helping. I don’t know...like, if they think it’s better, but then they struggle too, right, because then it seems like they are losing their selves a little bit by going that way...

PAR11 explored the complexity of choosing between western medicine or Anishinaabe medicines. She elucidated the sense of betraying yourself by choosing the western medicine. It is undoubtedly not a clear-cut decision that people are making. PAR4 also illustrated how patients move between choosing western medicine or Anishinaabe medicines but may eventually come to use both sources of treatment.

PAR4: Some believe in the western, very much so in the western medicine. Where you know, they go for the whole gamut of radiation and chemo and then others will wait and try what the [traditional] medicine doctor... [has] given them in regards to the natural medicines, like the barks or roots, and stuff like that.

Interviewer: Yeah. Do you think it's, it's important to offer kind of that perspective, the traditional perspective as well as the western perspective?

PAR4: Yeah, if they choose to, I would think, yeah, I mean that's giving them an option...I do know of one female that opted to see the medicine man before she went and actually saw the western physician or nurse practitioner... [she] didn't want to take anything, any medicines, that she wasn't familiar with...she really trusted in this traditional doctor, so she saw him first and then slowly gradually...came in and saw her regular physicians.

Like PAR11, PAR4 demonstrated that people are going to grapple between a western approach to health care and an Anishinaabe approach to health care.

Trust. The sub-theme of trust also emerged as significant for service providers. Because trust is strongly linked to relationships, it has been placed as a sub-theme under this section.

PAR4 noted that Anishinaabe people do not always have trust within the health care systems and will elect to use their own Anishinaabe practices when it comes to health care. She

made the point that having a choice between both perspectives is important. The notion of trust within the health care system is one that was brought up by 11 of the participants. All 11 participants discussed the lack of trust within the western medical system. One participant discussed what would help rectify the absence of trust of the western medical system. PAR3 stated that:

He got all his teeth pulled out...that's traumatic. So, you know, it's the older generation, like I said before they're not very trusting...And, they're too afraid to speak up to the doctors because they think they are not allowed to voice their opinion...

PAR1 stated:

He was questioning his meds, you know, losing that control, and it would have been nice to have a little bit more when we would go to the hospital. People I found caregivers [at the hospital] didn't believe us... it was almost like nobody believed us [with] the stuff he was going through...

PAR3 and PAR1 relayed that patients are afraid to speak up and even when they do, they are not believed. Essentially, they have no voice and, as a result, there is lack of trust. Along with not having a voice regarding their treatment, patients felt traumatized by cancer treatment (such as having teeth removed prior to treatment). As PAR7 described in the next quote, patients became fearful of the medical professions:

...They could be afraid of the doctor (PAR7).

This lack of trust appeared to fester into fear as explained by PAR6 who links lack of trust to the colonization process by settler society. PAR6 explained this process:

...that's...right from colonization where they were told...to put up with it and do what you're told, and don't complain...Yeah, so they don't, they'll just live with it... they'll just

lie [about] the pain...it's a huge trust issue...Huge trust issue, and, you know what, I feel...that a lot of the doctors...are not culturally sensitive, and they will just throw anything at them... (PAR6).

In the next passage PAR12 illustrated how deep the mistrust of the western medical system runs; there was fear that the western medical system will appropriate or steal Anishinaabe medicine for themselves. This lack of trust is linked directly to colonized histories where Anishinaabe medicines have been devalued in the past:

Yeah, I can tell you a story about the healer that we bring in. He had a patient that had cancer and he gave him traditional medicine...and when he went back to his doctors... it was gone...eliminated the cancer out of his body...his doctors wanted to know what he took who he saw...the patient had given the Traditional Healer's name to the doctors, so the doctors called the Traditional Healer and said, can we talk to you, we want to know what you had done, what you had given, and Traditional Healers are not so quick to give out their medicines, the properties, or even the description on how to prepare it because we know from history that the western people, western medicine, try to take that medicine and patent it for their own...he said, No, I can't. I can't tell you that. I don't have permission from my elders...They're not really quite...share their knowledge when it comes to how to prepare their medicine...it will be patented and taken away, and we won't be able to use it...It makes you wonder if it was for their own knowledge or did they plan...the western doctors, going out to find somebody to go harvest the medicine and bring it back and then to dispense it themselves as...

While the interview was in process, I, as the interviewer, perceived the outreach from the western doctors as positive. As I reread this discussion, I realized that PAR12 was trying to

explain the deep mistrust that exists, and that she was maintaining the view that the intentions of the western doctors may not always be good.

PAR12 provided another example of how western doctors are not always supportive of Anishinaabe knowledge and traditional healing practices. This participant illustrated the different approaches to practicing medicine. Near the end of the quote, the participant indicated how patients are free to make their own choices with regards to health care when engaging with a traditional healer. It is the perception of PAR12 that this approach is in contrast to western medicine where choices are often made for you.

There is a family that had brought in their grandmother to get traditional medicine, and the healer had given her medicine, but when they took her back to the hospital and they told the doctor that they went to see this Traditional Healer...[the doctor said], no, I don't think that you should give it to her ...it was a bed sore ...their western medicine was not helping her at all... she is on her death bed because her blood has been poisoned by this stuff that's in her body...so maybe if they would have allowed her to prepare the medicine for grandma ...who knows what would have happened. Because, you know, sometimes they, the western medicine people, say yeah and sometimes they don't, and a Traditional Healer will never, never, tell a patient to not take the western medicine. They would say, take this, but also continue to take your other medicines that your doctor has given you. They would never tell them to stop taking their western medicine. So it's kind of ironic, not ironic, but it's just how that operation works, if they would have allowed this grandmother to take her western [and] her traditional medicine, who knows where she would have been today... They're having to deal with... with losing the grandmother (PAR12).

The deep mistrust is echoed throughout this sub-theme and illustrated throughout the last two passages. PAR9 verbalized the lack of trust in the health care system, but offered strategies on how to rebuild or encourage trust between patients/families/communities and the western health care system. PAR9 also discussed the importance of relationships and feeling a sense of familiarity with their health care practitioners.

...From my experience, people just want to have a relationship with their caregivers, that's their doctor or their nurses, or their family, whoever is coming in, they want their healing journey to be as smooth and easy as possible and if they can feel familiar and close with those that are working with them, they have a lot easier journey...so, laughter for instance in our culture is one of the best things. Like I said in my presentation, I was saying that if you can form that bond quicker where you can become at a level where you can laugh with your caregiver you are already 50% there forming that relationship..... Those who choose to laugh and try have a will to live, rather than those that are going to spiral downward... (PAR9).

In summary, this theme titled Relationships, with a subtheme of Trust, discussed two important areas. It provided much insight into the importance of family and community in terms of providing support to a patient. In addition, given the longstanding history of colonization of First Nations peoples, there is much mistrust that exists towards western health care systems and practitioners.

West- Environment

The environment emerged as a third theme within the interviews. Twelve participants identified and discussed how cancer is linked to the environment. Participants also discussed the need to return to Anishinaabe ways as form of healing. The environment and land based

Anishinaabe practices were identified as a way to cultivate healing. The 12 participants recognized that the environment around them had become contaminated by industry and that this had threatened their ability to use the land/water for Anishinaabe healing practices.

In the two quotes that follow, PAR10 discussed a perspective on the direct connection between the environment and cancer by talking about how pollution in the environment ends up affecting the food chain by contaminating the food and water supply:

I think that cancer is a direct result of all the environmental pollutants and contaminants that are in the air, the water and the earth as well as the chemicals and pollutants that are in the food and the water that we ingest every day. When you look at the rates of cancer and the increase of that over the last several decades, you can see it... it totally aligns with what is happening in the environment (PAR10).

In another excerpt PAR10 further explained how environmental contamination is affecting First Nations. She used the example of how mines are set up in close proximity to First Nations, and that this is likely linked to high rates of cancer and mercury poisoning:

I think that the Canadian government should really take control over what is acceptable standards in prescription medication, but also, the foods, and even what is acceptable for environmental or gas and oil emissions from the companies as well as what is happening with mining...there are so many examples where there are mines where the adjacent First Nations has incredibly high rates of cancer and mercury poisoning and so on. So, there's a direct correlation between the industry that we allow into our territories and cancer, and I think that's the first thing that needs to happen is the government really... [needs to rein] that back in, where over the last few years they have really kind of opened the flood

gates and so now you see major increases of pollution and...I think really unacceptable (PAR10).

What is highlighted within these two quotes by PAR10 is the overwhelming feeling that the environment is a direct cause of cancer among Anishinaabe peoples. PAR12, PAR4, and PAR7 further drew attention to the reality of First Nations relative to environmental contamination. PAR 12 talked about how cancer appeared to be more prevalent now than in the past and linked the changes to a chemical corporation that is located directly across the road from the community:

When I was growing you never heard that cancer word, you know, it might have popped up once, and I remember as a child thinking – what is cancer- you know, never, never knowing, and as the years go by as you get older, and I can partly blame the chemical corporation right across the road from us that, you know, the air emissions, the water and the soil, and all that stuff is... is affecting our lifestyles, our communities because within the past, just within this past year, we have had one, two, three... three people who have died from different kinds of cancer (PAR12).

In the next example PAR4 expressed concerns about the uranium mine located right across the road from the community and living under the threat of potential spills:

Well, you know what, they're [community members] really conscious about the environment because we have, like I said, the uranium site right across the road from us, so they're very leery and cautious about any kind of spills, because there was a spill here years ago in our community. And what they did was, they were notified eventually, and they did have a doctor coming in to do blood testing on children that were in daycare, and the report that I've been reading, the reports that... and out of the.. I can't remember how

many, maybe there may have been about 13, but out of the 13 there about seven that have been diagnosed with cancer. Yeah, so they contributed like they always say, you know, I kind of tend to believe them that it has to do with the environment with the refinery here, where's that stuff going, do they had any more spills where we haven't been informed, they're just very leery about... about... chemical across the road (PAR4).

In the next excerpt PAR7 also discussed the proximity of a mine to the community and the perception that the contaminants from the tailings has resulted in higher rates of cancer.

Sun, air quality, water quality, because if there are some mine tailings in the water and contaminants from the tailings that can contribute. I've seen it. There is a Copper Mine on Lake X (omitted identifying lake) so...there was a lot of people in that area, that lived in that area, ended up with cancer, various types of cancer...[PAR7 goes on to say] I've seen deformed fish come out of that lake. They had big growths on their head, big growths on their sides (PAR7).

In the previous examples, PAR12, PAR4, and PAR7 all discussed the reality that their communities' proximity to mining and industry has had on members' physical health. PAR7 not only explained that she felt that industry proximity has a direct correlation to cancer rates within the area, she also pointed out the effects that this has had on the wildlife that people depend on. PAR3 also indicated that the wildlife has been affected when she stated, "The fish is full of mercury, we know that".

In the examples that follow PAR5 and PAR10 reflected how people in the community are conscious of the effects of environmental pollutants and the impact that this has on Anishinaabe ways of living. The excerpts showed how First Nations peoples are being constrained in terms of where they hunt and fish.

Yeah, and we couldn't even use the lake water, although people do use the water from the river, but I know when people do go back into the hunting [camps], they can't use the water up in the... up in the bush (PAR5).

...So, they [band council] have been encouraging us [community members] to go towards X, X, X, X, [several names of identifying communities omitted] for our hunting and fishing, and I think that's a great idea. That's a great act of self-determination, to actually hunt and fish on what is our traditional territory, but then, at the same time, you know, you got to think, well, what factories are in those areas and what mines are around, and, you know, what is in the system in those regions as well that could have an impact, on the animals and the fish, so, yeah, that's what I wonder as well about (PAR10).

The following quotes demonstrated the returning to Anishinaabe ways of using the land and the environment around them as a form of healing:

...getting back to living off the land would be really good for me. And I'm sure for everybody, like keeping active, and growing your food and making your jams and jellies and pickles[to put] away for the winter and you make them yourself which is what we are going to be doing there [health centre] at the end of August...I have got a few people that are signed up for my canning sessions, anyhow, just making our own produce... instead of eating processed foods which are high in salt and sugar and everything else that is not good for us. Yes, that would be good...like even, mentally even, talking our produce from Mother Earth would be really [good], it's going to help us. It's going to heal us (PAR5).

They go back into doing their traditional activities to cope. Because being on the water, we're deep water people. When they're on the water, that's a connection and that's distressing. Because that gives them that added energy. When I was sick I noticed that as soon as I was out on that water I felt a whole lot better, or if I'd go in the bush. I didn't have to hunt, I didn't have to catch anything, just being in that bush, that was energizing. Just being there. [PAR7 goes on to say]...if they're not connecting. I think you truly want to heal somebody, take them out in the bush (PAR7).

Our grandmothers way back when, [were the care takers of the water] mainly with the water, because the water is the women's water [it] is our life, we cannot survive without it, praying for the water every day, [caring for the water by] making sure it's in a copper vessel or a vessel that has good energy, I mean, you are not going to drink water from a lead pipe-right? It's the same principle, water become healing a...but [to] me this water up here [in Northern Ontario], I'm not from here, is untouched. When I touch the water up here, it's like a smudge for me. I am just like – oh goodness, all my worries are gone – I'm just, like, WOW, like it's medicine to me. So, I am a firm believer in that as well, getting back to the land, I am referring to the water as well, like the rain as it cleans... (PAR9).

Although these three quotes displayed the deep connection that Anishinaabe peoples have to the environment, and that Anishinaabe peoples continue to use the land and water (environment) as form of healing, the previously discussed quotes by PAR5 & PAR10 pointed to environmental issues with the land surrounding Anishinaabe communities. The practices which participants PAR5, PAR7, & PAR10 discussed are vital to Anishinaabe peoples, however, they appear to be under siege by industry. This will be further discussed in the next quotes. PAR10 told of the

devastation that environmental pollutants left behind on her traditional hunting territory, and how this has prevented people from being able to harvest medicines, fish, hunt, and garden within the community. PAR10 is acutely aware of the barriers of participating in Anishinaabe land based practices to promote healing.

Yeah, yeah, I can think of an example right now in my community, which is X [identifying community omitted], where traditionally X was used as a stopping point along the travel route of XX [identifying water way omitted] and it was used as a stopping point where people came to harvest medicines so there are specific medicines that grow on X that don't grow in many other places so people would come there like a 150, 200, 300, however many years ago. They would come and harvest the medicines, and, more recently, about 100 years ago, we had a town, and we had, you know, the x [identifying industry omitted] railway coming through, and there was a great fire, and there was all of this contamination that X left behind, and it is sitting there in the community and has not been every properly cleaned or removed. So, so all of XX[identifying area omitted] harbor is completely polluted, and, yeah, that's a recreational area for us so we camp there, we do our ceremonies there, we do our fasting, we swim there, and ,if you were to go down [and put] a foot, [in]whether at the beach or in the ground anywhere there you would come up with, like, oil or cordite or something that was, that had exploded during that, that fire. So, what I am trying to say about this is that there are medicines, sweetgrass, there's everything growing in there, but we can't harvest it or we can't use it because it's polluted or contaminated, and I am not sure why we haven't really taken... taken it to the next level.

In summary, this section discussed how environmental pollution through industry has contaminated the land around Anishinaabe territories, thus putting at risk Anishinaabe peoples' ability to access the land for purposes of healing. In this context, healing would be going back to Anishinaabe ways of doing to gather strength and coping mechanisms to deal with the physical struggles that cancer presents.

North -Supportive Services

All 13 participants identified various elements of community supports that people may need while undergoing cancer treatment. The participants also emphasized that these supports should be made available to both the patient and family. Participants also discussed the importance of having practical information about what to expect during treatment and after treatment, and coping techniques. Participants placed emphasis on the ability of patients undergoing cancer treatment and their families/communities to be able to access culturally appropriate and relevant services.

Twelve participants discussed in detail the need to have information regarding what to expect during cancer treatment, after treatment, and on coping techniques. The participants also indicated the importance of more detailed explanations from physicians regarding the cancer and the process of treatment. PAR3 noted:

First stage [stage 1 cancer], and very tiny [tumour] you would think you would have just taken the [part of the] lobe [of the lung], [instead of the one whole lung], so there's education that's needed. They [the patient] needs to understand that you [the doctors are] going to explain things better to them...inform her on why things were done and what was exactly was done.

PAR12, on the other hand, indicated having access to physical material is important because many First Nations peoples tend to be visual learners. PAR12 also pointed out having access to real life accounts of people who are struggling with a cancer diagnosis may help people who also struggling with accepting their diagnosis. Everyone copes differently and denial is one emotional response to coping with a life event that can be challenging or difficult. Sometimes “denial may get in the way of talking about cancer. It can cause tension in a relationship if one person is in denial, while the other person has accepted the diagnosis and wants to get on with things” (Canadian Cancer Society, 2016, para. 14). PAR12 explained further:

I think with us, we're really visual learners. We are hands on and we are visual. So I'm thinking maybe a DVD of, say, this is Carol's story from the start to end. And then, kind of a mini- interview with her, her family, how they coped, maybe she went through denial the whole time, something like that...I know it's okay to feel this way. I know its okay not to be coping good. I think that would be something (PAR12).

PAR11, also discussed how patients struggle accepting their diagnoses. In the quote that follows PAR11 articulated this struggle and pointed out that some patients deny their illness until they are close to death. This points to a need for supports around assisting patients in dealing with their illness and moving towards acceptance. The struggle around denial was also echoed by PAR11. In the quote that follows PAR11 articulated this struggle and pointed out that some patients deny their illness until they are close to death. This points to a need for supports around assisting patients in dealing with denial.

Denial, yeah, big time denial, and then I think, how is it going [to]...play out. They still have to maintain there's nothing wrong, all the way to the end, and then it's not until

probably the last stages where literally they are on their death bed that they will accept it (PAR11).

PAR11 and PAR12 both highlighted that a patient may struggle with accepting their cancer diagnoses and that if more information was made available to them in a way that was conducive to the way in which they learn, such as a video about lived experiences, that this may assist with normalizing the cancer experience for patients. This in turn would support people who are struggling accepting their diagnoses.

In the next two excerpts, PAR12 and PAR10 outlined some important elements that should be part of any educational materials that are developed for patients and their families. These include materials on coping, lifestyle changes, needs of a patient undergoing cancer treatment, ways families can support, and the journey of cancer and treatment. PAR10 explained that information is needed for understanding the process of a patient's cancer journey in a step-by-step guide. What is not conveyed in this quote, but was discussed, was that the information provided should be available for the provider to disseminate to the patient and their families.

I think it would be, like I said it would be the needs. So, maybe one section could [be] coping, another section could be lifestyle changes, what they are going to need to go through, another one could be how to support family, just anything that they are going to need (PAR12).

No, I would say, an actual visual chart of the journey. I think that is really important, like step one is, you know, you're testing or step two is learning the results, and step three is choosing your treatment, and step four is looking at your support system and the financial planning for it all...it's mapped out for them, so they can see what's ahead. And...that they could see if they choose to stop at any point in that journey ...what does that look

like. What is the impact, so, or what the time frames should look like – to really help them be successful and beating it...I think that's important. Perhaps other people's stories, like a case study, but from the perspective of, like, the whole family or a whole community [how they] worked with the patient where, say, it was a flying [in] community and the patient did not have immediate family, but had extended family and then, or the immediate family were all under 18 or something...[also] a big Q & A, rating charts...and how do you feel if you're feeling this way...here's some suggestions for what you can do – A, B, and C, right. And then maybe that's where you have a partnership with the area services and then they are all listed there (PAR10).

Twelve of the participants also discussed the cultural needs of First Nations patients and their families. These participants conveyed what kinds of things would be needed to provide culturally relevant services for First Nations patients and their families while they were going through cancer treatment. Two of the participants were specific about service providers offering a smudge bowl with sacred medicine to each patient. This is significant because many First Nations people use the smudge bowl with sacred medicines to pray and help ground them.

PAR12 explains:

So, maybe have little smudge bowls. With your smudge, your tobacco, your cedar, maybe your sweetgrass...and even a small round stone. To represent their grandfathers and another one could be a prayer stone. Because a lot of our people need to touch something

Similarly, PAR10 also discussed that the sacred medicines might be helpful for patients while going through cancer:

Culturally, I think that not everybody know[s] what their options are, so even a listing of what different medicines [that] have been helpful...but also what different ceremonies

might [have been helpful and]; testimonials from that [has been] done – got their name, [for] example, or went to in a sweat, or drank a tea and found that that actually helped them, like that would be helpful even a listing of [cultural] protocols...

The next few quotes draw attention to the different elements that can be utilized to provide culturally relevant services to First Nations patients and their families. PAR13 suggested a mix of Anishinaabe cultural practices and other cultural practices as a way to assist patients and families in coping.

...we've had traditional drummers come and sing for us, we've had spiritual teachings....oh yeah, we haven't pipe ceremony yet, but we talk about...life... I do have an eagle staff. I brought that one time, we talked about that, how simple life is, and how they [the] animals teach us to live. (PAR13).

PAR9 discussed having medicines available including medicine people (traditional healers) and physical outdoor space that brings you back to the natural world:

They are so many right here, there's just so much, having the medicines available, having the medicines people available, or ceremony available, having safe space that isn't around a million buildings... (PAR9).

In the next quote PAR9 reiterated the importance of having physical outdoor space for individuals to go to ceremony during their illnesses:

...[going to the elders within the community] having them lay out a piece of land, a piece of water that is, in the community they could say yeah, okay [this is a good place to] fasts and that's okay to do this [here] and designating those places for those [cancer patients] individuals who, can go there and do their ceremony and not be out all night in the cold...[PAR9 goes on to say] I have got to say [there should be] resources [where people]

drive them [patients to] retreat where...they can get a weekend [and have] people who can come in with their drums, people who can help them [patients] make their own drums, people who can help them birth [their drum].... (PAR9).

Five participants articulated the significance of Anishinaabe cultural practices and the effect that this has on Anishinaabe people through spiritual healing. This is highlighted in PAR12's explanation:

But they [people in the community] do know that it is there [the lodge]. They do offer tobacco, they do smudge when it's available, so they do, you know, a lot of that stuff. There's only like a handful of us that really, really follow the culture and participate, but you know, it's growing...we are doing our fasting next week. We have started maybe, four years ago with one fast... we had seven...it's getting bigger and people are more aware of their spirituality and what they are missing in their life and to me that is important...It's our identity. Some people walk around not knowing who they are, even though they say – okay I am the CHR or I'm the childcare worker or I'm this and that, but do they really know who they are? Do they really know their identity, and to me it starts off with your initial naming, what's you[r] clan, what are your colours...what's, your purpose. What's your whole purpose as you walk this journey...and that's all, to own their own spiritual identity, who are you as an Anishinaabe person, who you are as an Anishinaabe, what's your purpose, what's your whole role, because if you are a clan member, you know what your clan is, you know that responsibility and what that clan does... (PAR12).

PAR12 identified the significance of Anishinaabe cultural practices and effect that this has on Anishinaabe people through spiritual healing, but she also highlighted how the way of life is

integral to an Anishinaabe persons' identity. Later in the interview, she also spoke of healing, prayer, and spiritual connectedness with water, the earth, and all those around you as important elements of being. She went on to talk about the offers of prayers to those who are sick and her wish that her people would come and participate in culture.

In summary, the main themes that emerged in the East were Anishinaabe ways of living and the importance of culture and participating in culture as a way to maintain one's health. The participants also discussed the impact that colonization has had on First Nations peoples including the loss of cultural practices, and the effect this has had on peoples' overall health. In the South direction the participants reflected on the relationships and trust. Interestingly, the participants were clear that many First Nations people lack trust in western institutions including hospitals and doctors. Participants also talked about how important relationships are when people are going through the cancer journey. In the West, participants discussed how the environment has affected their health due to environment pollutions from industry. Participants also discussed the importance of land based traditional and returning to the land as a form of healing. In the North the participants discussed the need for supportive services to help patients and families with coping with a cancer diagnoses and treatment.

Chapter 6: Discussion/Conclusion

This research study aimed to identify the perceptions of service providers regarding the culturally relevant supportive services required for First Nations peoples during cancer diagnosis and treatment. This research took place in Northeastern Ontario and aimed to collect information to improve access to cancer care services. Northeastern Ontario was chosen because, as has been discussed in the Literature Review, there is little research in this particular area.

The interviews revealed several common themes among the thirteen participants regarding their views of First Nations peoples as they lived experiences of cancer care within their communities, and their respective needs during cancer diagnosis and treatment. Four major themes emerged from the interviews; Anishinaabe ways of living, Relationships, Environment and Supportive Services. An important sub-theme, Trust, also emerged under Relationships. This discussion will explore the relationship between the four themes relative to the literature.

Anishinaabe Ways of Living

Participants explored their perspectives regarding cultural practices as important to maintaining one's health and how colonization has had a negative impact on First Nations peoples' way of life. There is no doubt that the impact of colonialization has led to poorer health within the First Nations communities (Poudrier & MacLean, 2009; Loppie Reading & Wien, 2009). Many scholars, including Cote-Meek (2014), Poudrier and MacLean (2009), and Loppie Reading and Wien (2009) have described these negative effects of colonization as a loss of culture, the increase in social inequalities, and governmental racist policies directed at First Nations peoples. In particular, the participants also discussed the longstanding effects that residential schools have had on them as First Nations peoples and their communities. These

colonial policies are still affecting First Nations peoples and impacting their health. Taiaiake Alfred (2009) agreed and stated:

Colonialism, as it is understood by most people, consists in such things as the resource exploitation of indigenous lands, residential school syndrome, racism, expropriation of lands, extinguishment of rights, wardship, and welfare dependency...Indigenous people don't experience colonialism as theories or as analytic categories. Colonialism is made real in the lives of First Nations people when these things go from being a set of imposed externalities to becoming causes of harm to them as people and as communities, limitations placed on their freedom, and disturbing mentalities, psychologies, and behaviours. (p.43)

The participants in this study were deeply aware of the loss of culture and the ongoing assimilation practices by the mainstream or western society such as the Indian act and lack of understanding with Anishinaabe medicines. Similarly, Czyzewski (2011) also supported Taiaiake Alfred's (2009) point when she noted, "there are and have been direct effects of colonialism or colonial policies on Indigenous health. For example, the introduction of contagious diseases like smallpox...or the gamut of negative experiences within the residential schooling system" (p. 3).

The loss of culture and the effect that this has had on First Nations peoples is not only seen within the physical realm of a person's wellbeing but also seen within the psyche of a person. This is particularly highlighted in the data when PAR1 makes the comment regarding the walking wounded saying that "they're just numb. The walking wounded themselves". Duran and Duran (1995) also described the impact on the psyche of a person as manifesting in the concept of the walking wounded or as a soul wound. The assimilative practices by western society have

left many Indigenous peoples with longstanding cultural trauma, which continues today through intergenerational trauma (Czyzewski, 2011).

The participants linked how colonial practices have continued to affect Anishinaabe peoples today and have had effect on how Anishinaabe people participate in their traditional healing practices. The participants are quite clear that returning to Anishinaabe ways is vital to healing one's self in all quadrants (mental, emotional, physical and spiritual). It is reasonable to infer that using Anishinaabe ways when someone has been diagnosed with cancer would also assist with people's ability to cope with their diagnosis and/or even lend to using Anishinaabe medicines complementary to their treatment or as their treatment. The participants did discuss the importance of returning to the land and using land as a way of healing. What is important to understand is that Anishinaabe medicines are part of the land and therefore are part of the healing process that the participants were discussing. Similarly, on the concept of the therapeutic landscape, Wilson (2003) discussed the interconnectedness of land, health, and healing. Health, in this instance, cannot be achieved without the connection to land as a significant cultural component. Although there has been significant trauma that has occurred within Indigenous societies, the notion remains that returning to traditional cultural ways of life and maintaining a connection to the land is vital to both health and healing from the traumatic effects of colonization.

Many agreed (Taiaiake Alfred, 2009; Lavalley, 2009; Wilson, 2003) that healing for First Nations people from intergenerational trauma and the longstanding impact of colonization begins with the return to cultural practices and a reconnection to the land. Taiaiake Alfred (2009) articulated what the participants have said within their statements:

...complex relationship between the effects of social suffering, unresolved psychophysical harms of historical trauma and cultural dislocation have created a situation in which the opportunities for self-sufficient, health and autonomous life for First Nations people on individual and collective bases are extremely limited (p. 1).

This was echoed by the participants in this research project as many of them discussed the importance of ceremony and their Anishinaabe ways of living. Additionally, returning to land based traditions and cultural practices could be included in a toolkit as a way to further support and assist with the healing of cancer treatments. There could be a list of ceremonies and teachings compiled for service providers used when working with patients diagnosed with cancer. There could also be a list of traditional medicines including what each of the medicines are used for. In working with patients at the cancer centre, I have had many requests to go out to the land and place tobacco down and pray while the patient undergoes treatment. These are examples of how incorporating Anishinaabe ways of life is an important way to provide supports while a person is on the cancer journey.

The participants have identified that using Anishinaabe ways is an important aspect of the healing process and that when patients have been diagnosed with cancer the option to use Anishinaabe ways should be offered as part of their cancer journey.

Relationships

Relationships were also identified as an integral part of patients' journey during diagnosis and treatment of cancer. Participants in this research identified the importance of the connection to one's family as a central component of helping a patient through their cancer treatment. This is consistent with research by Mokuau et al. (2012) who showed that patients with cancer had better outcomes with treatment and treatment adherence when family connections were present.

This would point to the need to optimize family support and build community resources so that they are readily available in the community for the patient and their family. Burhansstipanov et al. (2001) and Whop et al. (2012) further supported the notion that supportive services that are close to home increase the quality of life and survival rates for people.

While participants identified the importance of family and community support during the cancer journey, the participants also juxtaposed poor coping and fragmented family dynamics as the direct result of colonial imposition for First Nations peoples. These experiences have limited peoples' ability to fully engage in supporting one another. As a result, community level supportive services have become important in communities. Although the literature does not speak about the need for supportive services within community because of limited coping by family and patients, the literature does highlight the need based on family being geographically closer to the patient (Mokuau et al., 2012). Supportive services offered within the community should also involve strategies to help strengthen families and/or should involve strategies that assess family dynamics and coping skills, which will be discussed further on.

Many participants have indicated that family support is important, however, the literature that I reviewed has shown that many families also suffer from dysfunction in one form or another. The participants have also indicated that there are some difficulties within families due to poor coping, and intergenerational trauma from the ongoing and lasting effects of colonization. It is clear that the need to support patients within their communities while they are going through their cancer journey is needed. There were suggestions by participants about having support groups; this is not always the most appropriate method of assisting with their issues. Each community will need to address their respective community's needs individually as no one community is homogeneous.

Trust. Trust was discussed as an important element of the relationship theme by the participants. They discussed the concept of trust with the health care provided. They indicated that lower levels of trust are often a factor in why their patients and families do not access health care services. It was interesting that the participants discussed how they themselves did not fully trust westernized institutions and yet they worked in the area of healthcare at local health centres, which rely heavily on western healthcare. In this regard, they appeared to view themselves and their places of work as different than the institutional services offered in the nearby city. The lack of trust in western institutions has been linked to the ongoing systemic violence, marginalization, and racism that First Nations people face within when accessing health care, which has been well documented and researched (Bourassa et al., 2005; Brown et al., 2011; Health Council of Canada, 2012; Kurtz et al., 2008; Sherwood, 2009; Thompson et al., 2011; Treloar et al., 2013). More work needs to be done to rebuild the relationships between First Nations peoples and mainstream society, otherwise the seeded mistrust will continue to grow and be passed on to the next generation. While we are far from a system shift, improving and providing community supportive services can assist with elevating patients experiences, coping, and adherence to treatments (Natale-Pereira et al., 2011).

Having community supports would address the gap in services as there are little to no services specific to the cancer journey. Supportive services such as the eventual development of a toolkit would give patients and/or their service providers the knowledge to assist with coping with a cancer diagnosis and/or an understanding of what a cancer diagnosis means for people. This, in turn, could have a positive impact on patients when they have to return to the cancer centre for treatment. The positive impact can translate to a patient feeling more confident and

understanding their treatment which allows them to ask more questions or advocate for themselves.

Environment

The participants also discussed the importance of returning to the land as a way of healing themselves and their communities. Since the participants were in a research study examining the psychosocial needs of patients while undergoing cancer treatment, one can draw a conclusion that when they were speaking about returning to the land they were considering this in the context of the cancer journey and healing. For example PAR7 states “they go back to...doing their traditional activities to cope...because that gives them the added, energy...I think you truly want to heal somebody, take them out in the bush.” In the theme Anishinaabe ways of living participants discussed using the land or the environment as way of healing; for example PAR9 stated “...we’re made from the earth, so in order to fix your body you have to [go] back to the earth and replenish yourself...”

They also discussed the devastating impact that industry has had on their traditional territory and the lack of regard that this has had on their way of life. Although participants recognized the impact of environmental pollutants on the land and waterways that surround their communities and traditional territory, they still called for a return to land based cultural practices as a way to heal. This deep sense of connection with mother earth still remains despite colonization and the policies to rid First Nations peoples of their title to the land. Both Taiaiake Alfred (2009) & Wilson (2003) have also discussed the significance of a return to land based practices for First Nations peoples with regards to their health.

Participants also discussed how, in certain areas, people can no longer practice Anishinaabe ways of livings such as cultivating medicines or even growing vegetable gardens,

because of the contaminated environment caused by industry. As a result, participants noted that they look outward from their communities and use other areas within their territory to access Anishinaabe practices. The significance of this is that even though land maybe considered unusable, First Nations peoples will continue to adapt and use their Anishinaabe knowledge and culture by looking for alternative places to practice their Anishinaabe ways. Based on the interviews with participants, there is no doubt that First Nations people are acutely aware of their surroundings and the effects that industry has had on their communities. Despite the continued attacks on Anishinaabe way of life and practices, Anishinaabe people continue to maintain their cultural ways of life and ensure cultural transition to future generations. When providing psychosocial services closer to home that incorporate Anishinaabe time honored practices for healing such as cultivating the land and water, First Nations communities will need to consider whether using this is practical for their patients.

Assumptions and Limitations

The key assumption for this research project is that there was a need to address the psychosocial needs of First Nations people in a culturally appropriate and relevant manner. The research may be limited because, at the time of year that data collection occurred, many potential participants could have been away on vacation (August to October). I attempted to mitigate this by casting a wider net to many communities. Another limitation is that this research cannot be generalized to all First Nations communities due to the limited number of participants who engaged from a specific geographical location. Therefore, the research will remain more localized in its application. Further, the information is based on the perceptions of service providers and additional research with patients and survivors is needed to fully explore their needs from their perspective and to compare and contrast the provider findings.

Supportive Services

The need for supportive services within First Nations communities is paramount. The participants consistently identified that they lack the expertise in oncology and need help to support their community members who are diagnosed with cancer. The participants were able to identify several supports that they would find helpful when assisting patients and their families during cancer diagnosis and treatment, which are consistent with the literature. Participants identified the importance of having the ability to show patients the step-by-step process of treatment and/or what the outcomes could look like without treatment. It was the view of participants that having the proper (oncology) language to be able to discuss with patients and their families would also give them a greater sense of how to support their community members. This adds to the academic literature because there was no literature that discussed having health care staff armed with information regarding oncology language as significant. Burhansstipanov, et al. (2012), discussed having (Aboriginal) patient navigators within the community that had the skill set (who had training in navigating the cancer system) to provide supportive services to cancer patients but did not discuss generic staff having access to tools that would assist them in providing support when discussing the cancer journey with patients.

Participants also identified the importance of providing support groups, Anishinaabe ceremonies, access to healers, and Anishinaabe doctors. Opportunities to reconnect with the land and water would assist patients and their families in their healing/coping while going through cancer treatment. Poudrier and Mac-Lean (2009) also indicated that traditional practices are an important part of a participant's ability to cope with and adapt to cancer treatment. One of the most important suggestions that participants identified was to gift a smudge bowl with all the medicines and a small smooth rock when people are diagnosed with cancer as way to ground

them and reconnect them to their ways of knowing and doing. This is a relatively simple way that could be easily incorporated into the care provided to First Nations patients.

Implications of the Study

When I started this research, I was looking for strategies that could assist workers in First Nations communities who have community members who are undergoing cancer treatment. My own experience working at the hospital taught me that there was a gap in culturally relevant and appropriate supportive services. This research confirmed that First Nations communities still experience many challenges in accessing culturally relevant and supportive services. There is still a strong sense of mistrust in the western health care system, which continues to impact peoples' ability and desire to access healthcare. The implications of this are great for First Nations people when their health is at risk. It is important to understand that the lack of trust is for a good reason, as many First Nations continue to suffer the consequences of the Canadian colonial legacy.

There is a gap in knowledge around cancer and the cancer journey, which pointed to the need for the development of a tool kit for communities. This has been demonstrated within the study. The limitation is that not all First Nations communities are the same and therefore each community will need to adjust the information, strategies, and delivery to meet their own particular needs.

This research also stressed the importance of the need for culturally appropriate supportive services in First Nations communities themselves. Having supportive services within a patient's First Nation would allow for easier access to supports that are critical to enhancing the wellbeing of a patient undergoing cancer treatment. These types of supports also assist with peoples' ability to cope with a cancer diagnosis.

The Truth and Reconciliation Commission call to action urges the federal government to close the health inequality gap between Indigenous peoples and non-Indigenous peoples by providing equitable services (Truth and Reconciliation Commission of Canada, 2012).

This study has affirmed the need for culturally appropriate supportive services for First Nations people undergoing cancer treatment, their families, and communities. The results suggested the lack of trust that exists with western healthcare institutions, which is rooted in longstanding effects of colonial imposition and systematic racism that continues to prevent First Nations peoples from accessing appropriate healthcare treatment putting their health at risk.

This study also affirmed the importance of relationships that First Nations peoples have to family, community, as well as to the land and water. In Anishinaabe worldviews, these elements are all interrelated and interconnected and therefore are important considerations in a First Nations person's ability to cope during cancer. The participants in this study suggested strongly that supportive services that incorporate family, community, as well as land and water based healing practices are integral in ensuring that the psychosocial needs of First Nations cancer patients are being addressed in a culturally relevant, safe and significant for the patient, family and community.

The results of this research may be used to inform the development of a toolkit to assist service providers providing care to First Nations patients undergoing cancer treatment. As stated previously, there are limitations to doing this since not all First Nations communities in the geographical area were involved in the study and therefore they may not feel that the information provided by the participants is relevant to their community. Also some of the people that participated in the study are no longer employed at the local health centre. This speaks to the turnover rate of employees. Therefore, being able to maintain interest and knowledge of

implementing such a tool kit could be difficult. Further, offering additional services could be an added duty that would require supplementary funding from the government to maintain the sustainability of the tool kit.

Strengths of the Study

The research project was framed with the concepts of the Medicine Wheel teachings. Using an Indigenous research methodology ensured that the project stayed true to an Indigenous worldview. The usefulness of using Indigenous concepts such as the Medicine Wheel within research ensures that the voices and worldviews of participating First Nations was maintained and assisted with not imposing a westernized worldview. The challenge of using an Indigenous research methodology is that western academia does not necessarily view it as a legitimate and a standalone methodology. Therefore, there is always the struggle of continually having to defend the use of an Indigenous research methodology.

Recommendations and Further Research

Based on the results of this research study I would recommend the following be considered for support workers providing supportive care to First Nations patients undergoing cancer treatment:

- 1) Promote use Anishinaabe knowledge and cultural ways to enhance and maintain health physically, emotionally, emotionally and spiritually;
- 2) Build capacity within families and communities to help support cancer patients cope with their cancer diagnoses and treatments;
- 3) Western health care practitioners need to build trusting relations with First Nations peoples;

- 4) Maintain the health of the land and water systems to ensure continued practise of Anishinaabe ceremonies; and
- 5) Provide front line health care service providers with knowledge about cancer and cancer treatments in a culturally appropriate format so that they are equipped to work effectively with cancer patients.

I hope that this research will be useful in broadening the understanding of the needs of service providers in First Nations communities who are working with First Nations patients during their cancer journey. More research from the patient's perspective and what they feel they is needed would be an essential aspect to explore. Further, the perceptions of the Oncology team would also be important to understand in terms of their level of understanding of the impact of a cancer diagnosis on First Nations peoples.

In closing the circle, I have worked in a respectful way and, in doing so, have honoured my Anishinaabe family and especially my grandmother. I have tried to keep the experiences of all those involved at the fore front of this research project.

Miigwech

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Appendix “A” – Semi-structured Individual Interview Guide

- Please tell me about what your job entails?
- Would you describe your role regarding providing supports or support services to people diagnosed with cancer?
- Why, in your opinion, do you think cancer exists?
- What are some of the main causes of cancer amongst people in your community? What do you think should be done about these causes?
- How long do you think people live with symptoms before they seek medical treatment and why do you think they wait a certain amount of time?
- What are some of the common themes people describe while at the cancer centre during diagnosis or treatment?
- How do you believe people cope once they are diagnosed?
- How do believe they cope when they are in active treatment?
- What kind of distress do you think people present with?
- What is currently done to decrease their distress?
- What do you think are some of the barriers to receiving psychosocial support?
- Would you have any recommendations for a toolkit that professionals like yourself could use to help your clients through their journey?

Appendix “B” - Letter of Invitation

Boozhoo, Aanii, Hello

My name is Sherri Baker and I am currently a graduate student at Laurentian University in the Masters of Indigenous Relations program. I am currently undertaking a research project that will examine psychosocial needs of First Nations patients in Northeastern Ontario. I am seeking participants who provide supportive services to patients diagnosed with cancer. I am interested in their experiences and perceptions of what the needs are for their clients. The goal of the research will be to gain insights that will assist in the development of a toolkit specific to providing support to clients diagnosed with cancer through a First Nations cultural lens.

The research is strictly voluntary in nature and participants can withdraw from the study at any time without any negative recourse.

Should you know of anyone who may be interested in participating, or if this research is relevant to their work, please forward this email.

Should you be interested in participating, please respond to either Dr. Cote or I (email addresses below) as a confirmation of interest.

Sherri Baker, BSW, RSW, 705-691-1628, sbaker@laurentian.ca

or

Daniel Cote, PhD, RSW 705-675-1151, ext 5081, Assistant Professor, School of Indigenous Relations, Laurentian University, dcote@laurentian.ca

Miigwech,

Sherri Baker

Appendix “C” – Introduction and Consent Form

INTRODUCTION AND CONSENT TO PARTICIPATE IN RESEARCH

My name is Sherri Baker and I am currently a graduate student at Laurentian University in the Masters of Indigenous Relations program. You are invited to participate in a research study on the psychosocial needs of First Nations peoples in Northeastern Ontario while on their cancer journey. This study is a requirement of my Master of Indigenous Relations graduate degree at Laurentian University, under the supervision of Daniel Cote, PhD, RSW.

Your participation in this project includes two parts. First I would like to interview you to understand your perspectives on the needs of cancer patients, or clients who are diagnosed with cancer. I will first ask you to do a face-to-face interview, lasting about 60 to 90 minutes that will be audio recorded. Alternately, this can be a telephone interview. About a month after this interview, I will send you the transcript of your interview and ask you to review it making any additions, deletions, or edits that you think are necessary. This will enhance the accuracy of the information and inform the ongoing analysis.

There are no risks for participating in this study. Your participation in this project is voluntary and you have the right to withdraw at any time without any consequence. At any time during the interview, you can request that the tape recorder be turned off or to terminate the interview. Confidentiality and anonymity are guaranteed and no names will be used. I will remove all identifiers from your transcribed interview so that no-one can identify you. I will erase the tape recordings once my Master’s thesis is complete, in about a year.

While there will be no direct benefit to you for your participation, the results of the study may help in-form the development of a toolkit for professionals with recommendations for interventions and pro-grams for First Nations people diagnosed with cancer. Should you have any concerns about the research itself, you may contact an official not attached to the research team regarding possible ethical issues or complaints. Their contact information is: Research Ethics Officer, telephone: 705-675-1151 ext. 3213, or toll free at 1-800-461-4030, or email ethics@laurentian.ca.

Name of participant: (printed) _____

Signature of Participant _____

Date: _____