AN EAGLE'S VIEW: PERSPECTIVES ABOUT DIABETES IN YEKOOCHE FIRST NATION, A FIRST NATION'S COMMUNITY IN NORTHERN BRITISH COLUMBIA

by

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Abstract

A substantial amount of quantitative literature documents the prevalence and incidents rates and causes of diabetes among First Nations, but few qualitative literature documents exist exploring First Nations perceptions about diabetes and its causes. This study utilized the Two-Eyed Seeing framework to explore Yekooche member's perceptions about diabetes. The research objectives of the research were: 1) to understand how Yekooche members define diabetes; 2) to explore Yekooche perceptions of diabetes; and, 3) to examine their beliefs and understanding of diabetes education and diabetes educational materials. This qualitative research addressed these objectives through interviews conducted with Yekooche First Nation. Analysis of the interviews generated findings which are presented in story form, providing insights into how participants understand the causes about diabetes, their experience with diabetes related complications, their fears and concerns of children developing diabetes, and the unexpected finding of their experiences with the effects of clear-cutting on their health.

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Acknowledgements

To my mother, Anne Michell and father, Allen Robert, I would like to give you the greatest thank you. It is because of you that I love learning. You bought us our first school desk where I spent a lot of time playing school, and you encouraged me to keep going to school no matter what the circumstances were. It is because of you both that I am where I am today in my life. *'uba ink'ez 'uloo snachailya, 'ink'esi'*

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Dedication

I dedicate this thesis to my brothers and sisters:

Allen Roberts Jr., Vern Roberts, Olivia Robert, and Rachel Roberts

And to my son

Wayde Michell

Chapter One: An Eagle's Eye View of the Problem of Diabetes among First Nations

1.1 *Tsi'balyan's* opening story

Tsi'balyan (Eagle) represents our history, culture and traditions. Tsi'balyan is a great spirit, knowledge holder and our protector (Bianca Michell).

Hadi', my name is Bianca Michell, I am the graduate student that has conducted this research. This research provides a qualitative investigation of Yekooche member's perceptions of diabetes. This thesis is written in story form using the metaphors *Tsi'balyan*[1] and *Goozih*[2], who are both the researcher and data collector – the graduate student. The purpose of writing in story form is to honour and reflect the relationship between Indigenous storytellers and academic researchers, and representing Indigenous oral stories in Western literary forms as Jo-Ann Archibald (2008) says: The writing structure I used in this research is also inspired by Cree scholar, Shawn Wilson (2008) who emphasizes writing and researching in a culturally appropriate manner, and one way to integrate a culturally appropriate component is by taking the role as a storyteller rather than as a researcher who writes in a structured western format. Wilson (2008) also notes writing in a storytelling form makes it easier for readers to absorb the information.

[1] Tsi'balyan translated means eagle

[2] Goozih translated mean whiskey jack

The story begins with a brief history of the effects of colonization on First Nation's people, followed by an introduction of *Tsi'balyan*, the events that inspired the research which transformed into a thesis, problem statement, research question, and the rationale for conducting the research in Yekooche, lastly, and an overview of the thesis.

Tsi'balyan found in literature that First Nations have poorer health conditions and outcomes when compared to the rest of Canadians (National Collaborating Centre for Aboriginal Health, 2011), which is thought to be one of the consequences of the lasting impacts of colonization. The sudden change of First Nations culture, traditions, and diet has caused a "disproportionate burden of disease and health disparities" (National Collaborating Centre for Aboriginal Health, 2011, p. 3), such as diabetes, cancer, and other communicable diseases.

Before the 1950s, diabetes was rare among First Nations in Canada (Virani, Strong, Tennant, Greve, Young, Shade, Kanji, and Toth, 2006). Over the last 60 years the prevalence of diabetes among First Nations communities in Canada has steadily increased (Harris, Caulfield, Sugamori, Whalen, & Henning, 1997). In 2000, Young et al. described Type 2 diabetes mellitus as an epidemic in progress. The prevalence of diabetes among First Nation is 3 to 5 times higher than the general Canadian population and has increased rapidly (Oster, Johnson, Hemmelgarn, King, Balko, Svenson, Crowshoe, & Toth, 2011). In 2004, the prevalence of diabetes in First

Nation was noted to be among the highest in the world (Mak, Whitehead, & Plant, 2004). First Nations also experience higher prevalence rates of diabetes related complications, such as cardiovascular disease, renal failure, retinopathy, and lower limb amputation which can have long-term implications on quality of life of individuals and communities experiencing diabetes (Hanley, Harris, Mamakeesick, Goodwin et al., 2003; Ho, Gittelsohn, Harris, Ford, 2006; Virani et al., 2006). The research represented in this thesis responds to the need to better understand the experience and perceptions of diabetes in story form in a specific First Nation.

1.2 Locating *Tsi'balyan* and the Inspiration for Research

Absolon and Willet (2005) state that locating one's self in our research is an "essential part of the research process; this process helps us gain the trust of the community and validation" (p. 97). These authors also state that locating one's self is a holistic process; it includes telling our story about our position in our life including spirituality, language, and my relationship to the land. The first chapter of this thesis will therefore commence with an introduction to my story, as the motivation for this thesis research journey, the vision that has guided the research journey, the problem statement, study goals, and an introduction to the location of the research. The following paragraphs are an introduction about me as the graduate student.

Hadi', my name is Bianca Michell. I am a Dakelh woman from Tache[3]. Our Dakelh language stems from the Athabascan language family along with the Dunne-za, Kaska, Nat'oot'en/Wet'suwet'en, Sekani, Tahltan, and Tsilhqoth'in (Carrier Sekani Tribal Council, 2011; Muckle, 1998). Our culture follows a matriarchal clan system. For instance, my mother, Anne Michell is *Lusilyoo*, therefore, my clan is also *Lusilyoo* (Frog Clan) and my son Wayde Michell is also Lusilyoo.

My father is Allen Roberts, son of Morris from Tache and Philomena Roberts of Yekooche and my mother is Ann Michell, daughter of Susie Michell of Yekooche and Gerhard Martin of Tutlinin, Germany. I have four sisters, Rachel Roberts, Olivia Roberts, Farrah Alexis, and Chasity Aslin, and three brothers, Vern Roberts, Curt Roberts, and Leslie Aslin,

The following paragraphs describe my inspiration to conduct research about diabetes. The themes shared in this thesis are very near and dear to my heart because my Baba (*'ustiyan*[4]) had diabetes and suffered from diabetes related complications. One of my conversations with my Baba was when we sat on the porch. He talked to me about his experience having diabetes. During our conversation, my Baba told me that he couldn't eat certain foods, and some days he couldn't feel his feet, or just was not feeling all that good. In 2009 my Baba passed

[3] Tache refers to 'tail end of Tache River'. Tache is one of three communities under what is known as Tl'azt'en Nation.

[4] 'utsiyan means grandfather.

away, and his passing inspired me to learn more about diabetes in the hope of teaching families and communities about the disease, specifically, prevention and management, and what diabetes is.

The loss of my Baba inspired me to learn more about the disease and to teach others about the disease, therefore, I became a volunteer at the Canadian Diabetes Association. The Canadian Diabetes Association provided me the opportunity to provide diabetes presentations in schools, different organizations, and in First Nations communities. During the presentations with First Nations, I had meaningful in-depth conversations about the disease with participants who shared their stories about having diabetes or knowing someone who has diabetes, and how the disease has affected their life. Most important, this encounter helped focus my interest in conducting research to increase understanding about how First Nations experience diabetes.

My journey also included learning from research about diabetes and First Nations through research articles and books that contained information about diabetes and First Nations in Canada. Unfortunately, I was not prepared for what I was about to learn. The more I read about health inequalities, socioeconomic equalities, poor housing, and higher rates of diseases, the more I became angry and heartbroken I became. Although heartbroken, I gained valuable information about diabetes, and decided to focus my research on how First Nations perceive diabetes.

Prayer.

Creator, I am struggling.
I would like to ask you for help and guidance with my thesis.
Please provide me with a vision that will guide me and help teach about diabetes.
Guide me with good spirits to write truthfully to help teach about diabetes. And in a way that all will understand.
Musi (Bianca Michell)

The 'Vision'.

Perched on the highest tree, I see people below who may be directly or indirectly affected by diabetes. If so, how can I help them understand how to prevent and/or manage diabetes? (Bianca Michell)

The vision *Tsi'balyan* had was the beginning of the research journey, which is now being shared in the form of a thesis. The following paragraph provides the important role the vision played guiding my research and the development of this thesis. In the vision quest, I transformed into *Tsi'balyan*, which provided me with an 'Eagle's Eye View' of: (1) the significant emotional, physical, mental and spiritual impacts that diabetes has on First Nations' people health and well-being; (2) the research methodology to conduct my research; (3) the interview questions and process; (4) discussion and recommendations, and (5) the development of the thesis title. However, for the purpose of this research, I was left with creating a research question which led me to seek guidance from an Elder. In any vision quest, it is protocol to seek guidance from an Elder. During the visit with the elder, over hot tea and bannock, the Elder told me: "You cannot know what hurts [our] people by looking at them, you must ask and listen, and then you can help them." This was the

beginning of my research journey of that led to this thesis and informed the creation of my research question (See Section 1.4)

1.3 Significance of the issue.

Diabetes is a major concern in many First Nations communities and there is a need for developing diabetes educational materials that are culturally appropriate, culturally sensitive, literacy appropriate and interactive. Current diabetes educational materials lack information about the importance of eating local traditional foods, such as wild game and fish, and that hunting and fishing traditional foods promotes physical activity.

The rationale for this research study lies within the documented findings in the literature that most research about diabetes and First Nations is conducted using western methodologies and methods. Perceptions of diabetes tend to be written with a biomedical knowledge orientation, and often neglects holistic perceptions of disease such as the inclusion of spirituality, disease and health and wellness.

Diabetes was first documented in First Nations populations in the 1950's, and much remains unknown about what First Nations people's perceptions are about diabetes and how their perceptions affect their health and wellbeing (Ghosh, 2012). It is therefore time to increase our understanding about First Nations experiences and attitudes about diabetes, and how diabetes affects their health and wellbeing. Since most knowledge about diabetes stems from a western point of view, First

Nation's worldviews, beliefs and values are often overlooked and their experiences and ways of knowing and knowledge about the disease excluded. In addition, despite some preliminary research efforts about diabetes among First Nations populations, there are major gaps in knowledge that may help improve First Nations quality of health and decrease diabetes prevalence among this population (Harrish, Naqsbandi, Bhattacharyya, Hanley, Esler, & Zinman, 2011).

1.4 Research Goals and Objectives

The overarching goal of this study is to learn more about First Nations perceptions about diabetes, drawing on the experiences in Yekooche, a First Nations community in Northern BC. The specific research question that has guided this research is: *What are the perceptions, understanding, and beliefs about diabetes of community members in Yekooche First Nation?* The objectives of the research were:

1. to understand how Yekooche members define diabetes
2. to explore Yekooche perceptions of diabetes
3. to examine their beliefs and understanding of diabetes education and diabetes educational materials

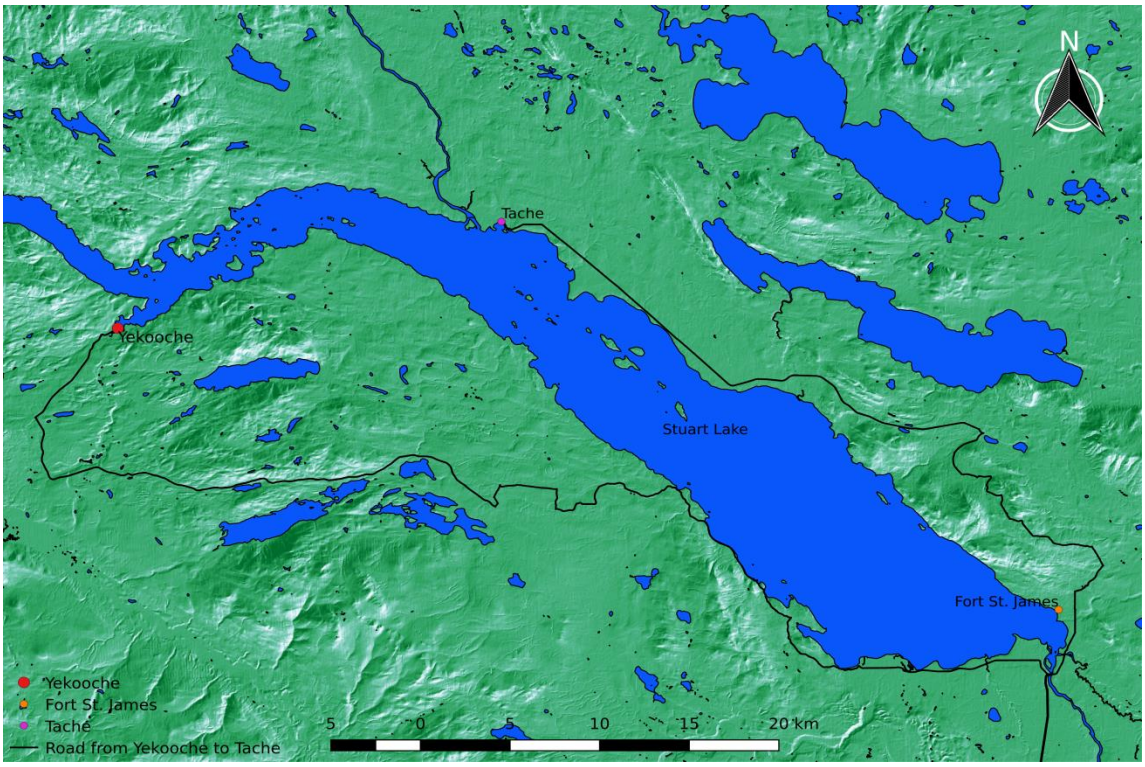
1.5 Research Location

Tsi'balyan and *Goozih* traveled to Yekooche where the research was conducted. Yekooche[5] is located at the northern end of Stuart Lake, B.C, in northern BC, approximately 75km from the nearest municipality, Fort St. James. Yekooche can be

[5] Yekooche translated, Ye koo refers to Cunningham Lake and Che refers to the end or trail of Nankut Creek (Yekooche First Nation, n.d.)

accessed by traveling on Stuart Lake or by vehicle on the Whitefish forestry road (See Figure 1). To conduct the research I traveled on the Whitefish road which provided me the opportunity to see bears, moose, deer, wolves, coyotes, fox, and their most populated furry friend, the incredible amounts of rabbits. I also had the opportunity to travel to Yekooche by boat from Tache. There were not too many animals to see, however we were able to see eagles nesting and pictographs from my ancestors.

Figure 1. Location of Yekooche First Nation.



Location of Yekooche First Nation on Stuart Lake, British Columbia, Canada by Google Maps. https://roadsidethoughts.com/bc/yekooche-map.htm

The choice to conduct the study in Yekooche was influenced by cultural similarities and family ties. Yekooche speaks the same traditional dialect, Dakelh as Tache (the community I am from), and hunting and gathering practices are similar. My family ties with Yekooche stem from my grandmother Susie Michell and mother, Ann Michell, who are from Yekooche. I was also raised in Yekooche for the first years of my life.

1.6 Organization of Thesis

This thesis has five chapters. **Chapter 1** provides an introduction to the research, the researcher, the research location, and the inspiration for the research. **Chapter 2** provides an overview of the literature relating to the research question and themes of this thesis. The first section of this chapter will provide you with the understanding of the conceptual lens, Two- Eyed Seeing which this research and thesis follows. The literature review is presented in relations to two knowledge systems: western science and Indigenous knowledge. The Western Science knowledge provides an understanding of looking at diabetes through Western lens: how Western science defines diabetes, the types of diabetes, the causes, and its complications. The Indigenous knowledge section provides an Indigenous perspective of how diabetes and its causes are defined through an Indigenous lens.

Chapter 3, presents the research methodology and methods. The research was conducted using an Indigenous approach to explore Yekooche's perceptions about diabetes. Data was collected through semi-structured interviews of eight members of Yekooche First Nation. Interviews were audio recorded, transcribed, and analyzed using thematic analysis.

The findings arising from the analysis of the semi-structured interviews are presented as stories in **Chapter 4**. The findings are written in themes identified using thematic analysis, and then discussed in relation to relevant literature.

A discussion of the thesis recommendations and the limitations of the research is presented in **Chapter 5**.

Chapter Two: Literature Review and Framework on Perceptions of Diabetes

Tsi'balyan will present an understanding on differences between Western and Indigenous perceptions of diabetes. The chapter will provide an overview of the difference between disease and illness; second, the conceptual framework used; third, I will explain western science's definition of diabetes, the different types of diabetes, and the causes of diabetes; lastly, I share First Nations perceptions of diabetes.

2.1 Conceptual Framework – Two-Eyed Seeing

The literature view is presented using the conceptual framework, 'Two-Eyed Seeing'. Two-Eyed Seeing is an approach to valuing both Indigenous and Western knowledge that was developed by Mi'kmaq Elders Albert and Mudena Marshall and has been promoted in collaboration with Dr. Chery Bartlett in Cape Breton (Hallström, Guehlstorf, and Parkes, 2015). The approach encourages balance, collaboration, and respect between Western and Indigenous ways of knowing, in hopes to find new and innovative ways of research and community engagement (Hallström, Guehlstorf, and Parkes, 2015). Moreover, the conceptual framework is a guide to help structure the literature review, conceptualizing, and conducting the research (Rocco & Plakhotnik, 2009). In an Indigenous approach to research, the conceptual framework "emanates from the religion, cultural traditions, norms, language, metaphors, indigenous knowledge systems, community stories, legends

and folklore, social problems, rapid social change, or public policies as opposed to conceptual frameworks from universalistic or Western literature" (Chilisa, 2012, 102).

In addition, Two-Eyed Seeing allowed *Tsi'balyan* to 'shine light on' (Harder, 2017) a phenomenon that is important to understand from First Nations perceptions about diabetes. Two-Eyed Seeing represents a First Nations group's understanding and experiences about diabetes (Bordage, 2009, para. 1); as well as the four aspects that make up a research paradigm as noted by Shawn Wilson (2008), a Cree scholar who says ontology is "a belief in the nature of reality. Your way of being, what you believe is real in the world…", epistemology, "which is how you think about that reality"; methodology, "… how you are going to use your way of thinking to gain more knowledge about your reality", and the paradigm that includes axiology, "a set of morals or a set of ethics" (p. 175). The following section outlines the role of Two-Eyed Seeing in the literature review.

2.2 Two-Eyed Seeing and Literature Review.

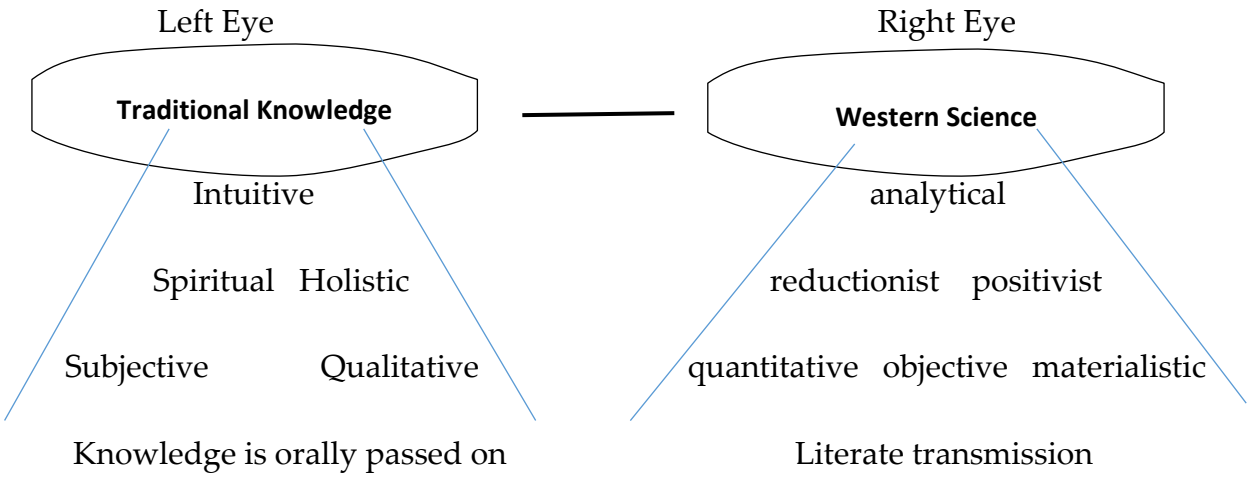
The 'Vision'

Perched on the highest tree, I see people below who may be directly or indirectly affected by diabetes. If so, how can I help them understand how to prevent and/or manage diabetes?

In keeping with the principles of Two-Eyed Seeing, *Tsi'balyan* felt it was important to understand the differences between Western Science and Indigenous

Knowledge, including a description of some of their origins and features. In reflecting on what Western Science and Indigenous knowledge can learn from each other, Mazzocchi (2006) notes that Western Science stems from both philosophies of Ancient Greece and the Renaissance; has traditionally been conducted through analytical and reductionist methods; is positivist, materialist, objective and quantitative; and based on an academic and literate transmission. It also isolates its objects through simplified and controllable experimental environments. In comparison, Indigenous traditional knowledge is described by Mazzocchi as being more intuitive, holistic, spiritual, and does not make distinctions between empirical and sacred. It is primarily subjective and qualitative, and knowledge is passed on orally from one generation to the next by elders.

Figure 2. Two-Eyed Seeing.



A depiction of Two-Eyed Seeing highlighting the difference between Traditional Knowledge and Western Science. Informed by ideas presented in Western Science and traditional knowledge by Mazzocchi (2006).

In addition to understanding the origins and features of Western Science and Indigenous Knowledge, *Tsi'balyan* felt that it was equally important to understand the differences between how perceptions of disease and illness are presented. Literature shows that perceptions of disease and illness differ among cultures; for example, Western perceptions of diabetes focus on the biology of the 'disease', whereas Indigenous people focus on the 'illnesses' – their experiences. In the article, *The confusion between disease and illness in clinical medicine,* David Jennings (1986), argues that there is a difference between disease and illness. He defines disease as a "Biomedical disease demonstrable pathophysiology or pathochemistry and is diagnosed by the demonstration of pathologic features" and more objectively, while "disease is a matter of physics and chemistry whose presence is betrayed by physical signs" (p. 866); whereas illness is defined as an "experience whose presence is often communicated by complaint" which "cannot be investigated by methods of biomedicine" (Jennings, 1986, p. 866). The following sections will examine ideas about Western and First Nations perceptions about diabetes as a disease and as an illness using the conceptual lens known as 'Two-Eyed Seeing'.

Informed by these characteristics of different knowledge systems, and with the intention of benefitting from both forms of knowledge, the remainder of this chapter will examine the different but complementary ways that diabetes can be understood

from the right eye (Western Science) and then from the left eye (Indigenous knowledge).

2.3 Right Eye: History and Western Knowledge about Diabetes

In this section, *Tsi'balyan*, guided by current literature, provides a brief history about the origins of diabetes, followed by descriptions of Type 1, Type 2, and gestational diabetes.

2.3.1 Brief history about diabetes.

Diabetes has a long history, dating back to 1500 BC. As a background to the different perspectives on diabetes that this thesis will explore, it is interesting to consider the first documented cases and definitions of diabetes. Chukwuemeka Nwaneri (2015) provides a history of diabetes in his article: "*Diabetes mellitus: A complete ancient and modern historical perspective.*" Diabetes was first suspected in 1550 BC by the Egyptian papyri, in "ancient Indian and Chinese medical literature" (Karamanou, Protogerou, Tsoucalas, Androustsos, & Poulakou-Rebelakou, 2016, p. 1), and in 1552 BC was identified as 'to regulate …excessive urine' by Hesy-Ra, an Egyptian physician (Nwaneri, 2015, p. 28). Aulus Cornelius Celsus (30 BC-50 AD) of Greece made the first attempt to define the symptoms of diabetes by describing the disease as "excessive urination in frequency and volume, and painless emaciations" (Nwaneri, 2015). In 230 BC, an Egyptian physician, Apollonius Memphites used the

prefix 'diabetes' for the first time to denote an excessive passage of urine and ascribed its aetiology to the kidney" (Nwaneri, 2015, p. 28).

The term diabetes, a Greek word for 'run through or siphon', continues to be used to describe diabetes. In 1889, Minkowski and Von Mering, after a pancreatectomy on a dog, found the pancreas "was a gland of internal secretion important for the maintenance of glucose homeostasis" (Karamanou et al., 2016, p. 5). Their discovery in the role of the pancreas helped pave the road to Banting and Best conducting experiments which led to the discovery of insulin (Karamanou et al., 2016). In 1921, Banting and Best began experiments on diabetic dogs by administering insulin into their body. This experiment led to the discovery of the role insulin had on diabetes management, and saved millions of people who suffered with diabetes, which led diabetics to live a longer and normal life (Karamanou et al., 2016). Therefore, through a 21st Century western science lens, diabetes is now defined as is a metabolic disease; which is characterized as a group of diseases that affect how the body uses sugar (glucose) typically "resulting from defects in insulin secretion, insulin action, or both" (American Diabetes Association, 2010, p. 62).

Today, diabetes is classified into three categories: Type 1 (insulin dependent) diabetes, Type 2 (non-insulin dependent) diabetes, and gestational diabetes (Diabetes Canada, 2017). As a chronic disease all three types of diabetes lead to

long-term damages to blood vessels, organs, nerves, loss of vision, heart disease, amputations and death as a result of the complications (American Diabetes Association, 2010). The following paragraphs differentiate the three types of diabetes.

Type 1 diabetes. The Canadian Diabetes Association (2015), American Diabetes Association (2015), and Mayo Clinic (2015) state that Type 1 diabetes sometimes abbreviated as T1d is typically diagnosed in children and young children, between 9 months and 2 years of age (Simmons & Michels, 2015). The disease is known as an autoimmune disease in which the pancreas produces no insulin, a hormone in the body that is used to gain energy from the food we eat. Insulin is used to control the levels of glucose (sugar) in the blood. Without insulin, glucose builds up in your blood instead of being used for energy. It is considered an autoimmune disease because the body's immune system will destroy the insulin-producing cells located in the pancreas, called beta cells (Diabetes.co.uk, 2017). When the body destroys the insulin, glucose builds up in the blood rather than used for energy (Diabetes.co.uk, 2017). The Mayo Clinic (2015) found that in those who have type 1 diabetes, the "body's own immune system- which normally fights harmful bacteria and viruses – mistakenly destroys the insulin-producing (islet) cells in the pancreas" (para. 5).

It remains unclear as to what the actual cause of type 1 diabetes is. The Mayo Clinic (2015) states that two possible causes are genetics and exposure to certain environmental factors, such as viruses. The genetic predisposition for Type 1 diabetes is HLA complex (human leukocyte antigen) located in chromosome 6 (Simmons and Michels, 2015) which triggers "an immune response in the body" (Atkinson, Eisenbarth, & Michels, 2014, p. 6). Simmons and Michel (2015) note that many of those who have the high-risk genes do not develop Type 1 diabetes, and that the cause of many Type 1 diabetes cases is related to environmental factors, such as viral infections "that trigger and perpetuate the autoimmune disease process prior to hyperglycemia and T1d" (p. 382). In fact, Simmons and Michels (2015) note that, when the disease occurs at a young age, between 9 months and 2 years of age, the fetus may have been exposed to a viral infection in utero (p. 382). Another environmental factor that is believed to lead to the onset of type 1 diabetes is "with infant and adolescent diets, vitamin D and vitamin D pathway constituents" (Atkinson et al. 2015, p. 3).

Maahs, West, Lawrence, Mayer-Davis (2010) note that information regarding the "incidence, prevalence, and temporal trends" of Type 1 diabetes varies worldwide (p. 2). The authors stated that most research about Type 1 diabetes comes from developed countries with "better established public health surveillance systems and diabetes research infrastructure" (Maahs et al., p. 2). Moreover, two

commonly known type 1 diabetes research projects are the Diabetes Mondiale study (DIAMOND) and the Europe and Diabetes study (EURODIAB) which are finding trends in type 1 diabetes. The DIAMOND study was a 10 year project that examined and characterized the global incidence, mortality, and health care for childhood diabetes. It found that approximately 4.5% of the world's population under the ages of 14 have Type 1 diabetes with the lowest incidence rates in China and South America, and higher rates reported in Sardinia, Finland, Sweden, Norway, Portugal, United Kingdom and Canada (Maahs et al., 2010). The DIAMOND project notes that incidence and prevalence rates are increasing in some countries due to "rapid social change" and "population exposure to putative etiologic factors for T1D" (Maahs et al., 2010, pg. 3).

Despite the global study by DIAMOND that shows Canada as one of the countries that have high incidence rates of Type 1 diabetes, the Public Health Agency of Canada (2011) states that Canada does not have a public-based surveillance study that confirms "the ratio between the two types of disease." As a result a national estimate of Type 1 diabetes is unavailable. The only study that provides data regarding the incidence and prevalent rates of Type 1 diabetes and Type 2 diabetes was developed in British Columbia by the Provincial Health Services Authority's Population and Public Health Program in 2006/2007 to "distinguish between Type 1 and Type 2 cases in administrative data" using an

algorithm method (Public Health Agency of Canada, 2011). The study found that 90% of those who had Type 1 diabetes were between the ages of 0 and 19 years of age (Krueger, 2010, p. 3). Of particular importance for the research presented in this thesis, is Kreuger et al's finding that Type 1 diabetes was uncommon among Aboriginal people. The lack of research and Public Health Surveillance systems is a major gap in knowledge of Type 1 diabetes in Canada.

Type 2 Diabetes. Type 2 diabetes is a chronic disease that prevents the pancreas from producing enough insulin, or prevents the body from adequately utilizing the insulin. An interference in insulin production or utilization causes an increase of glucose (sugar) in the blood (Canadian Diabetes Association, 2015). According to the World Health Organization (2015), "Type 2 diabetes is much more common and accounts for around 90% of all diabetes cases worldwide" (para. 2). WHO (2017) noted that the main causes of Type 2 diabetes are "excess body weight and physical inactivity." Other known risk factors associated with the development of Type 2 diabetes are presented in Box 1, using data from the Canadian Diabetes Association. (2015):

Box 1: Known Risk factors associated with development of Type 2 diabetes, adapted from Canadian Diabetes Association (2015).

- Having a parent, brother, or sister with diabetes;
- Being a member of a high-risk group of Aboriginal, Hispanic, South Asian, Asian, or African decent;
- Having health complications that are associated with diabetes;
- Having given birth to a baby that weighed more than four kilograms (nine

pounds) at birth or having had gestational diabetes (diabetes during pregnancy);
- Having been diagnosed with prediabetes (impaired glucose tolerance or impaired fasting glucose);
- Having high cholesterol or other fats in the blood;
- Being overweight, especially if that weight is mostly carried around the waist;
- Having been diagnosed with polycystic ovary syndrome;
- Having been diagnosed with Acanthosis nigricans (darkened patches of the skin);
- Having been diagnosed with psychiatric disorders: schizophrenia, depression, bipolar disorder;
- Having been diagnosed with obstructive sleep apnea;
- Having been prescribed a glucocorticoid medication by a doctor

Despite the number of risk factors, Type 2 diabetes is largely preventable and can be delayed in people who are at high risk by a healthy diet, weight control, not smoking, and physical activity (Lindström & Tuomilehto, 2003). For example, someone who participates in physical activity that is moderately-intensive for at least 30 minutes a day for five days, and consumes food that is low in fat and calories has a high chance for delaying the development of type 2 diabetes (National Institute of Diabetes and Digestive and Kidney Diseases, n.d.).

Gestational Diabetes. Gestational diabetes is another type of diabetes that only affects women. This disease only occurs during pregnancy and is a temporary disease. Desisto, Kim, and Sharma (2014) mention that mothers who are diagnosed with gestational diabetes are more likely to experience pregnancy and delivery complications such as "infant macrosomia, neonatal hypoglycemia, and caesarean

delivery" (p. 1) than those without gestational diabetes, and are more than 7 times more likely to develop type 2 diabetes within 5-10 years after giving birth, and their children are at higher risk of developing diabetes.

Diabetes complications. Diabetes related complications are common. The International Diabetes Federation (2015) states that those with diabetes have "an increased risk of developing a number of serious health problems" (para. 1). They also note that those who have chronic elevated glucose levels are at greater risk of developing one or more microvascular or macrovascular disease (International Diabetes Federation, 2015, para. 1). The following are examples of microvascular and macrovascular diseases that may be associated with diabetes (Fowler, 2008):

- Microvascular complications in those with Type 2 diabetes are classed as retinopathy, neuropathy or nephropathy. These complications occur due to consistent and uncontrolled hypertension, severe hyperglycemia, and high cholesterol levels (Folwer, 2008; International Diabetes Federation, 2015). The following is a description and definition of the three mentioned microvascular diabetic complications by the International Diabetes Federation (2015):
    - Diabetic retinopathy (eye disease) causes a reduction in sight or blindness;

- Diabetic neuropathy (nerve disease) is defined by damage to nerves throughout the body, mostly effecting the extremities in areas such as the feet; this is known as peripheral neuropathy. The nerve damage causes loss of feeling, pain and tingling which increases health risks such as injuries going unnoticed which can lead to possible amputations, and
- Diabetic nephropathy (kidney disease) is characterized as damage to the small blood vessels in the kidneys which may result in kidney failure. This disease is seen more in those who have diabetes than those who not have diabetes.

- Macrovascular complications, also known as cardiovascular disease, refers to damage to the heart or its blood vessels by consistent high blood pressure, high glucose levels, and high cholesterol levels (International Diabetes Federation, 2015, para. 2). The International Diabetes Federation (2015) notes that those at risk are more likely to develop coronary artery disease, which may lead to a heart attack or stroke.

2.3.2 The impact of diabetes on First Nations populations.

Since this research is focused on First Nations perspectives on Diabetes, it is important to consider what Western science knowledge is available about the

impacts of diabetes on First Nations populations in Canada, in addition to the global understanding introduced above.

Unfortunately, knowledge of diabetes on First Nations populations is not as detailed as might be anticipated, especially given the recognised higher rates of Type 2 diabetes in Indigenous people worldwide (Chen, Maginano, & Zimmet, 2012) and the higher rates of Type 2 diabetes in Canada (Dyck et al., 2010). This section provides some examples of specific studies that have examined Diabetes in First Nations communities.

In 1999, there was only one study regarding the prevalence of gestational diabetes among First Nations in Canada. Rodrigues, Robinson, and Gray-Donald (1999) studied the prevalence among Cree women in James Bay, in Northern Quebec. Rodrigues and colleagues found that the prevalence of gestational diabetes among the Cree women in James Bay in the eastern region of northern Quebec was 2 times (12.8%) higher than that of the general Northern American population which is reported at 3-5%. A similar study by Godwin, Muirhead Huynh, Helt, and Grimmer (1999) of Swampy Cree women in Moose Factory, James Bay found that the prevalence of Type 2 diabetes was 8.5%, which is still higher than that of the North American population.

A more recent study using a prospective survey of women admitted into the Saskatoon Royal University Hospital found that 11. 5% of Aboriginal women were

admitted for childbirth had higher gestational diabetes, which can be compared to 3.5 % of women from the general population to have gestational diabetes (Dyck, Klomp, Tan, Turnell, & Boctor, 2002). Studies also show that those who were obese or overweight were at higher risk of developing gestational diabetes, preeclampsia, infant macrosomia, and impaired glucose tolerance. For example, in a study by Brennand, Dannenbaum and Willows (2005), regarding the "relationship between pregravid weight, weight gain in pregnancy, and adverse maternal-fetal outcomes in Cree women living in James Bay, Quebec" found that 27.9% were overweight at the beginning of the pregnancy, 49.1% were obese, and 37.2% have infant macrosomia (grade 2 macrosomia).

2.4 Left Eye: First Nations perceptions about diabetes

In keeping with the Two-Eyed Seeing framework introduced above, this section examines diabetes from the left eye – presenting insights from the limited literature that is available with an orientation to First Nations perceptions about diabetes.

2.4.1 Documentation of First Nations perceptions about diabetes.

A study by Barton, Anderson and Thommasen (2005) explored the experiences of diabetes among First Nations in Bella Coola, British Columbia. The authors found that the participants believed that it was important to use both traditional and western medication to help control their diabetes; one of the participants stated, "I

had a problem with my stomach at the same time of diabetes. I couldn't keep my food in, couldn't eat or sleep. So I went for some Indian medicine and tried it. I felt better." (p. 244). They also found that participants understood that diet, exercise and weight control were essential to diabetes management but it was difficult for them to commit to a strict regime. The patient doctor relationship was also important to foster participants understanding of diabetes associated complications and to increase knowledge about how to better manage their diabetes. Baton et al. (2005) also found that participant found it difficult to communicate with health care workers, and as a result, turned to others who are affected by diabetes and have knowledge about complications and diabetes management. Lastly, Barton et al. (2005) found that participants understood that they needed to accept that they have diabetes and take full responsibility for understanding it as disease in order to live a healthy and balanced life.

A study in Baffin Island found similar experiences. Bird, Wiles, Okalik, Kilabul and Egeland (2008) found that Inuit with diabetes knew that for effective diabetes management, the doctor patient relationship was important as was sharing knowledge about diabetes with others. An important difference from the study in Bella Coola is that participants found it beneficial and important to eat 'country foods' rather than 'market foods', to stay healthy with diabetes (p. 20).

This existing work, though valuable, is limited in reflecting the experience and perceptions of First Nations people in Northern British Columbia about diabetes. These studies do not reflect a holistic approach of health and wellness. For example, none of these studies give any indication of participants voicing a spiritual component to their experiences and perceptions about diabetes.

2.5 Conclusion

Part of the conceptual contribution of the research presented in this thesis is to propose a more First Nations oriented framework and to design research that uses this to contribute to an expanded understanding and response to diabetes in First Nations communities in northern BC. The following chapter introduces the Indigenous research approach used to enable this to happen.

Chapter Three: Indigenous Research Approach

3.1 Introduction

In this chapter, *Tsi'balyan* felt that it is vital to understand the historical background of research practices that have influenced the development of an Indigenous research paradigm and research methodology. This introduction is followed by defining the Indigenous research and methodology that is fundamental to the purposes and personal relevance of this study. Maori scholar, Linda Tuhiwai Smith (1999) states, "Methodology is important because it frames the questions being asked, determines the set of instruments and methods to be employed and shapes the analysis. Indigenous methodologies are often a mix of exiting methodological approaches and indigenous practices. The mix within the academy, and parameters and common sense understandings of research which govern how indigenous communities and researchers define their activities" (p. 143).

As mentioned in chapter 2, the four aspects of a research paradigm are: ontology, epistemology, methodology, and axiology. Box 2 provides an overview of *Tsi'balyan's* position in the research paradigm:

Box 2. Four aspects of a research design.

- **Ontological assumption:** *Tsi'balyan* believes that 'diabetes is a trickster who lives alongside a person and when the body is weak from lack of physical activity, being overweight, genetic susceptibility, etc. (Right-Eye perceptions), diabetes enters the body (Left-Eye perception)'. This belief guided the research to seek knowledge about how First Nations experience and

understand diabetes, in other words, to determine "what is real" (Wilson, 2008, p. 33). The ontological assumption allowed an opportunity to examine the data by entering into an Indigenous realm and bring to life their experiences about diabetes through stories.

- **Epistemological assumption:** Hart (2001) states that "Indigenous epistemology is a fluid way of knowing derived from teachings transmitted from generation to generation by storytelling, where each story is alive with the nuances of the storyteller" (p. 8). The research process captured stories about diabetes that are brought to life in this thesis. Stories emphasize ones' "dreams and visions, and is intuitive and introspective, [and] arises from the interconnections between the human world, the spirit, and inanimate entities" (Hart, 2010, p. 8).
- **Methodological assumption:** Conducting the research and writing the thesis guided by Indigenous methodologies guided *Tsi'balyan* to fully engage with participants in the research process, be accountable to 'all my relations' (Hart, 2001, p. 9).
- **Axiological assumption:** Hart (2001) states that "Axiology is the ethics or morals that guide the search for knowledge and judge which information is worthy of searching for" (p. 72). *Tsi'balyan's* ethics and morals throughout the research is guided by the Four R's: respect, relevance, responsibility, and reciprocity. The following is *Tsi'balyan's* position in each guiding value of the four R's (Chilisa, 2012):
    - Respect. Honor and valuing the community's culture, respecting and honoring the relationship between community and researcher, and community involvement in the research process.
    - Relevance. Keeping at heart the importance and relevance of the study to the research and the community involved.
    - Responsibility. The knowledge that responsibility includes being aware of the responsibility I have to the participants, the community and the research.
    - Reciprocity. To assure the research is conducted to benefit the community, participants, and the researcher.

3.2 Historical Research Practices Involving Indigenous People

Research has improved the quality of our lives. Through research involving humans, we have increased our knowledge in humanities, natural sciences, engineering, social sciences, and health sciences (Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, and Social Sciences and Humanities Research Council of Canada, 2014). However, acquiring knowledge through research involving humans did not always follow ethical conduct of research practices (Canadian Institutes of Health Research et al., 2014). The following paragraphs give some examples of unethical research involving First Nations people in Canada.

Over the past century, there has been much research on First Nations, Inuit, and Metis people in Canada which has been "defined and carried out by non-Aboriginal researchers" and did not "benefit Aboriginal people or the communities" (Government of Canada, 2015, para. 3). As seen in Mosby's (2013) article, *Administering Colonial Science: Nutrition Research and Human Biomedical Experimentation in Aboriginal Communities and Residential School, 1942 – 1952*, research was conducted without consent, knowledge, and using unethical practices.

Ian Mosby, a historian of food and nutrition, published an academic paper on unethical health research on First Nations. In his paper, Mosby notes that in 1942, a study was conducted in five Cree communities by a group of scientific and medical

researchers to 'study the state of nutrition of the Indian by newly developed medical procedures' (Mosby, 2013, p. 146). The research consisted of "physical examinations" such as "blood tests, and x-rays on nearly 400 Aboriginal residents of these communities" (Mosby, 2013, p. 146). However, prior to the examinations, the researchers found that many of the community' residents were suffering from malnutrition and hunger. The authors note, "conditions were deplorable where the old people were almost starved and were plainly not getting enough food to enable them to much more than keep alive" (Mosby, 2013, 146).

As, Mosby (2013) notes, the researchers continued their research, regardless of the unhealthy conditions of participants. The findings of this study influenced more nutritional studies on reservations and residential schools which lasted until 1952. Studies conducted found that there was a high prevalence of malnutrition and tuberculosis on reserves and residential schools. Though the studies found connections between poorer health conditions and nutrition, these studies were conducted with unethical practices and without consent. For example, studies conducted in residential schools consisted of putting children into controlled and treated groups, with both groups being denied adequate food. MacDonald, Stanwick, and Lynk (2014) note that,

> In one experiment, the treatment group received supplements of riboflavin, thiamine and/or ascorbic acid supplements to

> determine whether these mitigated the problems – they did not. In another, children were given a flour mix containing added thiamine, riboflavin, niacin and bone meal (p. 64).

In another example of unethical research involving First Nations in Canada, members of the Nuu-chah-nulth community had samples of their blood collected by Dr. Richard Ward in the 1980's, who claimed that the blood samples were for a study regarding rheumatoid arthritis. Instead, the blood samples were transferred around the world for genetic testing for genealogy, also known as genetic anthropology (Brunger, 2013).

Maureen Lux, a professor at Brock University, published an article in 1998 on tuberculosis vaccine trials in the 1930's called, *Perfect Subjects: Race, Tuberculosis, and the Qu'Appelle BCG Vaccine Trial*. In her article, she describes that, in 1921, children in Qu'Appelle, southern Saskatchewan were tested for tuberculosis (TB), and results showed that, of the children who were tested, 92.5% had a positive reaction, which indicated that the children were infected with the bacteria or exposed (Lux, 1998). As a result of the study, there was growing concern about the spread of the disease to non-Aboriginal people living adjacent to communities with high TB infections, which caused the Government of Canada to take action to stop the spread of tuberculosis, "the menace on reserves" (p. 282), and look for a solution. Although it was known that improved living conditions will control and decrease the spread of

TB, it was viewed that conducting experiments using BCG vaccinations was a "far less expensive method of controlling tuberculosis than the alternatives of case-finding, lengthy sanatorium treatment, and improving living conditions" (p. 287). Thus began the BCG vaccination experiment involving Aboriginal infants. The experiment was conducted between 1933 and 1945, and involved 609 Aboriginal infants – half the infants were given the vaccine and half were not. The results showed that the prevalence of TB on reserves was staggering, and that the greatest threat to the lives of those living on reserve was not TB, but was poor living conditions and poverty causing the rapid spread of the disease. Although the study found the cause for the spread of TB, of the 609 infants in the experiment, 77 had died before their first birthday, and of these, only 4 had TB.

These are only a few of the many unjust, unethical and without consent research practices on First Nations, Metis, and Inuit people in Canada, and many similar studies had been conducted on other Indigenous populations around the world. As a result Indigenous scholars and communities began to speak up and demand a change in research ethics regarding First Nations, Metis, Inuit, and Indigenous people around the world. This led to a convergence of voices for change in the approaches to research involving Indigenous People.

3.3 Voices for changes in research and Indigenous peoples.

> "It appals us [Indigenous people] that the West can desire, extract and claim ownership of our ways of knowing, our imagery, the things we create and produce and simultaneously reject the people who created and developed those ideas and seek to deny them further opportunities to be creators of their culture and own nations" (Smith, 1999, p. 1).

Scholars, researchers, Indigenous people, students, communities, and Elders got tired of being 'subjects' and began voicing their concerns about how research was being conducted in their communities by government agencies (Assembly of First Nations Environmental Stewardship Unit, 2009; Castellano, 2004). In 1992, a meeting between scholars, researchers, Indigenous people, students, communities, and Elders and the Royal Commission on Aboriginal Peoples (RCAP), the attendees brought up the issues in research (Assembly of First Nations Environmental Stewardship Unit, 2009). The issues that were addressed were: research practices neglected to inform participants and communities of what information was being collected and its purpose, taking knowledge without consent or knowledge of the process, and that research methods did not respect or acknowledge traditional knowledge, culture and traditions, and were not culturally appropriate (Assembly of First Nations Environmental Stewardship Unit, 2009). Many Aboriginal nations protested, noting "We've been researched to death!" (Castellano, 2004, p. 98).

Not only were Indigenous communities coming together about the issues in research practices in Canada, scholars such as Linda Tuhiwai Smith helped to inform the world by writing about how Indigenous people were being treated in research. In her book, *Decolonizing Methodologies: Research and Indigenous Peoples*, she wrote,

> … the term 'research' is inextricably linked to European imperialism and colonialism. The word itself, 'research', is probably one of the dirtiest words in the indigenous world's vocabulary. When mentioned in many indigenous contexts, it raises a smile that is knowing and distrustful (Smith, 1999, p. 1).

Scholars such as Linda Tuhiwai Smith and Indigenous peoples around the world helped develop an Indigenous research paradigm and Indigenous research methodologies. Academic thinkers, writers and researchers such as Bagele Chilisa (2012) , Shawn Wilson (2001, 2008), Margaret Kovach (2010), and Linda Tuhiwai Smith (1999) argue that Indigenous research methodologies are a response to Western research which has tended to exclude Aboriginal involvement, consultation, permission, and has shown a lack of respect for traditions, culture, values and traditional knowledge. These scholars also argue that Indigenous research methodologies are a response to the lack of research conducted about emotional, mental and spiritual health controlled by research controlled by social,

health and natural scientists for economic gain. The history of western research has caused Indigenous people to develop an attitude of mistrust, animosity and resistance to research and researchers. The Indigenous scholars' collective shows courage, dedication and determination for change in research processes has helped to protect Indigenous people around the world and enable researchers, like myself, to use an Indigenous approach.

3.4 Indigenous Paradigm and Methodologies

In this section, I will explain the importance of why I chose to use an Indigenous approach for this study. An Indigenous research paradigm decolonizes and indigenizes the more "dominant research methodologies" (Chilisa, 2012, p. 39). Within the paradigm is the development of the Indigenous research approach that enables me to create a framework that I can use to capture the lived experiences, values, and history of those who may otherwise be belittled and marginalized by Euro-Western research paradigms (Chilisa, 2013, p. 19), in addition, it provides me with the opportunity to actively participate in the research processes.

On a more personal note, using the Indigenous approach helps me to honor and acknowledge the processes of decolonization, resilience, and rebuilding and reassertion of traditional knowledge through the research process. The five phases of decolonization are (1) rediscovery and recovery, (2) mourning, (3) dreaming, (4) commitment, and (5) action (Poka Laenui, as cited in Battiste, 2000). Laenui states

that each phase of decolonization can be experienced in any combination and one or more at a time (Battiste, 2000, p. 152).

The process of resilience helped me to overcome adverse challenges, to recover from and survive adversarial conditions throughout the research process, and gave me the ability to adapt to life regardless of harsh conditions. I was able to focus on the success of my thesis research and journey rather than the failures. In addition, resilience in research is important because it shows that we are moving forward in research using a method that is designed to build trust and positive relationships with researchers and communities (Fleming & Ledogar, 2008).

The rebuilding and reassertion of the traditional knowledge process was like a breath of fresh morning air for me. It opened doors that enabled me to include our traditional knowledge into the research which made it authentic to who we are as "Indigenous scholars". Marie Battiste & Henderson (2000) use the following description of Indigenous knowledge as.

Knowledge is the expression of the vibrant relationships between the people, their ecosystems; and the other living beings and spirits that share their lands. All aspects of this knowledge are interrelated and cannot be separated from the traditional territories of the people concerned (Battiste & Henderson, 2000, p. 42).

The use of Indigenous Knowledge in research is extremely important, specifically when conducting research with an Indigenous group because Indigenous Knowledge is translated through stories, language and their ways of life. Battiste and Henderson (2000) comment that language provides an accurate understand of Indigenous knowledge.

3.5 Research Process: Data Collection and Data Analysis

This section describes the methodology and methods used in this study. In keeping with the conceptual framework of the Two-Eyed Seeing, *Tsi'balyan* used both an Indigenous approach and Western research methods in this study. The Indigenous approach in the research design focuses on conducting the research in a harmonious and respectful manner, building and strengthening community relationships, respecting culture as you collect stories, honoring the stories told and presenting them in a story format. Western research methods provided me tools to conduct research such as the semi-structured interviewing for gathering data and thematic analysis for organizing data. These Western research procedures guided the research tools to help me ask appropriate questions that are relevant to the research and their stories are analyzed to address the central problems of the research (Smith, 1999, pg. 143). Other Western research concepts used to guide the study were sampling, validity, and reliability which are to eliminate any researcher and participant biases from the findings (Chilisa, 2012, pg. 86). However, in

qualitative research, critical subjectivity is used during the research process known as research-based self, brought selves, and a situationally created self (Chilisa, 2012). Each process has its direct influence on the research inquiry; it is suggested that the researcher "critically reflect on self as knower, redeemer, colonizer, and transformative healer" (Chilisa, 2012, p. 174). I wanted to be a transformative healer.

3.5.1 Role of the researcher.

Western research methodologies teaches students that the role of the researcher lies with the definition of being an instrument (Denzin & Lincoln, 2003) and our primary role as a research is: data collector, data interpreter, and data analyser. The term 'instrument' is a colonized term which objectifies the researcher.

However, from an Indigenous approach, rather than portraying myself as an instrument whose sole purpose is to gather data, I approached the community and participants in a holistic and culturally appropriate manner (Wilson, 2001, 2008) by introducing myself as *Goozih*[6], a bird who loves to venture out and observe everything. In my communications with the community and participants, I told them I am like a *Goozih* seeking information about diabetes. They loved this metaphor. Transforming myself from an 'instrument' into one of our iconic birds lessened the tension and increased their willingness and openness to share their stories for this research study.

[6] Goozih: whiskey jack

3.5.2 Community engagement.

Research is similar to our culture in that, it is customary to have a community consultation or ask permission from the community and elders to hunt and gather in their territory. Gathering data in a community is like gathering berries or medicinal plants and first requires *Tsi'balyan* to meet with the community. According to Canadian Institutes of Health Research et al. (2014) the purpose of Community engagement is:

1. To build a respectful relationship between researcher and community;
2. Encourage dialogue about community and participant collaborations with the researcher; and,
3. Provide an opportunity for the researcher to explain the ethics and principals that guide the research process, such as: *Respect for Persons, Concern for Welfare, and Justice.*

The community engagement process included several stages. Prior to recruitment and interviews. I informed the community of the research I would be conducting in the community at a community engagement meeting. At the meeting, members had the opportunity to ask questions about the research process and dissemination of the findings. During the meeting, members acknowledged the research, and registered no objection. After the community engagement meeting, I felt confident to proceed with moving forward to the recruitment process.

3.5.3 Recruitment strategies and process.

After the University of Northern British Columbia Research Ethics Board approved this research study, *Tsi'balyan* used purposive sampling techniques, with homogeneous and snowball sampling as a subset to recruit participants. Patton (1990) states that the strength of purposive sampling lies in selecting information-rich cases. The homogenous sampling strategy helps identify the specific group to be studied (Patton, 1990). The snowball sampling approach involves asking the interviewed participants to "identify others who they believe have knowledge or information on the phenomenon under study" (Chilisa, 2012, pg. 169). The following is a description of the recruitment strategies I used for this study. Posters were displayed at the school, band office, and health centre. In addition, posters were distributed to all occupied dwellings. The information on the posters provided the requirements to participate in the study. The requirements were: (a) must be First Nation, a registered member of Yekooche First Nation (b) be 19 years of age or older, (c) need to be living on-reserve for at least one year (d) the participants must be available for six to twelve months (if the researcher should need any clarification on data collected), and (e) have an interest in diabetes. Prospective participants contacted me by phone, email or Facebook to set a time and place for the interview.

3.5.4 Data collection.

Lavallée (2009) notes that, when choosing a data collection technique, it is important that the research is "respectful of and includes Indigenous protocols, values, and beliefs that are important to the specific community" (pg. 28). I collected primary data using semi-structured, open-ended interview questions which allowed me to seek further clarification or more detailed information when required, using probing questions. The interviews were conducted in person and one-on-one. The greatest respect was taken during the interview process because as a First Nations person who has historical, traditional and cultural knowledge, I am innately protective and cautious about sharing our sacred knowledge which was reproduced, preserved, and conveyed through oral traditions from generation to generation (Hulan & Eigenbrod, 2008). Therefore, I took extra steps to ensure that each interview was conducted in a holistic and culturally appropriate manner. To ensure *Goozih's* interviews were conducted in a culturally appropriate manner, specific steps were undertaken and are summarized in Box 3.

Box 3. Steps taken to ensure a culturally appropriate interview. Informed by the research methodology, the following steps were taken (by *Goozih*/the interviewer) to ensure a culturally appropriate interview.

1. I situated myself
2. I gave the participant the information letter and consent form which they read and had the opportunity to ask questions about.
3. I informed each participant that their identity will be protected by using a pseudonym. This was an important process because Yekooche is a small

community and this ensured that participants are not identified in this study.
4. I showed the participant the recording device so they knew how the data will be collected.
5. I answered the participant if s/he had any questions, then proceeded with signing the consent form.
6. I proceeded with the interview which was conducted using an interview protocol.

The interviews were conducted using an interview protocol. The interview protocol was used to guide me with specific and probing questions about the studies subject, and enabled me to conduct the research in a conversation style (Jacob & Furgerson, 2012). The interview protocol consisted of 10 questions, which were divided into 3 components: background questions, colonization, the cause of diabetes, and then I did a closing. The background component asked about their knowledge about diabetes. The colonization component asked participants about their perceptual experiences about diabetes. Hart (2010) states that, perceptions, from an Indigenous perspective includes 'metaphysics of inner space' (p, 8). The closing component was for participants to have an open dialogue to include their perceptions about diabetes.

A hardcover notebook was used for fieldnotes that enabled me to capture detailed descriptions of the participants' activities, behaviors, actions, and interpersonal interactions and organizational processes during the interview (Emerson, Robert, Fretz & Shaw, 1995). After each interview, I wrote a reflective

journal to document my thoughts and feelings about something observed during the interviews (Kumar, 2011, pg. 130).

3.5.5 Transcription of audio files.

The digital audio files were uploaded to a program called Sound Organizer, which I used for transcribing the interviews. All primary data was transcribed by myself, transcribed into a word document, in English and verbatim. A copy of the transcribed interviews was given back to the participant for verification and feedback.

3.5.6 Analysis of data.

Thematic analysis was used to analyze the data for my research. Thematic analysis is considered a foundational method in qualitative research and is defined as a method for identifying, analyzing and reporting themes or patterns found within the data (Braun & Clarke, 2006). Daly, Kellehear, and Gliksman (1997) describe thematic analysis as a process that seeks out themes that are important to the explanation of the phenomenon being researched. Creswell (2007) notes that the data analysis process is significant to the research through giving the researcher the chance or opportunity to sift through data and highlight "significant statements, sentences, or quotes that provide an understanding of how the participant experiences the phenomenon" (p. 61). The following paragraph is a description of the journey *Tsi'balyan* traveled in the data analysis process which was guided by

Braun & Clarkes' (2006) six phases to identify, analyze and report themes or patterns found within the data:

> *Goozih* first read and re-read all transcripts while following the audio files, and read and re-read the fieldnotes and reflective journal entries. After familiarizing myself with the raw data, I coded all interview transcripts. Coding was guided by thematic analysis. Once coding of the interviews was completed, I reviewed the codes to formulate themes. During the coding of themes phase, I read through the main themes to illuminate candidate themes. All themes were then read and re-read to define and name the themes. I used the same process for the fieldnotes and reflective journal. Lastly, the themes were named and presented in the findings in relation to participant perceptions.

Fieldnotes and journals contained feelings from each interview and were treated with the utmost respect. For example, entries were honored and treated with the same respect a person would receive at a *Balhats*[7].

3.5.7 Plans for dissemination of research outcomes.

Tsi'balyan will provide a feast in the community to share research findings through storytelling (presentation) and a short summary. In addition, a full text

[7] Balhats translated is governance system.

document will be gifted to Yekooche in honor of sharing their stories and their hospitality.

Chapter Four: Findings: Yekooche First Nations Perceptions about Diabetes

4.1 Introduction

In this chapter, *Tsi'balyan* presents the findings generated from *Goozih's* interviews with Yekooche members and *Tsi'balyan's* analysis of these interviews. The interviews were the main source of data used to answer the research question: *What are the perceptions, understanding, and beliefs about diabetes of community members in Yekooche First Nation?* The objectives of the research were: 1) to understand how Yekooche members define diabetes; 2) to explore Yekooche perceptions of diabetes; and, 3) to examine their beliefs and understanding of diabetes education and what diabetes educational materials would be useful.

Due to the sample and interview size and the Indigenous Left Eye way of seeing, pseudonyms are used for interview quotes which also protect participant identity. Box 4 is a list of the pseudonyms used.

Box 4. Pseudonyms of participants.

- Tl'alhchooz (hummingbird)
- Sus (black bear)
- Soh (robin)
- Nanghuz (fox)
- Datsancho (raven)
- Shas (grizzly bear)
- Yuzi (elk)

Five of the eight participants shown in Box 4 were females and the remaining three were males. Two of the participants were Elders, two were youth, and the remaining four were middle aged adults. All participants are Yekooche community members and live in the community. Guided by the conceptual lens, Two-Eyed Seeing, the results of the thematic analysis of the interview data, fieldnotes, and the reflective journal will be presented in this chapter.

Analysis of interviews and the resulting stories were guided by the conceptual lens, Two-Eyed Seeing. The Western approaches to conduct the research were: purposive and snowball sampling to gather stories; semi-structured processes for interviews, fieldnotes and reflective journal used to assist in the development of the findings, and thematic analysis to generate themes. The thematic analysis of the transcripts resulted in three main stories (or themes): (1) Understanding their lived experience about diabetes; (2) Gaps in Diabetes Education; and, (3) environmental changes decreasing health and wellness. The Indigenous approach was writing stories as told by each participant. This writing form provides a true and holistic depiction of their perceptions. A discussion of the three stories (themes) follows in Chapter 5. Here *Tsi'balyan* presents the three themes.

4.2 Story (Theme) One: Understanding their lived experience about diabetes

In this section, *Tsi'balyan* presents the stories gathered from participant about how diabetes is perceived.

Out in an open field, *Goozih* has a conversation with *Yuzi* (elk), an Elder in the elk herd about his experience and understanding about diabetes. *Yuzi*, says, "Umm, either you get low blood sugar or high blood sugar diabetic. Umm, that's about all I know" [and] "can't eat certain things, ahhh, he don't enjoy the food he use to enjoy, can't drink that nice tasty pop, and umm, slows everything down." Yuzi understands that diabetes "slows your body process, you gotta watch what you doing, mostly your feet they say, and can't eat too much, what they call it? White food. Or potatoes, bread. Dairy food" and *Yuzi* believes that the reasons for diabetes is "too much fast food." and says "I think our traditional food, moose, fish is a lot better for our health." While looking into the distance towards the sunset, *Yuzi* says, "I don't know. All our elders ate all of those and haven't heard any of them having diabetes." *Yuzi* finished telling his story about his understanding about diabetes and walks back into the forest.

Tl'alhchooz (hummingbird) says:

> Diabetes is a sugar level that you have to control with your body. Sometimes it comes out of affect and you have to take pills or gotta watch your diet. Or get a needle if it's too diabetic…I guess. Diabetes is when somebody's sugar is too high or too low. From what I understand, when you get an infection, it takes longer to heal. And when your diabetic gets too high, it can cause your heart to stop. Or

if it is too low, it still can cause your heart to stop. For some people, we have to understand what the high and the low is to see what it is we can do for our diabetic people, and we have to know what kind of diabetic they stand in. What category. Cause there's, I think, the ones that are taking the needle, those ones are the ones that's most dangerous. And we are an hour and a half away from the hospital, so trying to rush them down, it's like time consuming and gotta try to get them to the hospital as fast as we could. Any kind of diabetes has to be with caution.

During our conversation, *Tl'alhchooz* looks to the forest, and says in her delicate *Tl'alhchooz* voice:

We don't have enough meat or fish. When we run out of food before the winter is over, some medicines we can just gather during the summer or certain time of the year, … then we have to go to nado way. I mean white man way.

During a visit with *Sus* at his den, *Sus* (black bear) tells his story about his perceptions about diabetes:

Yeah, ahhm, there's actually a few people, my friends and stuff, they have diabetes. Some of them have to inject themselves with a

needle every day, and that seems like a pretty harsh thing to do to yourself every day, is to get injected with insulin every day, I guess. There are all types of it too, there's type 1, 2, & 3 I guess. How many types are there? There's quite a few. Seems like for me it's a scary thing anyways. I know that, I wouldn't want, I don't know. I pray to God that I don't get it, or have to do that to myself, or my kids, or my nephew or nieces, or any. Just to see what they go through, you know, missing their foods that they eat. Their salt and their sugars, you know what I mean? They haven't have it anymore. Now that must be really bad.

In a separate visit, *Shas* , a scruffy old grizzly bear, talks about his perceptions about diabetes:

let's see, diabetes is, gee I don't know how to describe it. Diabetes, ahhh, I guess it's a illness that you get that can be cured at an early age I guess. Not too sure. Or once you get it, there's not cure for it I guess. And all I know is that there is two types of it. There's type one and two. That's it. Diabetes is ah, definitely a white mans, caused from the white man. Like every other disease, is caused by white man. If it was up to us, we would be nice and healthy yet and living off the land, but no. So everything now a days we have to get adapted to these new lifestyles and so everybody is getting more

lazy, in front of the TV, eating more canned meat. So, but it's hard now a days, I mean…with the inflation with everything too. And up here, it's the, we don't have much work up here also, so. That's the other thing, if people had work they would be able to get vehicles or skidoos and that to go hunting, but no, there's not much work and a lot of people are on SA[8] and when you're on SA, you pretty much only shop once a month. Without moose and that, I mean, you got no choice to get ground beef and all that fatty stuff, canned meat, like all that stuff, anything canned pretty much. Things that will last. So I don't think that people ever look at it that way, for people on reserves and that, and I don't think that it's only on reserves, also in town for people, for the Caucasian people also. So for them to get the supply to last one month, it's gotta be canned. So, there you go. All that salted stuff in every body. All races of life. I just would like to see more out there about diabetes and First Nations. Educate people. Start educating people on it right away so people don't have to suffer with it. That's it. Because if you have diabetes, it just so limited stuff that you can do with your life after that. You can't be active like you use to be. You are pretty much labelled after you got it. Your, there's only certain things you can do, and eat. You can't eat your traditional foods like you use to, once you've got

[8] SA translated is Social assistance.

it. You always gotta cut the fat off the meat. Things like that, all the good parts. All the good stuff we lived off of for so many years is, now no more good for us, because once you get it. That's it. Amen.

4.3 Story (Theme) Two: Improve Diabetes Education and Materials

In this section, *Tsi'balyan* presents stories *Goozih* gathered about gaps in diabetes education, suggestions to improve diabetes education materials, and increasing diabetes knowledge in their youth.

Datsancho (raven), comfortably nestled on his perch tells *Goozih*, who sits in rain with his feathers all fluffy, tells his experience with diabetes education. *Datsancho* was only able to answer with a simple answer as he has little experience with diabetes education, "I got a hand out once", *Datsancho* also mentions that, "…the most experience I had was talking to you" (You meaning *Tsi'balyan*, the researcher). *Goozih* asks *Datsancho*, what tools can be created to make it easier to learn? Datsancho replies, as he moves his finger on the table, "If you make coloring books with pretty pictures, just kidding. That's actually a really good idea. If it was explained in class, like Carrier class". *Goozih*, wanting to know more about his ideas about teaching kids about diabetes asks *Datsancho* to elaborate on this topic, *Datsancho* says:

> Like diabetes being part of our First Nations gene. And, it's like something you should learn while you're a kid. Cause our, there are members in our family that have or has had diabetes. So, it's just something that kids should know. Plus I see how much sugar they consume in a day. That's important to pay attention to.

In a conversation with <u>*Nanghuz*</u> (fox), she says, "Most workshops that I saw about diabetes is, just they told us about our sugar levels. What kind of foods we could eat and can't eat. And, well that's the only kind of workshops that I've been to." <u>*Nanghuz*</u> mentioned that she learned that, if someone has diabetes, "That you need candy or sugar or something when your sugar levels are too low. And, you need medication I think it was when your sugar levels are too high." Staring at her paw print in the mud, she also says, "Kinda scares me to have too much sugar now. And all the stuff that we eat contains too much sugar. That's processed with sugar. So…having the traditional foods does help, cause we don't add sugar in our food." *Goozih* asks <u>*Nanghuz*</u>, to explain what tools can be created to make it easier to learn? She says:

> Having the numbers of, how much people actually die from it. The education of it. Like how we can help someone that didn't know that they have diabetes. And to be able to help. Because we are so far out. We don't have access to anything 24 hours a day, just for 7 hours we have access to

> our community center. And that's only from Monday to Friday. Other than that we have to go into Fort. And there is limited access to vehicles too, and drivers. And have no way to get across (waiving her had towards Fort St James, pointing to the lake), cause there is hardly anyone with boats. Or skidoos.

Soh (robin), a gentle bird, hasn't had much experience with diabetes workshops. *Goozih*, gently nestled beside *Soh's* nest, asked *Soh* to talk about her experience with diabetes workshops, presentations, and/or other diabetes related educational materials, she replies, "I haven't really gone to any of those. That's what I would like to do is…to go to stuff like that so that I could know what to expect."

In an interview with *Tl'alhchooz* (hummingbird), she tells *Goozih*:

> I been to couple workshops but they're not real specific. Like I would like to know is, more, the prevention and the treatment if they do get diagnosed, and if they are diabetic, what do, what signs do we look for? I went to diabetic, ahh, I watch people come up here and do things with diabetic people, I like what they do, and we are allowed to ask questions. This is what we need for our reserves, so people can understand what they are dealing with.

Goozih asks *Tl'alhchooz*, "Describe what could change in diabetes education that would make it easier for you to understand?" She replies, "Pamphlets with pictures, actual pictures on it. The prevention, how they could prevent from becoming a diabetic. And pictures again when you are a diabetic. What to look out for, signs and symptoms, what could happen when diabetic gets out of hand". Before flying off *Tl'alhchooz* says in a soft voice and worried eyes:

> We need more education on this. Maybe a one-on-one with the ones that are diagnosed with being diabetic cause they don't know how dangerous it is to their health. Some think just cause they are taking medication or taking injections they will be ok. And alcohol is a big factor. They don't know how much sugar is in that, how much that alcohol that sugar takes, like what they need in their body it takes it away from them. People have to understand what they are dealing with, it should be made aware of the family members, so they know what to expect, what to do, if something goes wrong with them. Cause some people think that they are just drunk and they don't diagnose them right away and they just send them away.

Out in the deep forest, *Goozih* sees *Shas* (grizzly bear) sitting in a meadow. *Goozih* flies down and lands on *Shas'* shoulder and begins asking about the diabetes

educational tools. *Goozih* asks Shas about his experience with diabetes and *Shas* says:

> Nothing, I don't even see flyers around. There really is no, haven't really seen anything. Until when you started coming around with it. Never was a workshop on it, have never seen our staff even talk to members about it. Never seen a workshop or anything about diabetes. And people don't know if they have until it's too late. There's ways of preventing it, like staying healthy and eat properly to prevent from getting it. But you gotta teach people at a very very young age. Start teaching them about it. And they should be teaching about it in school with those little kids, right now.

When *Shas* has completed eating his mouth full of grass, *Goozih* asks *Shas* about how educational materials can be improved? Without hesitation, *Shas* says:

> ummm, I would say, slides, pictures. Ah, handout pictures with slide shows is always the best ways to learn. And use real people with diabetes for slide shows and movies and that. Have them talk about it. Like video people that have diabetes and how it affects them to have them to explain how it affects them. The things they have to go through to, the times they have to see doctors, and the cost of all these stuff too, and travel. All that

stuff they have to go through just because they did not eat healthy and that. Now they have to go through all these hurdles and that, just to live now.

4.4 Story (Theme) Three: Environmental Changes

In this section, *Tsi'balyan* presents stories *Goozih* gathered about perceptions of how changes in their environment affects their health and wellness.

Goozih looked at <u>*Nanghuz*</u> with disbelief about what was being shared. In our conversation, <u>*Nanghuz*</u>, who loves walking through the forest says:

> All of the clear-cutting, all of our wildlife needs to go further in to find food, and shelter and to be able to protect themselves from hunters. And, and all the clear-cutting, people stepped and drove all over our berries. So we have no, no way of going back to that same place to pick our berries. Even with our medicine, we can't find any of it anywhere because of that. Whether or not if we try to protect it, they always try to find ways to clear-cut here, and the space they left they clear-cut that the next day. So they will be clear-cutting all of our land. Whether we want them to or not. Then, regrowing back from the beginning, but you already lost all of the moose and all of the wildlife go further back in, and all the berries.

Swatting at some *dohgha* (moss) hanging from the tree, <u>*Nanghuz*</u> also says that she is "Getting worried about your plants and animals come back. Because it takes a

while for the trees to start growing back and things to start back again. Having all that and having no traditional foods and only have to eat the foods that are made. How you say that one? Have to eat store bought foods.

As *Goozih* is listening to <u>*Nanghuz*</u> tell her story, <u>*Datsancho*</u>, from the tree top says, "That kinda takes away from the animals their life, their home. Their food. It's like it disturbs their little life. Which kinda disturbs ours too. Because animals go a little further where is no clearcutting. Where there is no human activity. So that leaves us to travel further. It's just giving us a little more work, but that's ok."

During our conversation, <u>*Sus*</u>, as he looks into the forest states:

> Clear-cutting interferes a lot. Well even with the small insects, comes from the air right from the moose, cause, all the insects and all the animals, they live off of each other. They eat each other, like eat moose and stuff like that. But, like, bees and, birds, you know all that accesses the, grouse. There's nowhere for them to go. Cause this place, there is absolutely no trees around here man, holy cow. They took a lot of trees out. There is no moose around here no more.

<u>*Sus*</u>, looking into the distance continues on with his story:

> Yeah, well bear, well yeah, they took all of that. Those people they took, they cut it all down, they have no access to berries or anything around here.

They have to somewhere else. And there is a lot of bears around here, but, there, don't understand, where, how they get their berries and stuff. Ah, yeah, just so sad that all these trees are coming down and they're making more clear-cuts even closer man, looks like at 68, you see they are making a road in there. Obvious, it's obvious it's for logging. They're probably going to log in the winter. It's only time they build roads like that is close to winter, they don't work in summer time cause of days like this, it gets too muddy. So they like to work in the winter time. That's what I'm thinking, they are going to be hauling out more logs and gonna be that much more bare for us. And it takes a long time for trees to grow back too, even though they tree plant. Just so sad, and all this windfall, and stuff like that, and all this beetle kill too, that made all the tree falls. Makes it that much harder for the moose and bears and that to get around in the bush and stuff. Man it was hard, just yesterday we were looking around for that moose we were shooting at and climbing all over those trees, holy shit, it was fucking crazy man. My shirt man, my whole shirt was practically all wet from my sweat. Just climbing and crawling under, climbing under, and crawling over.

Drawing on the ground with his claws, *Sus* states:

Me, I was following where those moose they go. Cause they took out all the branches and stuff over the trees and stuff with their stomach I guess.

Yeah, that's where I was following them, but yeah, I can see them, they are really really struggling in there man. They are really struggling. Yeah, our animals are really dying off. Pretty near, they are end up moving somewhere else. Which they probably already are. Something will happen. Somewhere.

Sus also tells his story about when he was cub of the adventures and experiences he went on:

When we get a ride or somebody invites you with their truck or something, we can go hunting. But when I was younger, there was a guy who lives around here. […] used to, us we were just young little boys, I was about, at least 9 or 11 years old, he use to walk us way up those old trails back there. We used to walk up there. And we use to walk all the way up to Cunningham too. Have to walk all the way to Cunningham by this wagon road. He always used to walk us, walk us around to go hunting. We shot a moose once, we shot a deer once, we shot lots of grouse. But that was just the one times that we shot, that was the only time I remember shooting a moose and deer. All those times we walked, we never shot anything, but we always tried. They made us go with him too eh. Made us sandwiches out of his own house, and brought us juice, and stuff like that.

Yuzi (elk) also shares a story about when he was young about what the forest was like. He says, "Once when we had nice clean forest, our oxygen was a lot better. Animals were in a lot better condition than now. And was more." The air was once so clean for "singing, your lungs, in really good shape if you can sing for a really long time. And for, dancing, it's ahh, a good way of keeping your body in shape by the movements. All our elders use to do that eh. They use to have dance almost every night. They all stayed in good shape on account of it."

Tl'alhchooz, a good friend of *Yuzi*, says that "I am afraid of whatever they spray in the bush, like we cut down, we get the logs from the bush to dry our fish and our dry meat. Whatever we need to dry. And I am scared of what they put, what they spray in the bush and we pick up those wood from the bush. And a lot of times I think that maybe this is causing diabetic amongst our people."

On the other side of the river, *Goozih* meets up with *Shas* who provides a heartfelt story about his perceptions of clear-cutting:

> it affects us very bad because clear-cuts, when clear cuts are made, our animals leave. Not only does our wood leave, our animals leave also. So not only does it affect our animals, it affects our land also. It affects our berries, our plants, our air, it affects in every way. Cause the less, the more clear cuts we have the less animals we will have…to hunt. Because the animals

will go further and further away for food. And, they do not like it in the open because that is wolf territory, makes it easier access for wolves to get at them, and the grizzlies. So they don't stick around in this open any more. And with this global warming, it's just too hot for them to be in the open. And clear cuts, and with global warming and clear cuts, everything dies, just dries right up. And nothing, pretty much just grows back there. Except for mushrooms. So it affects us really really bad and it's one thing that we've always been fighting about here is clear cuts. We notice it every year that it's getting harder and harder to get our, our wildlife. Foods that we normally eat. And clear cuts also affects our fish big time, cause all that garbage, and all that from the clear cuts, the water, the rain water's got nowhere to run. It either flows into the streams or just dries up. The more clear cuts we get, the less water we get in the streams to.

When *Shas* goes hunting he says he has to travel by "Foot, on foot. By truck, by boat and motor, by quads, skidoos" [and] "each year we have to travel farther and farther. Like, the more clear cuts there is the further we have to go for, to get our moose or bear. Not only is that, our traditional foods, the more clear cuts there the further we have to go for everything." *Shas* expresses his concern about issues of having to depend on a vehicle for hunting, he says, "It affects us a lot because without it, we're not getting physical fitness we get out of it by exercising our lungs

and body when we sing and dance. So it affects us big time," and that, "Clear-cuts and forestry affects us big time, like I said, the more clear cuts there is, the further we have to go for our animals, therefore, if we can't get our animals, we have to go to Overwaitea and buy more canned meat and bologna. And smack-a-roni (macaroni)."

Soh, a mother, says that clear-cutting affects her "In a lot of ways" because "There's not much of anything around anymore. You can't go out hunting, you can't go out berry picking. It's hard to find stuff," and when she goes out hunting and gathering with her family, "You don't see any wild life like we use too. You don't. Use to be berries on the side of the road, now there's nothing. You have to go looking further in the bush for anything that you want" and the only way to hunt and gather is by "Vehicle. Cause now there is no trees or anything around, hardly that, you can't just go out and take a walk. Use to walk but now have to use a vehicle in order to get further into the bush and stuff."

While holding her babies under her wings, *Soh* states her concerns about clear-cutting and the future:

> is that the kids aren't getting enough of learning about their traditions. Not like it used to be. Because of everything that is going on. There is different stages of diabetes and the kids might get it early, and get it early

enough and the kids can't do anything like that. Now you can, they look forward to doing something else instead of going out and doing what they are supposed to. Like most of the kids get stuck to the TV or games, instead of going out and picking berries like we use to, or going fishing or going hunting

4.5 Conclusion

In this chapter, *Tsi'balyan* presented findings arising from analysis of *Goozih's* interviews. Based on the stories gathered, three main themes were identified: (1) Understanding their lived experience about diabetes; (2) Gaps in Diabetes Education; and, (3) environmental changes decreasing health and wellness. The Indigenous approach, was presented through stories as told by each participant. Each story contains a holistic representation of their perceptions of diabetes and environmental changes.

Chapter Five: Discussion, Recommendations, and Conclusions

In the final chapter of this thesis, *Tsi'balyan* presents an Eagle Eye view of the research as a whole, presented as four components. First, *Tsi'balyan* outlines a summary of the key findings and a discussion of the research. The second component provides recommendations for the community and future research. Next, the limitations of the research are discussed, for example, issues with traveling to the community. Lastly, the chapter ends with *Tsi'balyan's* conclusion of the research.

The 'Vision'.

Perched on the highest tree, I see people below who may be directly or indirectly affected by diabetes. If so, how can I help them understand how to prevent and/or manage diabetes? (Bianca Michell)

The vision (objective) of this study was to explore the perceptions, understanding, and beliefs about diabetes and diabetes education in the Dakelh community of Yekooche.

5.1 Summary of Key Findings and Discussion

First Nations perceptions about diabetes have not been adequately explored. There is only a small base of literature aimed at qualitatively explaining how First Nations understand and experience diabetes. Drawing from the conceptual framework, Two-Eyed Seeing, *Tsi'balyan's* goal with this research was to answer the

question: *What are the perceptions, understanding, and beliefs about diabetes of community members in Yekooche First Nation?* Specific objectives of this research were to: 1) to understand how First Nations define diabetes; 2) to explore Yekooche perceptions about diabetes; and 3) to examine their beliefs and understanding of diabetes education and diabetes education materials. Another key finding and discussion presented here include the insights into how culture and environment influences and clear-cutting influence Yekooche perceptions of diabetes.

5.1.1 Yekooche First Nation's definitions and perceptions of diabetes.

Tsi'balyan's sought to understand Yekooche member's definitions and perceptions of diabetes (Objective 1 and 2). Through use of semi-structured interviews, participants shared their understanding and experience of diabetes. The research found that Yekooche members understand diabetes from both a First Nations cultural and a western lens.

The findings presented in chapter 4 highlighted a variety of ways that Yekooche members perceive diabetes from a western lens. Participants talked about how diabetes physically effects the body and is caused by increased blood sugar levels. Members also refer to diabetes as a 'white man's disease.' The label, 'white man's disease,' refers to illnesses that were introduced in communities by settlers. Similarly, a study by Boston and colleagues (1997) explored Cree perspectives of diabetes and also found that the Cree attribute the causation of diabetes to the 'white

man'. Young et al. (2000) note that Aboriginals consider diabetes as a white man's illness or disease; a disease that was introduced to Aboriginal people, and this is similar to other communicable diseases such smallpox and tuberculosis.

Interestingly, participant's knowledge and experience with diabetes stems from knowing someone with diabetes. Participants learned that diabetics require medication and insulin injections through their friends and family members who are diabetics. Additionally, participants learned that diabetics have to watch their diet by eating less junk foods, drinking less pop, and consuming less calories and foods with starch.

5.1.2 First Nations perceptions of diabetes education materials.

Tsi'balyan also sought to explore Yekooche member's perceptions of diabetes education materials. Findings indicated that participants have little or no experience with diabetes workshops and diabetes education materials (Objective 2). Participants identified that more diabetes education would increase their knowledge about how to prevent and help their family and friends manage their diabetes. Additionally, having access to more diabetes related workshops would improve their knowledge about the effects of diabetes. A study by Gaudreau & Michaud (2012) had similar findings that there was little access to education resources and training sessions, for Algonquin women and a need for developing education resources relevant to their needs and culture (p. 143).

Findings also indicated to improve diabetes education materials the need to include more pictures and videos that share First Nations stories about living with the disease, and are more interactive materials, such as coloring books. Coloring books would make it easier to teach their children about diabetes prevention. In their study, Ho, Gittelsohn, Harris, & Ford (2006) had similar findings that, by teaching children about diabetes at an early age "could be an effective way to prevent diabetes" (p. 94).

5.1.3 First Nations perceptions of environmental changes.

Tsi'balyan also gained insights into how culture and environment may influence perceptions of diabetes. The First Nations Health Authority (nd), note that the environment is a vital component to First Nations health and well-being (para. 1), and that First Nations have an interconnected relationship with the land and environment for spiritual, physical, mental, and emotional health, and for their foods. The findings in this thesis demonstrated that changes in the environment, such as removal of trees in their traditional hunting and gathering areas is perceived to have effects on their health and wellness. As mentioned earlier, Yekooche hunt moose, bear, deer, and trap beaver and other small animals. Gathering medicines and berries are also vital to their health and wellness and preservation of culture. In their study, Young and colleagues (2000) note that changes from hunting and

gathering to consuming modern foods is believed to contribute to the causes of the diabetes epidemic.

While this thesis was focused on perceptions of diabetes, the findings demonstrated that participants perceive clear-cutting has directly affected their health and wellness. The term often used in their stories is clearcutting. Clearcutting means that *all* trees in a designated are cut (Canada, 2015). Parlee & Geertsema (2012), have similar findings, as in their study, they found that participants said they have noticed that there are noticeable changes in their wetlands, and issues for hunting as a result of clear-cutting.

Participants in *Goozih's* interviews perceived that, as a result of clearcutting, they have to travel further to hunt and gather. In their stories, participants say that traveling further is an issues because they do not have vehicles of their own, therefore are forced to buy store bought foods. Similarly, Roslin (1995) notes that as a result of clear-cutting, that there is less food, and much of the land is being raped.

Participants also perceive that clearcutting is changing the environment. In their stories, they say that berries no longer grow back in the areas that were clear-cut, birds die or move. Prior to hunting by traveling with motorized vehicle, hunting was done by walking, but with the removal of trees, wild game move

further from areas that are more difficult for hunters to access, and they have to use a motorized vehicle to hunt.

Chemicals from machinery seep into the ground contaminating the ground and surrounding watersheds, making fish sick. Their concerns about clearcutting are similar to Grassy Narrows First Nation, in northwestern Ontario. Leaders of the community state that clearcutting is affecting the animals and fish, and small lakes in their homeland (Jody Porter, June 17, 2015).

5.2 Recommendations and contributions from an Eagle's Eye View

Based on the results of this research, there are multiple suggestions and contributions and recommendations for future research and regarding First Nations perceptions about diabetes. Researchers and/or community members may use the results of this thesis to improve community knowledge about diabetes by increasing workshops within the community, and have up-to-date diabetes education materials at the health centre, school, and band office, and conceptual framework contributions.

Type 2 diabetes is increasingly being observed in First Nations children and starting at an early age (at home and school), teaching children to live a healthy lifestyle can decrease diabetes rates among First Nations children (Young et al., 2016).

It is important to develop culturally appropriate diabetes prevention and management programs in the community. Diabetes prevention programs would include traditional physical activity such as going for a walk in the forest and picking berries, and encouraging people to eat more traditional foods. Diabetes management programs to teach how to cook traditional foods without cooking oil and replacing rice with potatoes from their community garden foods. In addition, having programs that increase physical activity, such as walking in the gym and going for walks on trails located near the community would help. Diabetes management programs would also include increasing knowledge about diabetes medication.

Future research should be directed towards further understanding of how clearcutting effects the health and wellbeing of First Nations people. Engage community members, specifically hunters and gatherers, and those who fish.

Lastly, conceptually, the findings from this research have contributed to improved understanding of the relationship between Western science and Traditional knowledge within disease knowledge. Based on study, *Tsi'balyan* found the Yekooche First Nations perceive disease from a Western and Indigenous lens. As mentioned in chapter 2, according to Jennings (1986) there is a difference between disease and illness - disease is objective and illness subjective.

5.3 Limitations of the Research: Eagle's Eye View

There were multiple limitations in this research. These limitations included the challenge of travel to the community, space for interviews, recruitment, and funding. Yekooche is located approximately 240kms from Prince George and traveling on the forestry road is risky as the forestry road is active with logging trucks, and during one trip to Yekooche, the road had a washout and giant potholes which caused me to do a 360 degree turn, and during the summer, there were times I traveled and there was low visibility due to excess dust.

Interviews were conducted at the community school and in a trailer available for visitors. Access to locations were dependent on the availability of space and time of day. The limitation was background noise during the interviews because both locations are public and have multiple uses – many people access both locations.

Another limitation was recruitment. Regardless of distributing flyers handed out to each home, at the band office, school, and health centre, Yekooche members were still unaware of the research. In future research, information sessions with food and snacks to recruit participants would be useful.

Also, funding for the research was limited. Funding for travel to the community was limited. As a result, I was only able to go to Yekooche a few times for recruitment and interviews. I was able to attend Yekooche five times.

In any research, the student or researcher needs to be aware of and responsive to changes that can interfere with the study. In this study, there were health related issues in the community that caused a delay in the research, and a need to adapt and adjust research timelines.

The final limitation is undertaking the conceptual lens of Two-Eyed Seeing. It was difficult to write this thesis that includes western knowledge about diabetes and incorporating an Indigenous approach of writing this thesis in a story form.

Though there were challenges in this study, I am honored to have had the opportunity to study perceptions of Yekooche members. This study allowed me to gain research experience, build a relationship with the community, and conduct this study using Indigenous and Western knowledge.

5.4 Concluding Remarks

In summary, this research presented stories of Yekooche First Nation's member's perceptions of diabetes. The aim of this thesis was to better understand First Nations perceptions of diabetes. This research demonstrated that First Nations perceptions of diabetes are influenced by both Western science and their traditional knowledge. *Tsi'balyan* in this thesis examined Yekooche member's perceptions of diabetes because Yekooche is a community with strong cultural knowledge, who

want to continue to hunt and gather their traditional foods, and live in a unique cultural environment.

This research empowered the voices of First Nations voices through storytelling and health. This work has demonstrated the importance of bridging First Nations perceptions about diabetes, learning about First Nations understanding about health and wellness through storytelling, and the importance of conducting research that benefits Indigenous people.

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Appendix

Appendix A: Yekooche First Nations Study Approval

YEKOOCHE FIRST NATION

Finance Office
1890 Third Avenue
Prince George, BC V2M 1G4
Ph: (250) 562-0592
Fax: (250) 562-0530

Band Office
Ph: (250) 649-2044 ext. 8044
Fax: (250) 649-2031
www.yekooche.com

November 25, 2015

To Bianca Michell,

We have received your request for permission to conduct research in Yekooche for your diabetes project. Chief and Council fully supports your pursuit of a graduate degree in the Health Science Program at the University of Northern British Columbia. Therefore we are granting your request to conduct interviews in the community to further your research project. We look forward to receiving a copy of the final report.

Mussi,

Chief Allen Joseph

Councillor Vanessa Joseph

Councillor Mary Jean Thomas

Councillor Mathew Joseph

Appendix B: Ethics Approval

UNIVERSITY OF NORTHERN BRITISH COLUMBIA

RESEARCH ETHICS BOARD

MEMORANDUM

To: Bianca Michell
CC: Margot Parkes,
Henry Harder

From: Paul Siakaluk, Acting Chair
Research Ethics Board

Date: May 11, 2017

Re: **E2015.1116.107.01**
An eagle's view: Perspectives about diabetes in Yekooche First Nation, a First Nation's community in northern British Columbia

Thank you for submitting a request for renewal to the Research Ethics Board (REB) regarding the above-noted proposal. Your request has been approved.

We are pleased to issue renewal approval for the above named study for a period of 12 months from the date of this letter. Continuation beyond that date will require further review and renewal of REB approval. Any changes or amendments to the protocol or consent form must be approved by the REB.

Good luck with continuation of your research.

Sincerely,

for: Dr. Paul Siakaluk
Acting Chair, Research Ethics Board