Diabetes in The St. Regis Mohawk:
An Ethnography

by

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Abstract

Type II diabetes is viewed by researchers as an epidemic within the American Indian population. Adult American Indians are 2.3 times more likely to be diagnosed with Type II diabetes as compared to non-Hispanic whites. Although many studies previously addressed this topic as it relates to the incidence, prevalence, and risk factors in the American Indian population, few studies to date were found that explored the American Indian’s perception of diabetes, and their health care management practices as it relates to culture. The purpose of this ethnographical study was to explore, describe, and understand how American Indians the St Regis Mohawk Tribe perceive and manage Type II diabetes. The primary research question examined how culture influences health maintenance and management of Type II diabetes among the Mohawk American Indians. Utilizing ethnographical methodology, the sample was 15 participants from the St Regis Mohawk Tribe in Akwesasne, New York. The primary data source was the interview using open-ended questions in face-to-face personal interviews. The data analysis and findings of the study resulted in the identification of five major themes relevant to the topic and research questions: (a) It’s like the whole reservation is diabetic, (b) Everything I am going through is brand new, (c) Feeling like you are sinking in quicksand, (d) Breaking the cycle, and (e) Keeping the circle strong. The findings of this research study offered fresh understanding of the daily challenges faced by American Indian people living with Type 2 diabetes.
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Chapter 1: Introduction

For many years, Type II diabetes was viewed by researchers as an epidemic within the American Indian population (Barton, 2005; Berry, 2009; Jacobs, 2014; Lee, 2002; Tiedt, 2013). According to Indian Health Service (IHS, 2012), adult American Indians are 2.3 times more likely to be diagnosed with type II diabetes as compared to non-Hispanic whites (16.1% vs. 7.1%, 2009). In recent years, researchers referred to Type II diabetes as a national epidemic that impacts different cultural and ethnic groups within the U.S (Abate & Chandalia, 2003; Carnethon, 2008). The disease is 1.5 to 20 times more apt to impact Hispanic/Latinos, Asians, African Americans, and American Indian populations, with diabetes ranking highest among American Indians at 33% (Spanakis, 2013).

Chapter I is a presentation of the proposed study entitled, Type II Diabetes in the St. Regis Mohawk American Indians: An Ethnography Study. Although many studies previously addressed this topic as it relates to the incidence, prevalence, and risk factors relevant to the American Indian, few studies to date were found that explored the American Indian perception of diabetes, how they manage their disease; and identified the health care practices they use for successful management.

This chapter begins with a brief introduction followed by a discussion of the following headings: Background of the Problem, Problem Statement, Purpose Statement, Nature of the Study, Significance of the Study, Conceptual Framework, and Operational Definitions.

**Background of the Problem**

According to The Centers for Disease Control and Prevention (2015), approximately 29.1 million people or 9.3% of the U.S. population have diabetes. In 2012, estimates of U.S. population over age 20 with prediabetes had reached 86 million, while those under the age of 20 years with a diagnosis of either type 1 or type 2 diabetes were about 208,000 (Centers for Disease Control and Prevention, 2016).
Research has indicated that the epidemic of type 2 diabetes has impacted different cultural and ethnic groups within the U.S. Hispanic/Latino, Asian, African, and Native-American populations are 1.5 to 20 times more apt to have type 2 diabetes (Carnethon, 2008). In fact, diabetes prevalence is ranked highest among American Indians (33%), with Non-Hispanic Blacks at 12.6%, Hispanic Americans at 11.8%, Asian Americans at 8.4%, and Non-Hispanic Whites at 7.1% (Spanakis, 2013).

The Indian Health Service of 2010 U.S. census reported a population of 2.9 million American Indians from 567 federally recognized tribes. Within this population, adult American Indians are 2.3 times more likely to be diagnosed with type 2 diabetes as compared to non-Hispanic whites (16.1% vs. 7.1% 2009) (IHS, 2012). In fact, the American Indian death rate due to diabetes is 1.6 times higher than the U.S. population (34.5 vs. 21.8 per 100,000 in 2008) (IHS, 2012). McLaughlin (2010) reports Type 2 diabetes was the fourth leading cause of death in American Indians in 2009.

In the general population, complications arising from diabetes are rampant in the American Indian population (O’Connell, 2010). These complications are important because they cause considerable burden not only in quality of life, but also in the high rates of morbidity and mortality. Howard (1999) and Resnick (2004) both acknowledge that the risk of comorbidities increases with the development of diabetes, and more importantly, diabetes in the presence of additional risk factors such as obesity, smoking and high glycemic levels. The magnitude of these complications in the American Indian population is enormous. The risk for cardiovascular disease is 3-8 times that of the general population, with the risk for heart disease and stroke 2-4 times that of the general population (IHS, 2012). In addition, comorbidities complicate diabetic treatment, substantially influencing the individual’s ability to manage the disease, and decreasing quality of life (O’Connell, 2010).
O’Connell (2010) also documented a higher prevalence of comorbidities as compared to U.S. adults with diabetes. The overall prevalence rate for hypertension among American Indian diabetics was 61.2% as compared to 31.5% for U.S adults with diabetes. Cerebrovascular disease was 6.9% as compared to 5.5%, renal failure 3.9% as compared to 2.3%, neuropathy 16.8% as compare to 7.6%, liver disease 7.1% as compared to 3.4%, mental health disorders 19.2% vs 10.4%, and lower limb amputations were 1.8% as compared to 0.1 (O’Connell, 2010, p 1466-67).

Type 2 diabetes is not just a disease of adult American Indians but also increasing in children. In the span between the years 1990 and 2009, type 2 diabetes in American Indian youth between ages 15 and 19 rose 110% (3.24 vs. 6.81 per 1,000) (Indian Health Service, 2012). The Center for Disease Control predicts that without a change in life patterns, one in two American Indian children will develop Diabetes Type 2 within their lifetime (Naranyan, 2003). In a study aimed at determining diabetes prevalence among American Indian and Alaska Native young people, Acton (2002), noted that within an 8-year span, there was a significant increase in the diagnosis of diabetes (71%), and stressed that diabetes should be considered a public health threat in this population. Acton (2002) noted that young people with diabetes will be at increased risk for the development of diabetes related complications at a much earlier time in their life, as well as increased disease burden.

Diabetes and cultural diversity are linked together. Given its prevalence among various ethnic groups, it is important to have an understanding of cultural practices and values, and very appropriate to consider what constitutes traditional (non-Western) medicine and healing (Heisler, 2006; Schoenberg, 2008). Hill (2003) discovered that both traditional medicine and knowledge are connected to one’s lifestyle, and would include nutrition, and physical, spiritual and emotional views and behaviors. Malloch (1989) comments on traditional health teachings based on the tenet that illness is prevented by
maintaining a balance between physical, emotional, spiritual, and mental elements, and a traditional healthful lifestyle. Colomedia and Wenzel (2000) argued that good health for Indigenous people involves traditional activities such as ceremonies, language, songs, listening to elders, beliefs and healing practices, and values, all handed down generationally.

Previous studies suggested various beliefs regarding diabetes. These beliefs impact diabetes management. These encompass circumstances that brought about diabetes, diabetes treatment, medications, and lifestyle changes. Boston’s (1997) study of the Cree found them to view diabetes as a white man’s disease, while Satterfield’s (2003) participants felt an “American lifestyle”, stress, family history, and poor eating habits were issues causing the disease. Mohawk and Cree people in Ontario felt diabetes was caused by an imbalance in lifestyle and Western habits (Cosby 1996), and Jacob’s study (2014) of the Lumbee Indians in the southern U.S. noted a belief that genetics and lifestyle, as well as predestiny were behind the disease.

In looking at beliefs regarding diabetes treatment, many felt confused and torn between Western medicine and traditional healing. In a study of First Nations people in Hamilton, Ontario, a central theme noted was that of juggling two worlds. Boston’s (1997) study referred to it as tension related to modern medicine and “the old ways”. The Haida of British Columbia felt drawn to traditional ways of gathering and medicine (Grams, 1996), while the Nuxalk also in British Columbia used both western and traditional medicines.

When looking at lifestyle interventions, a combination of socioeconomic factors and culture are noted. Boston (1997) found limited understanding of the appropriate foods to eat, as well as limited access to obtain them. Also, while traditional foods might be desired, there was no game availability. Grams (1996) observed the importance of food in cultural gatherings and ceremonies, while Tiedt (2013)
suggested dietary restrictions limited the ability to take part in ceremonies. Satterfield (2003) found participants citing lack of time for cooking meals, lack of access to fresh foods, and no time to exercise.

**Problem Statement**

Within specific ethnic populations, American Indians have the distinction of having the highest diabetes incidence and prevalence over all, and it continues to be on the rise. The American Indian death rate due to diabetes is 1.6 times higher than the U.S. population (34.5 vs. 21.8 per 100,000 in 2008), and new cases of kidney failure related to diabetes in this population are 1.9 times higher than the general population (33.3 vs. 15.3 per 100,000 also in 2008) (Indian Health Service, 2012). Type 2 diabetes was the fourth leading cause of death in American Indians in 2009 (McLaughlin, 2010).

Although many studies previously addressed this topic as it relates to the incidence, prevalence, and risk factors relevant to the American Indian, there is limited knowledge on how American Indians address and manage their diabetes, as well as how big a part culture plays in this management. Few studies to date have explored the American Indian perception of diabetes, how they manage their disease; and identify what health care practices they use for successful management. Qualitative studies have been done with American Indians and diabetes in the mid to western parts of the U.S: however, there is a research gap on how Eastern tribes describe and manage their diabetes within the context of their specific culture.

**Purpose Statement**

The purpose of this ethnographic study was to explore, describe, and understand how American Indians from the St Regis Mohawk Tribe perceive and manage Type II diabetes. The aim was to understand how Mohawk culture affects adjustment and acceptance to a life with diabetes, as well as the interventions associated with diabetic care from a Mohawk perspective.
Significance of the Study

This study is significant both personally and professionally to address the problem facing American Indians in the management and care of Type II diabetes. American Indians fit into the high-risk category for acquiring diabetes given the risk factors of family genetics, and their propensity for inactivity and obesity. Additionally, American Indian children are also developing the disease at an earlier age also. Cardiovascular disease, hypertension, and hyperlipidemia play a part in the development of diabetes, and American Indians experience these issues (O’Connell, 2010). These diseases decrease their quality of life and place an economic burden on both themselves and their families.

With regard to the nursing profession, this study is significant as a major step to address the challenges the American Indian face with the progression of Type II diabetes. The results of the study will provide insight for improving care and management for adults living with Type II diabetes. In practice, nurses have a vital role in the initial management of Type 2 diabetes in primary care, which is largely directed towards assisting patients to understand the nature of the disease and become self-managers. As a healthcare professional, the ultimate aim is to be able to provide guidance and culturally specific diabetes education for fostering change in the care of the American Indian.

The findings of this research study will add to the present body of nursing knowledge regarding American Indian people living with Type 2 diabetes. It will provide cultural relevance and assist in the ongoing development of new strategies designed to increase positive outcomes for diabetes prevention and management. It will offer fresh understanding of the daily challenges faced by those American Indian people living with diabetes, thereby enabling nursing to respond in culturally appropriate ways of knowing that can promote an atmosphere of healing and hope, with meaningful, insightful care.
Nature of the Study

The design of the ethnographic study focused on the American Indian St Regis Mohawk experience and perception of Type II diabetes. Ethnography is a qualitative research method that allows actual participation in the daily routines of participants. Focused ethnography examines a specific problem contextually within a smaller group of people. The sample for this research was largely purposive in nature. However, snowball sampling and active solicitation was employed. Fifteen enrolled members of the St Regis Mohawk Tribe, living either on or off the reservation, were interviewed.

Research Questions

1. How do the members of the St Regis Mohawk Tribe living with Type II diabetics define and describe the disease?

2. What cultural factors influence the health maintenance and management of Type II diabetics among the American Indian Mohawk?

Conceptual Framework

Leininger’s Culture Care Theory will provide the conceptual framework for the present study. The central focus of the Culture Care Theory is the discovery and explanation of specific cultural factors that influence the health, wellbeing, illness, and death of individuals and groups (Leininger, 2002). The theory will be used in the present study to understand and explain care that is culturally relevant, safe, and advantageous to people of diverse cultures with a focus on promoting health, well-being, and healing (Leininger, 2006).
Leininger (2002) identified the importance of an accurate understanding of culture as it relates to the planning and implementation of nursing care. This care must correspond to and have meaning in the individual’s cultural beliefs, traditions, and principles. This linking of culture and care promotes compliance to prescribed therapies, the possibility of healing and restoration, and cultivates an ongoing desire for wellness (Leininger, 2006). In summary, the basic assumptions of Culture Care Theory proposed by Leininger are the following:

- Individual’s health care practices, cultural care values and beliefs, religious and spiritual practices, language and social attitudes shape their worldview

- Beneficial for interventions, education, and nursing care to be patterned around the client’s culture

- Lack of cultural sensitivity can cause stress, conflict, and noncompliance.

The Culture Care theory as well as the accompanying Sunrise Enabler could assist the researcher in framing the research question, and provide an outline for creating tools to gather data. The use of the Sunrise Enabler, by its very design, will also facilitate the categorizing, describing, and detailing of Mohawk responses to both their diabetes and the provided interventions at the Diabetes Center. This in turn will enable the researcher to look at differences and commonalities, barriers and facilitators, as well as worldview specifics in order to evaluate the overall efficacy of care provided, as well as tell the diabetes story of the Mohawks of Akwesasne. A detailed discussion of the theories are presented in Chapter II Literature Review.

Operational Definitions
Cultural Practices: Values, beliefs and ways of life of a particular group that guide thinking, reasoning, judgments, and actions (Leininger, 2002)

Culture Care Theory: The basic assumption of the Culture Care Theory is that an individual’s health care practices, cultural care values and beliefs, religious and spiritual viewpoints, language, and social attitudes shape the worldview of the individual cared for (Clarke et al, 2009)

Diabetes management: Programming and interventions designed to assist in the management of diabetes. This could include education, diet counseling, medication, fitness, support groups.

Diabetes: A chronic disease that occurs when the body is unable to produce and/or utilize insulin. Classified as Type 1 (failure of the pancreas to actually produce the insulin) and Type 2

American Indian: The people living in the Western hemisphere prior to the arrival of the European settlers. These can also be referred to as aboriginal, indigenous, and First Nations. Among these, the Mohawk Tribe is the most eastern tribe of the Iroquois Confederacy (Six Nations) and is located in the Northeastern portion of New York. (St Regis Mohawk Tribe, 2014)

The Indian Health Service (IHS): A federally funded agency within the Department of Health and Human Service that provide health care assistance to approximately 2 million American Indians belonging to federally recognized tribes (Sequist, 2011).

Type II Diabetes: A lifelong (chronic) disease in which there is a high level of sugar (glucose) in the blood. Type 2 diabetes is the most common form of diabetes. Body cells become resistant to insulin resulting in a high level of glucose in the blood. This is usually seen in people over the age of 40, who are overweight, and have a history of diabetes in their family.

Assumptions and Limitations
Based on the nature of the study, it can be assumed that the participants’ responses to the interview questions will reflect honesty and thoughtfulness. It is further assumed that the sample represents the St. Regis Mohawk American Indians population with Type II diabetes. Geographically, data collection will be conducted within the St Regis Mohawk Tribe in Akwesasne, New York. As such, findings may not generalize to other American Indian regions throughout the United States.

Summary

Chapter 1 provided a summary of the study of Type II Diabetes in the St. Regis Mohawk American Indians. The statement of the problem, purpose of the study, significance of the study, and the research questions were presented. Chapter 2 that follows is the review of the literature. The focus of Chapter 2 is a review of peer-reviewed journals on the selected topic of this study.
Chapter II: Literature Review

The purpose of this ethnographic study is to explore, describe, and understand how American Indians from the St Regis Mohawk Tribe perceive and manage Type II diabetes. The aim is to understand how Mohawk culture affects adjustment and acceptance to a life with diabetes, as well as the interventions associated with diabetic care from a Mohawk perspective. Chapter II provides a review of the literature on the topic of Type II Diabetes in The St. Regis Mohawk American Indians.

The literature review presents a collection of information gathered from peer reviewed journal articles, books, and dissertations. Multiple electronic databases were used which included ProQuest, Google Scholar, and Medline. Key search terms and combinations of search included but not limited to the following: Type II diabetes, American Indians, Type II Diabetes management, Indian Cultural Tradition in Diabetes Management, and St. Regis Mohawk American Indians.

Type II Diabetes

According to The Centers for Disease Control and Prevention (2015), approximately 29.1 million people or 9.3% of the U.S. population have diabetes. To further support epidemic concerns, of this number, 21 million are actually diagnosed, and 8.1 million people or 27.8% of the population remain undiagnosed. In 2012, estimates of U.S. population over age 20 with prediabetes had reached 86 million, while those under the age of 20 years with a diagnosis of either type 1 or type 2 diabetes were about 208,000 (Centers for Disease Control and Prevention, 2016). Clearly, diabetes is an ongoing issue, with one study predicting as many as one in three adults in the U.S. with diabetes by the year 2050 (Boyle, 2010).
Diabetes and Cultural Diversity

Diabetes and cultural diversity are linked together. Given its prevalence among various ethnic groups, it is important to have an understanding of cultural practices and values, and very appropriate to consider what constitutes traditional (non-Western) medicine and healing (Heisler, 2006; Schoenberg, 2008). Defining these terms will allow the construction of a baseline of understanding that can provide assistance in framing the differences in Western and traditional medicine (Hill, 2009). The World Health Organization (WHO), defined “traditional medicine” as:

The sum total of knowledge, skills, and practices based on the theories, beliefs, and experiences Indigenous to different cultures, whether explicable or not, used in the maintenance of health as well as in the prevention, diagnosis, improvement of treatment of physical and mental illness (WHO, 2017, para 2)

Canada, Hill (2003), discovered that both traditional medicine and knowledge are connected to one’s lifestyle, and would include nutrition, and physical, spiritual and emotional views and behaviors. In an interesting interview conducted during the research, one respondent commented that “a smile or words of encouragement” can be good medicine, noting that Elder views of healing encompass interventions that look to prevent illness and change lifestyle, and are not necessarily ceremonial or curative (Hill, 2003).

In a study highlighting the role of elders in traditional medicine and healing, Malloch (1989) comments on traditional health teachings based on the tenet that illness is prevented by maintaining a balance between physical, emotional, spiritual, and mental elements, and a traditional healthful lifestyle. Elders in this study were also cognizant of the necessity of Western medicine, but stressed the need for all Aboriginal people to maintain their culture and traditional medicines. This is supported in
the work of Colomedia and Wenzel (2000) who argued that good health for Indigenous people involves traditional activities such as ceremonies, language, songs, listening to elders, beliefs and healing practices, and values, all handed down generationally.

In examining the provision of diabetes care to the American Indian population, it cannot be assumed that Western based diabetes management interventions will automatically be successful. Many American Indian communities preserve their traditional views of health and illness, choosing to combine their cultural values with that of Western medicine (Malloch, 1989; Waldram, 2005). Thus, it is important to have an understanding of how American Indians feel about life with diabetes, how they came to have it, and its treatment.

Previous studies have shown various beliefs regarding diabetes. These beliefs impact diabetes management. These encompass circumstances that brought about diabetes, diabetes treatment, medications, and lifestyle changes. Boston’s (1997) study of the Cree found them to view diabetes as a white man’s disease, while Satterfield’s (2003) participants felt an “American lifestyle”, stress, family history, and poor eating habits were issues causing the disease. Mohawk and Cree people in Ontario felt diabetes was caused by an imbalance in lifestyle and Western habits (Cosby 1996), and Jacob’s study (2014) of the Lumbee Indians in the southern U.S. noted a belief that genetics and lifestyle, as well as predestiny were behind the disease. Participants in Manitoba (Cree) saw diabetes as an all present and powerful disease that everyone has (Gregory, 1999). In spite of the varying beliefs regarding diabetes etiology, a common thread in most respondents appears to be lifestyle and genetics.

In looking at beliefs regarding diabetes treatment, many felt confused and torn between Western medicine and traditional healing. In a study of First Nations people in Hamilton, Ontario, a central theme noted was that of juggling two worlds. Boston’s (1997) study referred to it as tension
related to modern medicine and “the old ways”. The Haida of British Columbia felt drawn to traditional ways of gathering and medicine (Grams, 1996), while the Nuxalk also in British Columbia used both western and traditional medicines. However, they were more drawn to medicine plants and ceremonies. They were hesitant to give up their traditional diet, and less understanding of how Western medicine worked. Similarly, in a study of Lakota and Winnebago Indians in the Midwest, Struthers (2003) found the use of traditional ways achieved balance. Most felt that traditional ways improved outcomes. Prayer, medicine men and healing dreams were also discussed by these same participants.

When looking at lifestyle interventions, a combination of socioeconomic factors and culture are noted. Boston (1997) found limited understanding of the appropriate foods to eat, as well as limited access to obtain them. Also, while traditional foods might be desired, there was no game availability. Grams (1996) observed the importance of food in cultural gatherings and ceremonies, while Tiedt (2013) suggested dietary restrictions limited the ability to take part in ceremonies. Satterfield (2003) found participants citing lack of time for cooking meals, lack of access to fresh foods, and no time to exercise.

Type 2 Diabetes in American Indians

McLaughlin (2010) reported that the rate of diagnosed diabetes in the Pima Indians of Arizona to be 50%, the highest rate of diabetes in the world. The American Indian death rate due to diabetes is 1.6 times higher than the U.S. population (34.5 vs. 21.8 per 100,000 in 2008), and new cases of kidney failure related to diabetes in this population are 1.9 times higher than the general population (33.3 vs. 15.3 per 100,000 also in 2008) (Indian Health Service, 2012). Type 2 diabetes was the fourth leading cause of death in American Indians in 2009 (McLaughlin, 2010). In this discussion of statistics, it is important to note that the above numbers may not be a true representation of the prevalence and incidence of diabetes in this population.
Historically studies have indicated the under diagnosing of diabetes (for every two diagnoses, there is one undiagnosed) (Harris, 1998; Lee, 1995; Will, 1997). One reason for this is that data can only capture issues identified from health visits. If there is no visit during the time data is collected, it is not captured. Incomplete or non-reporting and underreported census counts round out possible limitations in data desired (Burrows, 2000). Acton (2002) supports this limitation in census counts noting that census does not account for movement of individuals between HIS and tribal health clinics between census collection years.

Complications arising from diabetes are rampant in the American Indian population (O’Connell, 2010). These complications are important because they cause considerable burden not only in quality of life, but also in the high rates of morbidity and mortality. Howard (1999) and Resnick (2004) both acknowledge that the risk of comorbidities increases with the development of diabetes, and more importantly, diabetes in the presence of additional risk factors such as obesity, smoking and high glycemic levels. The magnitude of these complications in the American Indian population is enormous. The risk for cardiovascular disease is 3-8 times that of the general population, with the risk for heart disease and stroke 2-4 times that of the general population (Indian Health Service, 2012). In addition, comorbidities complicate diabetic treatment, substantially influence the individual’s ability to manage the disease, and decrease quality of life (O’Connell, 2010).

In a study of American Indian adults living in Arizona, O’Connell (2010) documented a higher prevalence of comorbidities as compared to U.S. adults with diabetes. The overall prevalence rate for hypertension among American Indian diabetics was 61.2% as compared to 31.5% for U.S adults with diabetes. Cerebrovascular disease was 6.9% as compared to 5.5%, renal failure 3.9% as compared to 2.3%, neuropathy 16.8% as compare to 7.6%, liver disease 7.1% as compared to 3.4%, mental health
disorders 19.2% vs 10.4%, and lower limb amputations were 1.8% as compared to 0.1 (O’Connell, 2010, p 1466-67). In fact, O’Connell (2010) also noted that not only was the morbidity burden in American Indian adult diabetics 50% higher than that than of U.S. diabetic adults, but they would use 50% more health resources than their U.S. counterparts (p1468).

Earlier findings were conducted under the umbrella of the Strong Heart Study, a longitudinal study of cardiovascular disease and its risk factors among American Indians (Howard, 1999; Resnick, 2004; Wang, 2010). The Strong Heart Study, an ongoing longitudinal study that examined risk factors among 13 American Indian tribes was based in Oklahoma, Arizona, and North and South Dakota with over 4500 participants. Initially the phases looked at cardiovascular disease morbidity and mortality. It has since been expanded to include whole families and to examine genetic factors that are linked to cardiovascular disease and its risk factors, diabetes being one of them. It is hoped that the information obtained from this study can assist in the development of treatment and prevention strategies in a population with rising rates of obesity, diabetes and cardiovascular disease (The Center for American Indian Health Research, N.D.)

**Type 2 Diabetes in Children**

Type 2 diabetes is not just a disease of adult American Indians but also increasing in children. In the span between the years 1990 and 2009, type 2 diabetes in American Indian youth between ages 15 and 19 rose 110% (3.24 vs. 6.81 per 1,000) (Indian Health Service, 2012). The Center for Disease Control predicts that without a change in life patterns, one in two American Indian children will develop Diabetes Type 2 within their lifetime (Narayan, 2003). In a study aimed at determining diabetes prevalence among American Indian and Alaska Native young people, Acton (2002), noted that within an 8-year span, there was a significant increase in the diagnosis of diabetes (71%), and stressed that diabetes should be
considered a public health threat in this population. Acton (2002) noted that young people with diabetes will be at increased risk for the development of diabetes related complications at a much earlier time in their life, as well as increased disease burden.

Aforementioned, Type 2 diabetes is a disease that can be controlled by outside factors. These outside elements translate into circumstances that elevate one’s risk for type 2 diabetes. In a recent study related to prediabetes, Phillips (2014) makes an interesting but true observation. Along with referring to diabetes as an epidemic, affecting 11% of U.S. adults and 27% of those over 65, he notes the majority of cases are diabetes type 2. He also links it with “the success of society” (p2668). People live longer, eat more than needed, and do not stay active. Thus, increasing age, obesity, and inactivity are all outside or risk factors for diabetes type 2. This increases insulin resistance, and the body cannot compensate (Phillips, 2014).

These outside factors play an important role in the development of diabetes in the American Indian population. Cobb (2104) found American Indian men and women reported less physical activity than their White counterparts with 27.2% of American Indian men and 31.8 % of American Indian women responding that they have no leisure time activity. This compares with 18.0% White males and 20.8% White females answering the same question. In addition, American Indians had a higher prevalence of obesity than white men and women – 33.9% vs 23.3% for men and 35.5% vs 21% for women, as well as a higher prevalence of hypertension in both sexes in relation to White people (Cobb, 2014). Diet continues to play a role in the development of disease. American Indian diets have changed drastically over the last century, as traditional hunting, fishing and farming has been replaced by high calorie high fat subsidized food, fast food, and generalized American eating. Cobb (2014) also observes that few American Indian communities do not report metabolic syndrome that would include central
adiposity, elevated cholesterol, and insulin sensitivity (p. s487). Additional risk factors include immediate family members with diabetes, being of African American, Alaska Native, American Indian, Asian American, Hispanic/Latino, or Pacific Island descent, giving birth to a baby over 9 pounds or having gestational diabetes, treatment of hypertension, the presence of cardiovascular disease, HDL below 35 and triglycerides greater than 250 (NIDDK, n.d.).

**Diabetes in the Mohawk Tribe.**

St Regis Mohawk Reservation in Akwesasne, New York lies approximately 200 miles north of Albany, New York, and is bisected by both the US/Canadian border and the St Lawrence River (Cook, 2015). According to the Mohawk Council of Akwesasne (2017), the total population on the Canadian side of the reservation approximates 12,000 people, while the St Regis Mohawk Tribe claims approximately 11,000 on the American side. Additionally, 1,800 Mohawks are presently living off the reserve. Within the reserve, the undisputed land based amounts to 26,359 acres, with roughly 14,700 acres on the American side and 12,000 acres located in Canada (Mohawk Council of Akwesasne, 2017). Given the division of the reserve by international borders, there are two separate governing bodies. The Mohawk Council of Akwesasne is responsible for the Canadian portion, while the St Regis Mohawk Tribal Council governs the American side. The Mohawk Nation Council of Chiefs unites both Canadian and American councils into the one Mohawk Nation. Each of the separate councils is responsible for specific programming for their people. This includes medical, mental health and dental care, education, social services, tribal police, finance, economic development, and office of aging. Medical services for the American side are provided by a health clinic funded by Indian Health Service, New York State Department of Health, OASIS, and tribal monies (St Regis Mohawk Tribe, N.D.). The Canadian medical clinic is funded by the Canadian government and tribal monies.
The federally recognized St Regis Mohawk Tribe of Northern New York is served by the IHS Nashville administrative region. Within that region, the 2014 diabetes prevalence rate was 23% as compared to 12% in the total IHS population. This ranked the Nashville region as having the third highest diabetes prevalence rate of the 12 IHS areas (United South and Eastern Tribes, 2014). The Nashville region continues to struggle with diabetes control (United South and Eastern Tribes, 2014).

Other Nashville region demographics include but are not limited to the following: 61% age 65 and older diagnosed with diabetes, 41% age 45-64 diagnosed with diabetes, 15% ages 20-44 diagnosed with diabetes, 1% age less than 20 diagnosed with diabetes, and 20% females 17% males diagnosed with diabetes (United South and Eastern Tribes, 2014).

The St Regis Mohawk tribe is in receipt of grant funding from the Special Diabetes Program for Indians (SDPI) for diabetic programs and has been conducting diabetes programming for a number of years. Their area of focus is the Diabetes Prevention Program and the Healthy Heart Program, targeting diabetes, and cardiovascular disease risk reduction through a series of interventions directed at lifestyle changes. Areas of focus include case management, nutrition counseling by a registered dietician, and a personalized physical activity regime established by certified trainers. Access to this programming is done through the tribal health center. There are no restrictions on participants other than health clearance through the medical provider at the clinic.

Physical access is safe, with ample parking, clear sidewalks, and a bright, well lit gym. Once clearance is obtained, participants meet with a case manager and a trainer to establish a fitness and nutritional plan. A schedule is established for visits during the week, and their progress is monitored over time. A nurse educator and a trainer are present during fitness room activity to ensure safety and
healthy exercise. Prior to and after exercise, BP and blood glucose readings are obtained and recorded. Evaluations are done every 6 months to monitor progress.

Diabetes Management

The American Diabetes Association provides standards of care related to diabetes management in the general population. This consists of evidence-based practice supported by current research that can assist medical personnel in the diagnosis, treatment, and planning of diabetic care. These comprehensive standards include but are not limited to the following:

1. Strategies for improving care classification and diagnosis
2. Foundations of care and comprehensive medical evaluation
3. Prevention or delay of type 2 diabetes

Traditionally, diabetes management has included nutrition, medication, blood glucose testing, exercise, and treatment of hypo/hyperglycemic events (Gerard, 2010). With evolving technology and medication, the goal of diabetic treatment is to reduce the development of complications (King, 2005). According to the American Association of Clinical Endocrinologists (2009), a recent survey estimates that 22% of hospital admissions to be of diabetic patients, and in caring for them in hospital, regardless of the reason behind admission, discharge planning begins with admission. Management then, goes much further than the traditional methods as listed above, incorporating patient education, case management, active participation of the health care team, and prompt relay of information to the clinician (Phillips, 2015).

Factors that facilitate diabetes management include provider support, technology based education, personalized interventions, peer groups, and family support (Ross, 2015). In an assay of
various studies involving group education, Deakin (2009) noted positive results for those clients with diabetes, however individual personalized interventions had diverse results. Radhakrishnan (2012) found personalized interventions to be effective when discussing dietary fat intake, physical activity levels, and screening, but not as effective in medication compliance, glucose monitoring, smoking cessation, exercise and diet control. Another facilitating factor is that of a case manager and face to face communication (Brown, 2011).

Western and American Indian Cultural Tradition in Diabetes Management

Western medical management of diabetes has included nutrition, medication, blood glucose testing, exercise, and treatment of hypo/hyperglycemic events (Gerard, 2010). These services are offered in traditional Western settings such as acute care hospitals, and primary care clinics post discharge. Other types of management include intervention programs such as the Diabetes Prevention Program. These evidence-based programs are designed based on the premise that lifestyle changes can make a difference in reducing the risk of the later development of diabetes (DPP Research Group, n.d.).

A key difference in Western self-management and Native cultural traditions is related to healthcare visits with providers. In many instances, there is a lack of cultural sensitivity and knowledge in Western management. This creates a barrier between provider and patient and fosters an environment that is non therapeutic and promotes noncompliance (Waldram, 2005). Providers do not understand the ways and traditions of the people, and consequently are unwilling to listen and tailor their treatment to respect cultural beliefs.

Another difference is that of medication compliance. While many traditional healers and elders are supportive of Western medicines and encourage the use of both, there continues to be many American Indians who are distrustful of Western medicines. Boston (1997) concluded that the distrust
may in part be tension related to modern medicine and “the old ways”, noting that improved communication between provider and patient as well as community involvement in diabetic education could help bridge the issue.

Cosby (1996) found lack of confidence in the western doctors as a reason for distrust and the accompanying decrease in health visits. In addition, again related to communication, decreased knowledge in the understanding of why and what the medicines given were for. Barton’s (2005) work substantiated these findings, adding that the words of health providers were hard to understand. Parker (1994) found participants disappointed in the provision of healthcare, and related it to the past series of broken treaties and broken promises made long ago the American Indian people. This work was supported by Tiedt (2013) who related tension toward healthcare providers related to lack of trust and poor provider approach. In looking at the use of medicine in treatment of diabetes, there is little evidence of exclusive use of traditional medicine and exclusion of Western medicine (Waldram, 2005). Traditional medicine is holistic (spirit, soul, body), with an emphasis on prevention, a personal responsibility for health/sickness, and an understanding of nature. Western medicine/management is more analytical, emphasizing treatment of disease, with a scientific, approach. Health information is framed in terms of data (Malloch, 1989). The evidence appears to suggest that strategies to overcome distrust of Western medicine point to improved relationships between provider and patient, and culturally appropriate community involved education (Boston, 1997; Cosby, 1996; Parker, 1994; Tiedt, 2013).

**Diabetic Care Management Programs**

The Indian Health Service (IHS), founded in 1955, is a federally funded agency within the Department of Health and Human Service. Its responsibility is to provide health care to approximately 2
million American Indians belonging to federally recognized tribes (Sequist, 2011). The IHS strives to provide quality, culturally appropriate health care to all tribes within the United States. This is accomplished through IHS hospitals or health centers located within tribal, urban or IHS areas that provide a variety of services (Moss, 2016). This includes primary care, prescription drugs services, and various specialty services, depending on the center (Sequist, 2011). According to IHS (2012), services provided could include diabetes care, elder care, breastfeeding support, health promotion and disease prevention, HIV/AIDS care, pain management and injury prevention.

The IHS is divided into 12 geographical locations, which each serve a particular region (IHS, 2012). Health centers and hospitals are located within each tribal region. Urban Indian Health Programs are also in place to serve American Indians living in or near urban areas, although only 1% of the IHS budget is allocated toward the funding of urban health. This results in deficient access to health programming in urban areas (Forquera, 2001). Services provided by IHS are deemed “prepaid” from previous land treaties and executive orders (Moss, 2016). Thus, tribal members utilizing these services are not required to pay for provision of care (Urban Institute, 2014). Those served in all of these locations are able to use Medicare, Medicaid, VA, and private insurance to pay for care (Sequist, 2011). Rural location can impact on the ability to access care. Many have to travel distances, have unreliable transportation, and limited telephone and internet use (Sequist, 2011). In a previous study, Sequist (2004) reported less than one third of IHS physicians have good access to specialty care, hospital and mental health services, and diagnostic studies.

**Diabetes and Nutrition**

According to The American Diabetes Association (ADA) 2017 standards of care, the goal of nutrition therapy is the promotion of healthy eating habits highlighting a variety of nutritious foods in
adequate proportion. In doing this, patients will maintain or lose weight, stabilize blood glucose, lipid, and blood pressure values, and delay or prevent diabetic complications. Emphasis is also placed on looking to individual characteristics such as culture, literacy, motivation and access to healthy foods with the end result that of the provision of tools to make healthy choices in diet. Nutrition guidance with a registered dietician should occur soon after diagnosis with ongoing follow-up. However, this is the ideal and not the reality.

In a 2005 study, Siminerio noted that a large percentage of diabetics receive no nutritional education at all. This is substantiated by Ali (2013) whose examination of national data uncovered the fact that only half with diabetes actually receive diabetic teaching. Siminerio (2005) determined that rural patients were less likely to receive nutrition services than their urban counterparts. This was found to be because of the lack of diabetic educators or clinicians, providers not adhering to ADA guidelines, lack of access to services, and lack of knowledge that these services were even available.

For the American Indian, effective nutrition teaching is related to effective communication. Boston (1997) noted poor understanding of nutritional teaching among the Cree, poor eating habits, and limited shared understanding of what should and should not be eaten. In addition, there was interest in traditional foods such as game, but no access. Eating was a social area, and to not eat was provided was deemed disrespectful. Lautenschlager (2006) found lack of access to healthy affordable food. In many areas, a convenience store was the only option. As well, government surplus food is available but not healthy. Satterfield (2003 added the barrier of time. Fast food is easier to obtain. As well, the cost of nutritious food is prohibitive and funds for them are limited.
Diabetes and Medications

ADA (2017) guidelines for medication include oral agents as well as insulin, or a combination of both. This requires education and ongoing support and follow-up. According to studies done by The Diabetes Control and Complications Research Group (2016), the team approach delivered by physicians, nurses, dieticians and behavioral specialists along with the patient has been shown to improve glucose levels and as well as long-term outcomes. However, glycemic control in many situations is elusive (Ahola & Groop, 2013) with one study reporting only 39% of type 2 diabetics actually achieving successful measured glucose readings (Peyrot, 2005).

According to Ahola & Groop (2013), several factors affect management of blood glucose and other aspects of diabetes management. These would include a knowledge deficit related to diabetes management for both the patient and the family, decreased health literacy, decreased coping skills along with denial, the perception of loss of control over one’s life, depression, fear of hypoglycemia, lack of social support, poor provider support/communication. Lawton (2005) notes decreased perception of the seriousness of diabetes as well as a dichotomy in patient and provider understanding. Regimes prescribing once daily medications had a higher rate of compliance than those taken twice daily: 61 versus 52% (Dezii, 2002). Monotherapy regimes had more compliance than polytherapy regimes: 49 versus 36% (Dailey, 2001), and oral agents had better compliance than insulin: 86 versus 73% (Rajagopalan, 2003).

For the American Indian attempting to manage their medication, communication again becomes an issue. Boston (1997) reports a tension between modern medicine and traditional “old” ways. Cosby (1996) notes medication compliance is related to how much better one feels when taking as well as the rationale for why it is important to take. Also included here is lack of consistency with providers, and
feeling rushed through visits with no real explanations (Gregory, 1999), Barton (2005) reports minimal understanding of how Western medicines work, while Jacobs (2014) found respondents getting tired of taking their medications. Berry (2009) found the cost of medications and supplies to be prohibitive.

Self-monitoring of Blood Glucose

The American Diabetic Association (2017) maintains that self-monitoring of blood glucose is integral for effective therapy, allowing patients to determine their response to their prescribed diabetes regime. The resulting numbers are useful in the guidance of nutrition, activity, prevention of complications, and medication adjustment. The A1C blood test is an indicator of a patient’s average blood glucose over the preceding 3 months. According to the ADA (2017), routine A1C testing should occur initially, and then every 3 months as a part of routine follow-up care. This assists the provider in determining whether blood glucose targets and goals have been reached by the patient. ADA (2017) recommended level for the A1C is <7%. Glycemic control is essential in the management of diabetes. This is substantiated in various arms of studies done by The Diabetes Control and Complications Trial Research group (2000), where, glycemic control was found to be associated with significant decreases in the rate of retinopathy, kidney disease, and cardiovascular disease.

According to Elgart (2016), frequent self-monitoring of blood glucose levels has shown to meet and maintain optimal A1C levels. Successful monitoring is very much dependent on both the instrument and the user (ADA, 2016). In this, the patient’s technique should be frequently evaluated, as well as their understanding of the resultant numbers. In doing so, they are empowered to adjust their nutritional intake, exercise and medications (Grant, 201, 5). As with medication compliance, factors affecting blood glucose testing include knowledge deficit related to appropriate blood sugar levels (Gazmararian, 2009), depression leading to decreased motivation, and lack of social support. For the
American Indian, factors affecting compliance are similar to their White counterparts. Communication and knowledge differences are large factors (Boston, 1997, Cosby 1996). In addition, many American Indians are ambivalent about checking blood glucose or see its usefulness as limited, going by how they feel (Cosby, 1996).

**Diabetes and Body Weight**

According to the ADA (2017) and its recommendations, management of body weight is an important factor with diabetes care. Evidence consistently reports that progression from prediabetes to type 2 diabetes can be delayed in the presence of modest but continued weight loss (Balk, 2015; Mudalier, 2016). In addition, continued weight loss in moderate proportions has been shown to increase glycemic control and decrease the necessity of diabetes medications (Pastors, 2002). ADA (2017) recommendations for physical activity for both type 1 and type 2 adults include 150 minutes of moderate to energetic physical activity on a weekly basis spread over 3 days.

According to Boule (2001, 2003), a structured exercise regime lasting at least 8 weeks has been proven to decrease A1C in type 2 diabetics by an average of 0.66%, noting increased levels of improvement in A1C and fitness with increased intensity. Evidence on the benefits of exercise include: weight loss, blood glucose control, decreased blood pressure, cardio and respiratory fitness, decreased lipids, depression, kidney disease and retinopathy (Umpierre, 2011).

In the American Indian population, Boston (1997) found American Indian Cree believed extra weight was seen as healthy. This was supported by Grams (1996) work with British Columbian Haida who viewed thin people as not healthy or valuable with the belief that ancestors were strong people. In Ontario First Nations people, Cosby (1996) found a lack of or limited facilities in which to exercise. Along
this line, Barton (2005) found weight loss and exercise were hard to manage while Satterfield’s participants discussed environmental limitations in that there was no good place to walk.

**Common Barriers and Facilitators to Care**

Ross (2015) claimed that many diverse populations use complementary/alternative medicines (CAM) and spiritual interventions along with their Western medicine in the treatment of diabetes, but will neglect specific interventions such as glucose monitoring and exercise (Schoenberg, 2008). These may be viewed as barriers to care. This is also supported by a similar study of African Americans with type 2 diabetes (Bhattacharya, 2012). Participants viewed prescribed diet and activity as impractical and not culturally meaningful. Also noted with this population was a deficient skill set related to diabetes monitoring, a perception of absent social support during diabetes education, and lack of confidence in expected self-management (Bhattacharya, 2012). This is further explained by Lautenschlager & Smith (2006), who described the reasoning behind the neglecting of these interventions in their American Indian respondents. Many cited reasons for lack of exercise as beyond their control, assuming they needed special equipment or facilities. Some had already lost limbs and some had physical barriers that prevented them from extreme movement. Lack of compliance in glucose monitoring was noted to be a result of denial of the disease of diabetes, lack of knowledge, cost of the supplies with no or limited insurance, and homelessness. Some of their diabetic participants used traditional medicine either alone or in addition to western medicine. These included sweat lodges, healing ceremonies, herbs, powwows, and consumption of swamp tea. This is supported by Struthers (2004), who in addition, reported successful use of prayer, medicine men, medicinal plants, talking, tobacco, storytelling, chanting and healing dreams. Both Struthers (2004) and Novins (2004) have found that American Indian communities used both Western biomedicine and traditional healing methods either in conjunction with each other or independently. In many instances, the choice will depend on the issue.
Other barriers included financial issues (low income) which limited the ability to participate in treatment interventions, as well as purchase healthier food (Remler, 2011), low education/literacy which could limit personal understanding of diabetes and its treatments (Sadowski, 2012), cognitive impairments (vision, hearing, mobility) (Brewer-Lowrey, 2010), and geography/climate (Ross, 2015). According to Ogunwole (2006), American Indians living on reservations are the most poverty-stricken ethnic group in the US. Between 2005-2009, 26% of American Indians and Alaskan Natives lived in poverty. According to the USDA (2004) report on rural poverty, 17% of the population were of ethnic or minority origin, with poverty rates that are higher than the general population. The 2002 poverty rate for American Indians was 33%. This is in contrast to 11% (more than three times the rate) for non-Hispanic whites. For the census year 2000, the income of American Indians people was <75% of the federal poverty level, which was twice that of the general population. In the years reporting 1999-2001, there were 800,000 American Indians in poverty. The median income for males working full time was 28,919 with women reporting 22,834. In contrast, the general population median income was 37,100 for men and 27,200 for women.

In addition to poverty, hunger and lack of insurance were major issues. Finegold (2005) noted that 1 out of 3 American Indians had no health insurance. Food insecurity was twice that of the general population, and USDA estimates between 1995-1997 were 22% for American Indian homes with food insecurity and an additional 9% experiencing both hunger and food insecurity. Lawson (2013) also notes that American Indian homes may lack essential services such as plumbing and telephones, observing that American Indian homes are 14 times likely to have no plumbing as compared to the general population. For the American Indian diabetic, especially the elderly, these are very real barriers. According to Moss, Schell, and Goins (2006), the American Indian elderly experiences the poorest health
outcomes, have more chronic disease, experience the shortest lifespans, and have more functional decline than any other group of elderly people in the United States.

**Theoretical Models in the Study of American Indian Health Care**

Theory plays an important role in research and has many definitions. According to Neuman (1997), theory is defined as a general statement denoting a relationship between principles and a method to explain and predict the relationships. Theory may also be described as a framework that shapes understanding between what is observed and what is understood. It has great value in research in its provision of basic concepts that allows one to frame observations and impressions in a specific area, as well as connect with the vast knowledge other research has generated.

Kelly (2010) described three ways that theory provides value in qualitative research. First, it impacts research design, offering insight on ideas for research topics, as well as aiding in the formulation of research questions. Second, theory provides the rationale for the methods used to study the phenomena, analyze the data, and report the findings. Finally, it may provide the impetus for the development of new theory, adding new knowledge and understanding to what is already known. Quality theory is clear, structured, and coherent, has scope, is generalizable, and able to be easily applied (Morse, 1997). Clear statements on theory and its role in the research study promotes transparency in all explicate aspects of the process, and is key in the production of quality research (Kelly, 2010).

**Transcultural Nursing**

Madeleine Leininger (2002) defined transcultural nursing as a nursing practice that focuses on comparative human-care (caring) differences and similarities of the beliefs, values, and patterned lifeways of cultures. The objective of the nurse is to provide culturally congruent, meaningful, and
beneficial health care to people. Transcultural nursing is an essential component in the 21st century due to the ever increasing diversity and migration of the population, changing gender roles, increasing use of technology, and the ever growing needs of a healthcare system (Leininger, 1997). It can be conceptualized as a way of caring that blends an individual’s beliefs, values, culture and practices (Narayanasamy, 2002).

**Leininger’s Culture Care Theory**

The central purpose of the Culture Care Theory is the discovery and explanation of those specific cultural factors that influence the health, wellbeing, illness, and death of individuals and groups (Leininger, 2002). The theory may be used in research to understand and design care that is culturally relevant, safe, and advantageous to people of diverse cultures with a focus on promoting health, well-being, and healing (Leininger, 2006). Leininger (2002) identified the importance of an accurate understanding of culture as it relates to the planning and implementation of nursing care. This care must correspond to and have meaning in the individual’s cultural beliefs, traditions, and principles. This linking of culture and care promotes compliance to prescribed therapies, the possibility of healing and restoration, and cultivates an ongoing desire for wellness (Leininger, 2006).

**The Sunrise Enabler**

The Sunrise Enabler depicts the flow of Leininger’s (2006) theory and the cultural factors that influence healthcare. It is a visual reminder of the diversity of dynamics that influence the provision of care within any given culture as well as a guide in the consideration of the specific aspects needed to arrive at a holistic picture of the person, their family, community and culture (Leininger, 1996). Each of the tenets noted in the model (technology, religion, kinship, cultural values, politics, economics,
environment, language, ethnohistory, and education) were found to have significant influence and in fact surround culture care beliefs, values and practices (Clarke, 2009).

The basic assumption of the Culture Care Theory is that an individual’s health care practices, cultural care values and beliefs, religious and spiritual viewpoints, language, and social attitudes shape the worldview of the individual cared for (Clarke et al, 2009). Therefore, it is beneficial in all ways for interventions, education, and nursing care to be patterned around the client’s culture. Without such incorporation, stress, conflict and noncompliance will likely occur (Leininger, 2006). The theoretical tenets include but are not limited to the following: Both differences and commonalities are present between and within world cultures. Knowledge of these will enable the provision of improved care to cultures.

1. Certain worldview factors must be understood in order to provide meaningful care. These factors include religion, economics, education, technology, politics, kinship, ethnohistory, environment, language, generic (folk practices), and professional care.

2. Assumptive premises of Leininger’s (2006) theory include the following:
   a. Care is core and the focus of nursing
   b. Care that is culturally based is necessary for health and wellbeing
   c. Culturally based care is holistic and comprehensive, and must guide all action
   d. Culturally based care is necessary for curing and healing.

E, Caring can exist without curing, but curing cannot exist without caring.
McFarland (2006) notes approximately 300 research studies using the Culture Care Theory within the four decades prior to 2006. In addition, personal research has also uncovered several nursing care and practice applications of the theory that solidify its practicality. Wenger (1995) used the Culture Care theory to perform a study of Old Order Amish, looking to explain how their beliefs and values shaped their health care practices and decision making. She found that generic (folk) care had several meanings that included giving, receiving and humility. Using the Sunrise Enabler, she also found this care to be woven tightly into all their activities, including kinship, religion, community, culture and beliefs. Technology, however, was not a desired modality in their worldview. Dominant care meanings included: anticipatory care (being familiar with cultural ways), principled pragmatism (getting things accomplished as needed with family in traditional ways), and active participation in community life. Care then, for the Amish was framed as central to their identity and lifestyle. This was practically applied in a hospital setting as nursing cared for an Amish infant (Gibson, 2008).

Schumacher (2010) used the Culture Care theory to examine the beliefs and meanings surrounding care for rural Dominicans with the goal of identifying both generic (folk) and specific health care practices that promote healthy living. She used the Sunrise Enabler to assist in articulating care practices, health patterns and care meanings among the people. Results discovered three themes, the importance of family presence in care, respect and attention must be present in care and care practices, and the people used both folk remedies and professional care practices.

In another study based on the Culture Care Theory, Hernandez (2013) sought to describe and explain the cultural view of diabetes mellitus in Mexican American participants. Among the categories, patterns and themes identified through the use of the Sunrise Enabler, it was found that Mexican Americans focused on the maintenance of balance in their world, desired a balance of generic (folk) and
professional health care practices, and desired respectful, compassionate culturally appropriate care with open lines of communication.
Chapter III: Methodology

The purpose of this ethnographic study was to explore, describe, and understand how American Indians from the St Regis Mohawk Tribe perceive and manage Type II diabetes. Chapter 3 presents the research design and rationale for the present study. The methodology, population, sample and sampling procedures, procedures for recruitment, participation, and data collection, and data analysis are discussed in detail. This section concludes with a discussion of ethical procedures, and summary.

Research Method and Design

The research method for the proposed study is qualitative. The focus of qualitative research is exploring how groups or persons place meaning associated with a certain issue or problem. According to Strauss and Corbin (1990), qualitative research produces findings unrelated to statistical procedures or other means of quantification. Qualitative research is also used to uncover trends in thought and opinions, and dive deeper into the problem. Qualitative data collection methods vary using unstructured or semi-structured techniques. Some common methods include focus groups (moderated group discussions), individual interviews, and participation and observations. The sample size is typically small, and its size is not predetermined. Data collection continued in the present study until saturation was achieved and no new information was obtained.

The design of the proposed study was focused ethnography (Roper & Shapira, 2000) of the American Indian St Regis Mohawk experience and perception of diabetes. Ethnography is a qualitative research method that allows actual participation in the daily routines of participants. This equates to literally learning from those studied in order to discern what their world is like. Focused ethnography examines a specific problem contextually within a smaller group of people.
Leininger (2006) also referred to ethnography as a mini ethnonursing study. In this, a specific research question is highlighted with the goal of improved application in the healthcare setting. Because the questioning (focus) is more specific, the timetable for completion is much less than the traditional ethnography, which looks at all aspects of a culture. Ethnography has as its underpinning the philosophy of symbolic interactionism (Prus, 1996). The ontological belief is that of the existence of many truths and alternate realities that depend on a person’s culture and these must be described in terms of the culture (Mills, Bonner, & Fancis, 2006; Streubert & Carpenter, 1999).

In order to develop insight into the multiple realities of a culture, research takes place in the natural setting by researchers who spend much time in the field (Speziale & Carpenter, 2007). Streubert and Carpenter (2011) described characteristics of qualitative research to include valued subjectivity, multiple realities, discovery description and understanding, rich narratives, and a design that is not preplanned, but adaptable to the emerging characteristics of the data.

The researcher followed standard ethnographic data collection methods that included participant observation of daily activities and special programs, ethnographic interviews, and the analysis of artifacts (Roper & Shapira, 2000). Gaining entrée into the culture was accomplished through a series of connections already established by the researcher. The researcher is an enrolled member of the St Regis Mohawk Tribe, and works weekly at the diabetes center as a per diem nurse. Thus, there is already established trust and an ongoing professional relationship in place.

The researcher’s primary employment is within a Western medicine hospital. In addition, the researcher has been raised and trained in the dominant Western culture. These attributes aided in the provision of a cross-cultural viewpoint in the study. The researcher has established relationships with the director of the diabetes center, dietician, nurse clinicians, and training staff. Their ongoing
involvement in the research project added an important dimension that will increase interpretation and clarification of the data.

**Setting/Sample**

St Regis Mohawk Reservation in Akwesasne, New York lies approximately 200 miles north of Albany, New York, and is bisected by both the US/Canadian border and the St Lawrence River (Cook, 2015). According to the Mohawk Council of Akwesasne (2017), the total population on the Canadian side of the reservation approximates 12,000 people, while the St Regis Mohawk Tribe claims approximately 11,000 on the American side. Additionally, 1,800 Mohawks are presently living off the reserve. Within the reserve, the undisputed land-based amounts to 26,359 acres, with roughly 14,700 acres on the American side and 12,000 acres located in Canada (Mohawk Council of Akwesasne, 2017).

Given the division of the reserve by international borders, there are two separate governing bodies.

The sample for this research was selective and purposeful. However, snowball sampling and active solicitation were also employed. The main goal of these sampling strategies was to focus on particular characteristics of a population that are of interest, which enabled the researcher to answer the research questions. Fifteen enrolled members of the St Regis Mohawk Tribe were interviewed, and saturation was met. According to Roper and Shapira (2000), saturation occurs when no new data is obtained. All participants were enrolled members of the St Regis Mohawk Tribe living either on or off the reservation in surrounding communities. Participants were receiving health services from the health clinic and lived on the American side of the reservation. All participants were over the age of 18 years and diagnosed with Type 2 diabetic.
Data Collection

With approval by the University at Buffalo’s IRB and the St Regis Mohawk Tribal IRB (see Appendix E and F), data collection began in late October 2017. In ethnography, the primary data collection is carried out primarily through fieldwork. Fieldwork is defined as a form of inquiry that requires a researcher to be immersed personally in the ongoing social activities of some individual or group (Wolcott, 1995). The basic ethnographic fieldwork pertains to observation, interviewing, and interpretation as cyclic iterative processes. The ethnographer is the primary instrument and generally collects information through the elevated use of all of his or her senses. Observation is usually associated with the sense of sight, but in carrying out the observations, the ethnographer can raise all the senses of sight, hearing, smell, taste, and feel.

In the present study, fieldwork (living in the study community) for any period was not feasible; therefore, all observations occurred at the St Regis Mohawk Diabetes Center of Excellence located on the St Regis Mohawk Reserve. These observations were conducted during nursing visits, nutritional counseling, and physical activity in the Moving For Health (MFH) gym. Observations also occurred during participation in staff case management meetings, special patient activities, and associated tribal functions. A summary of observations was documented in field notes during each contact visit. The summary included the following: Who was present during the contact (pseudonyms); the main issues or themes that stood out during this contact; and the specific issues that were picked up from the observations that ethnographer might want to explore further at next contact or during the interview.

All interviews were conducted at the St Regis Mohawk Diabetes Center of Excellence located on the St Regis Mohawk Reserve in a quiet comfortable dedicated space after informed consent was signed. Interview times were held during the day hours being considerate of participant needs and life
demands. Conversational open-ended questions comprised the time together. The researcher employed, with permission, the use of a tape recorder during the interview process.

All interviews began with conversational open-ended questions. According to Polit & Beck (2004), qualitative research begins with generalized questions or topics that set the stage for conversation and allow participants to speak in a narrative fashion.

Open-ended questions included the following:

1. How do you describe a typical day of diabetes management?
2. What practices help you to keep your diabetes in check?
3. What is your earliest memory of family members with diabetes?
4. What kinds of Indian medicine do you use?
5. How does the Diabetes Center for Excellence help you in the management of your diabetes?
6. How has your diabetes altered the way you live life?
7. How did you feel when you found out you had diabetes?
8. What community support do you receive with diabetes?
10. How can health services improve in their provision of care for diabetes?

Field notes were kept during all observations, meetings, interviews and activities. These notes were written and reviewed as soon as possible after the experience in order to capture the essence of
what was observed and recorded. Charmaz (2006) described the contents of field notes to include anecdotes and observations, significant occurrences in the setting, participant language use, and the placement of participants in scenes. Data collection continued until saturation was achieved and no new information was obtained. A total of 15 participants were interviewed and met saturation.

**Data Analysis**

The focus of ethnography is to describe experiences within the cultural context, looking to understand behavior (Aldiabat & Navenec, 2011; Roper & Shapira, 2000). Ethnographic analysis occurs along with data collection. All observation data were taken directly from researcher’s field notes. Following the interview process, the audio recordings were transcribed by a professional transcriptionist. Data were then coded with all personal data removed. Analysis occurred inductively as the researcher looked to identify recurrent themes and categories in the transcribed interviews (Roper & Shapira, 2000). Data analysis included the interpreting and evaluating of the research. The raw data were analyzed by the researcher to make conclusions about the research.

All major qualitative methods employ coding techniques to help organize and analyze the overwhelming amount of data that are frequently collected during qualitative research. After transcribing text data, including field notes, recordings from interviews, and descriptions of observations, the data were formatted for coding in Microsoft Word. Proper coding will provide researcher with documented and well-organized answers to research questions. The coding results were efficiently integrated into the final report.

During this process, researcher looked for any emerging patterns, trends, beliefs, or processes. This step in coding yielded categories and themes (see Appendix A). These themes and categories allowed the researcher to construct the Mohawk view and experience of diabetes. Data were reviewed
with key informants which included the director of the center, a nurse at the center, the dietician, and a trainer. These individuals were of great assistance as they provided dimension and clarity to the data obtained.

**Ethical Research**

As the primary instrument of this study, the researcher has an ethical obligation to produce a valid and reliable study in an ethical and trustworthy manner. In doing so, the researcher applied three basic ethical principles: respect for persons, beneficence, and justice (NIH, n.d.). Respect for persons means that participants entering into the research will do so voluntarily and be fully informed. To satisfy this principle of *respect for persons*, participants were told that their participation is voluntary and their agreement to participate constitutes a valid consent. This element of informed consent required conditions to be free of coercion and undue influence (NIH, n.d.). Beneficence obligates the researcher to secure the well-being of all study participants.

The researcher has a responsibility to protect participants from harm, as well as ensure that they experience the possible benefits of involvement (NIH, n.d.). Balancing risks and benefits is an important consideration. All participants were treated in an ethical and respectful manner. The responsibility to protect and inform research participants was ultimately the researcher’s responsibility and was not ignored or delegated. Confidentiality of the participants is important in research projects (Merriam, 2009). The names of the participants were kept confidential, and the researcher assigned a code to each participant’s interview.

On the adult informed consent form (see Appendix B), participants agreed to allow the recording and transcription of interviews. These transcripts were stored securely as documents on thumb drives and were kept in a locked file cabinet in the home of the researcher for the required
period required by IRB. Aside from beneficence, the researcher kept the principle of justice in mind when selecting participants, obtaining consent, and conducting the study. The principle of justice applied in the present study means that this study was justified on the basis of a favorable risk/benefit assessment. All potential risks were presented to subjects and explained in the consent form to assist the prospective participant to determine whether or not to participate.

**Reliability and Validity**

There is a need to examine qualitative research to ensure quality has been met by the researcher. Four attributes of trustworthiness (rigor) can be applied qualitatively. There are (a) truth value; (b) applicability; (c) consistency; and (d) neutrality. Koch (1994) referred to truth value as credibility. It establishes whether the findings by the researcher actually reflect the subjects and context for which it was designed. Credibility is established when the descriptions of the experience are viewed by those who share the experience and they are able to recognize the descriptions. Koch (1994) suggested field notes and journaling as a mechanism for recording and reflection as well as allowing the participants to review the analysis. The researcher was only able to reconnect with three of the 15 informants to review transcripts. The three all agreed that what they reviewed was an accurate description of their thoughts and feelings.

Guba and Lincoln (1989) noted that in order for transferability to occur, research findings must be used in situations with populations that are similar in context to the original. Consistency or dependability occurs when the study is auditable. According to Sandelowski (1986), an auditable study is one in which other researchers can easily follow the decision trail which the original researcher used, arriving at the same general conclusion. Neutrality is referred to as freedom from bias (Sandelowski,
1986). Research findings must be an accurate result of information obtained from the informant in answer to the research question. They must be free of outside motivations and perspectives.

The researcher employed several strategies to ensure a quality and trustworthy study that has credibility and transferability. To insure credibility, the researcher sought to present the results in a thick and rich description of the data ascribed by Merriam (2002). Additionally, the researcher employed member checking, taking the transcripts back to the participants for validation and to note any inaccuracies in the statements. Additionally, to enhance reliability, the researcher used many different sources of evidence that included conducting open-ended interviews, observations, and preparing carefully written field notes. The key tenet is that findings or conclusion are likely to be much more convincing and accurate when based on several different sources of information.

**Conclusion**

Chapter 3 presented the research design and rationale for the present study. The methodology, population, setting and sampling procedures, procedures for recruitment, participation, and data collection, and data analysis were discussed in detail. This section concluded with a discussion of ethical procedures, and summary. Chapter 4 will be a full discussion of the results.
Chapter IV: Results

The purpose of this ethnographic study was to explore, describe, and understand the cultural influence of American Indians from the St Regis Mohawk Tribe living with Type II diabetes. Chapter 3 presented the research design and rationale for the present study. The methodology, population, sample and sampling procedures, procedures for recruitment, participation, data collection, and data analysis were discussed in detail. This section includes a discussion of the results, procedures, and summary of findings.

The overall research methodology for the proposed study is qualitative. The design of the study was focused ethnography of the St Regis Mohawk and diabetes. In order to develop insight resulting in thick description of this culture, research took place in the natural setting, on site at the reservation. Demographic data were collected at the beginning of each interview. This data coupled with personal interviews, observations, and field notes were used to provide as full a description as possible around the participants and diabetes.

Field notes were kept during all observations, meetings, personal interviews and other observed activities. These notes were written and reviewed as soon as possible, after the experience in order to capture the essence of what was observed and recorded.

Time on Site

According to Fetterman (1998), analysis is a most “engaging” piece of ethnography that begins when the topic is selected, and ends when the writing is complete (p 92). This was the case also in time spent in the various activities at the Diabetes Center. Fieldwork was conducted at the Diabetes Center of Excellence located on the St Regis Mohawk Reservation in Akwesasne, New York, and consisted of observational activities in the Moving for Health (MFH) room, taped interviews, and participation in two
scheduled events, a health fair, and the Wear Red Day. During observation in the MFH room and the
two events, ample field notes were taken and later reviewed. Data collection began at the diabetes
center in October of 2017 and continued through February 2018. A total of 30 hours was spent in actual
interview time over a 20 week period. However, the researcher gained entre in attendance and
participation in four-hour MFH sessions on a weekly basis from January 1, 2017 on through April 1,
2018. This time in addition to events totaled approximately 325 hours. In doing so, the researcher was
able to observe and participate in the activities in the MFG gym. Time was also spent speaking with and
developing relationships with attendees and staff. The researcher was also able to visit the various
restaurants and gas stations during that time period in order to capture a sense of community life.

In the MFH room, on numerous occasions, the researcher assisted with pre and post exercise
blood pressure and blood sugar screenings for each individual coming in to exercise. This included but
was not limited to the persons interviewed. Not all of those interviewed came in to exercise. However,
those that did spent approximately an hour using the treadmill, bike, elliptical machine, stepper, arm
exerciser, pulley ropes and free weights. Of the 15 interviewed, only 2 persons did not come in at all to
use the equipment. Most were consistent, while 3 participants were sporadic in their visits to MFH. The
researcher also observed the dietician, the nurse educators, and the nurse practitioner in their
interactions with participants. The MFH area provided extra opportunities for each to connect, educate,
and review additional concerns with the patients. The researcher was occasionally able to sit in on case
management meetings with the director, case managers and fitness staff. New cases, referrals and
patient updates and needs were discussed as staff was updated on health issues with specific
community members in MFH.
During the health fair, various community vendors were set up in the MFH room, each with particular services offered. These ranged from chiropractic services and healing teas to locally made facial products. One couple sold varieties of Indian corn and taught various ways to cook and serve it. During this time, the researcher was able to move freely among the vendors, visiting with and getting to know them. Yoga and meditation were demonstrated for all to participate in if desired, as well as a demonstration of traditional cooking. This particular one drew the biggest crowd and the small theater kitchen was packed with community members.

The Wear Red Day events consisted of yoga and meditation, and a one hour discussion on diet and heart disease by the nurse practitioner from the clinic. There were approximately 30 people, mostly community women in attendance, with numerous questions and discussion on this topic. While the nurse practitioner is not a member of the tribe, she has been employed there for a number of years, and has developed an obviously easy rapport with all of the community members attending as well as the staff. Conversation and questions flowed freely. A healthy lunch was served, and no one seemed in a hurry to leave after the presentation.

During the week, the diabetes center is a hub of activity, providing education, support, and socialization. There are MFH activities Monday through Thursday from 8AM – 12PM and 3PM-4PM for patients. There are open community swim classes each morning throughout the week. There are early morning and lunchtime open gym sessions for the community. This same building houses Mohawk language classes two evenings during the week.

The Diabetes Center also maintains a walking trail of approximately one mile around the western side of the center. They host events that combine the walking trail and healthy activity. Presently, the tribe is building a new administration building near the walking trail, so much of the
walking activity there has ceased. Prior to the building project, it was not uncommon to see deer and fox coming out of the woods surrounding the clinic.

The researcher has also spent time within the busy health and dental clinics, which are not housed at the diabetes center. Observational activities included speaking with the nurse practitioners working at the clinic and sitting in on the centering program for pregnant women. The community library was also a site visited by the researcher. There is a cultural center located beneath the library, which offers information on historical aspects of the St Regis Mohawk Tribe as well as the rich display of baskets and artifacts. The researcher spoke with the administrator of the center who offered much information on the community of Akwesasne. There are four restaurants in the community, numerous gas stations/convenience stores and smoke shops. There is also a large casino with two hotels. The restaurants served a variety of foods ranging from fast foods such as hamburgers, pizza, wings and subs to more standard dinner fare such as turkey, meatloaf, potatoes and vegetables. There was always corn soup (traditional food) on the menu. In all visits to local restaurants and eateries, most offered fresh dishes of garden or chef salads.

**Participants**

The final sample for the study included 15 enrolled members of the St Regis Mohawk Tribe living either on or off the reservation. The researcher met with the health director of the clinic who also oversees the diabetes center. After obtaining his approval as well as IRB, fliers were developed and posted at the health clinic, the pharmacy, the diabetes center, and the community at large. The nurse case managers also spoke of the study with their client caseload. While there were many people who voiced interest in the possibility of assisting with the study, over the course of 16 weeks, it was possible
to recruit only 15 interested participants. At least 5 interested persons scheduled appointments with the researcher but failed to attend.

According to Nieswiadomy (2012), sample size in qualitative research is typically small, and its size is not predetermined. While the sample size was not predetermined, it represented approximately 10% of the diabetic Mohawks at the diabetes center (150-160), and was also representative of the submitted plan to IRB. Roper and Shapira (2000) note that qualitative data collection continues until no new information is gathered and saturation has occurred. In this case, saturation had occurred at 15 participants.

All participants were over the age of 18 years and diagnosed with Type 2 diabetes. All were receiving health services from the clinic and lived on the American side of the reservation. Five of 15 participants reported early onset diabetes since they were in their early twenties (> than 30 years ago). Seven reported onset within the past 10-20 years. Two reported gestational diabetes or discovered their diabetes during early pregnancy, and two reported being prediabetic and borderline diabetic. The following section presents a summary of the demographics and basic characteristics of the participants (see Table 1).
### Summary of Participant Demographics

<table>
<thead>
<tr>
<th>Demographics</th>
<th>Characteristics</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age</strong></td>
<td>The mean age of the female participants was 59.7, ranging in ages between 22 and 83. In contrast, the average age of the men in the study was 73 years, the youngest was 62.</td>
</tr>
<tr>
<td><strong>Education</strong></td>
<td>All participants appeared well educated, spoke and understood the English language. At least four of the participants were college educated and three held master’s degrees.</td>
</tr>
<tr>
<td><strong>Employment status</strong></td>
<td>Nine were retired, five employed, and one unemployed.</td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td>Three men and twelve women participated in the study. All participants were members of the St Regis Mohawk Tribe and patients of the St Regis Mohawk Diabetes Center of Excellence located on the St Regis Mohawk Reserve.</td>
</tr>
<tr>
<td><strong>Marital Status</strong></td>
<td>Ten married, two widowed, one single, and one divorced.</td>
</tr>
</tbody>
</table>

All participants had access to quality health care through the St Regis Mohawk Diabetes Center of Excellence located on the St Regis Mohawk Reserve. Activities and support include nutritional counseling, physical activity in the Moving For Health gym, case management meetings, special patient activities, and associated tribal functions. With regard to medications, six participants were insulin
dependent. Others were maintained on oral medications for Type II diabetes inclusive of but not limited to Linagliptin, Glyburide, and Metformin. In addition, two were receiving Victoza injectables.

**Data Management**

All interviews were conducted at the St Regis Mohawk Diabetes Center of Excellence located on the St Regis Mohawk Reserve in a quiet comfortable dedicated space. The interviews were held during the day hours in consideration of participant needs and life demands. All interviews took place over a period of five months beginning in the fall of 2017. Data collection continued until saturation was achieved and no new information was obtained.

Prior to each interview, the researcher allowed adequate time to become centered, focused, and become truly engaging with the participants as they shared their personal experiences and feelings. The interviews began with the researcher briefly describing the nature of the formal interview to the participant and inviting them to reflect on their experience as American Indians from the Mohawk tribe living with Type II diabetes. Each interview was audiotaped and ended with the participants indicating they had nothing more to share about the experience.

Following the interview process, the audio recordings were coded with all personal data removed, placed in an e-file with password protection and transcribed verbatim by a transcriptionist into Microsoft Word. Field notes and observations, photos and newspaper clippings were also stored in a separate file. Each participant was assigned a letter/number code such as P01, P02, etc. Names were not used in any way during the coding, reporting or analysis phase. Once all data was transcribed and organized in Word, analysis could begin.
Data Reduction (Analysis)

Roper and Shapira (2000) note that qualitative analysis does not “just happen” (p93), but instead is a process requiring invested time and energy. Time is required in order to attain a personal awareness of each person and event. The ethnographical analysis is an inductive process as the researcher uncovers ideas from the data presented as opposed to preconceived opinions.

Each of the 15 transcripts were read and reread before beginning the analysis process. Then each was analyzed line by line in a search for themes and subthemes. Additionally, all transcripts were appraised numerous times while listening to the accompanying recording. Any questions arising were filled in by referring to field notes and memory. In ethnography, Roper & Shapira (2000) referred to the researcher as an instrument. In this, contacts, events, field notes, and artifacts are essential tools in the gathering of data.

As stated earlier, analysis began with the first interview and was ongoing and iterative. In doing this, the researcher made notes of additional areas to explore with subsequent interviews. Leininger (1991) described 4 phases of analysis for qualitative data. It is within this framework that analysis took place. Phase 1 covered all aspects of data collection including observations and preliminary interpretations. Phase 2 involved the coding and classification of data with identification of recurrent ideas. Phase 3 encompassed a closer examination of the data looking for saturation, recurring patterns or different explanations of data, as well as further confirmation of emerging ideas. Phase 4 included the creation of major themes and interpretation from the previous 3 phases.

Following the described analysis, categories and themes were then created from the coded concepts and mapped transcripts, Examples are shown in Appendix A. In reviewing the first transcript, 12 categories and 71 sub codes were cultivated. The second contact revealed four additional categories
and 42 sub categories. Each subsequent transcript was then examined, compared and contrasted to the ones before and those following. Fetterman (1998) refers to the importance of maps and flow charts in the visual representation of data in that they support crystallization and consolidation of material.

Initial categorizing and mapping of the fifteen transcripts uncovered 166 potential themes and accompanying 800 sub codes. Themes were examined in light of the research questions, and then reexamined looking past the research questions into cultural domains. Initial flow charts were revised to accompany the cultural reexamination. Further analysis, combination and reconfiguration of the categories led to 10 themes and 71 subthemes. Continued analysis and examination revealed five final themes with 18 relevant sub themes in accompaniment.

The researcher was only able to reconnect with three of the 15 participants for member checking. Transcripts were reviewed with the three, who agreed that what they reviewed was an accurate description of their thoughts and feelings. Initial and final themes and maps were discussed with faculty committee chair. This was done in order to insure transparency and validity.

**Findings**

The focus of this ethnography was to bring an understanding of how members of the St Regis Mohawk Tribe describe and manage Type II diabetes. All personal observation data were recorded in field notes at the time of the interview or during their participation in activities in the field. To protect the privacy of the individuals, the researcher’s observations were merged and included with the data analysis.

**Results of Data Analysis**

The data analysis resulted in the identification of five major themes relevant to the topic and research questions:
1. “It’s like the whole reservation is diabetic!”
   - “You’re Mohawk, you have diabetes.”
   - “Afraid for my loved ones to see me like that”
     - Blindness, amputations, sores, dialysis & death
   - Thinking about why diabetes occurs
     - “Alcohol”
     - “Need to go back to the old ways”
     - “Sedentary”
   - Getting a positive diagnosis of diabetes
     - “I pretended not to have it.”

2. “Everything I am going through is brand new”
   - Experiencing major changes in lifestyle
     - “Well I got my toes cut off... So I started exercising”
     - “People get overwhelmed by it”
     - “I was depressed”
     - “I enrolled in MFH”
   - Fitting work into the new routine
     - “Can’t eat in between and I could feel my sugar dropping.”
     - “Work interferes with a good routine.”
     - “My boss is great ... She says do what you need to do.”
   - Working on diet and exercise
     - “Baby steps”
     - “I hate to sweat”

3. “Feeling like you are sinking in quicksand.”
   - Sticking to and living the program
     - “I know what I am supposed to be doing.”
   - “Balancing body, mind and spirit.”
     - “They must be balanced out right.”
   - Remembering
     - “I have to be conscious of what I am doing.”
   - Being Native
     - “There is a root. You boil it into a tea for colds and joints.”

4. Breaking the cycle
   - Going back to basics
“Everybody works. No time for cooking.”

- Understanding
  “Some people don’t understand what diabetes is.”
- Talking and changing
  “Warn people about what diabetes can do”

5. Keeping the circle strong
- Educating families
  “educate the youth, but older people as well.”
- Strengthening the community
  “The diabetes center helped a lot of people understand their situation with diabetes”
- Looking to the future
  “I want to see my great grandson grow up.”

Theme 1

“It’s like the whole reservation is diabetic!” All informants felt that diabetes was pervasive in their lives as described in the four subthemes that were evident in this theme, and seemed to follow the natural flow of occurrence. Four components were evident in this theme, seeming to follow the natural flow of occurrence. These included: “You’re Mohawk, you have diabetes”, “afraid for my loved ones to see me like that”, thinking about why diabetes occurs, and getting a positive diagnosis.

Subthemes

“You’re Mohawk, you have diabetes. All of the participants were aware of the impact diabetes has made in the St Regis community. All except two had memories as young children of watching parents and grandparents, aunts, uncles, and siblings who have struggled with diabetes over the years, suffered complications from it, or have died related to its effects. There was consensus among the group that diabetes is very much present in the community and has affected most of the families there in one way or another, whether it is simply listening to talk about one’s illness, observing bodily changes
and disfigurements, assisting with medication administration, or attending funerals of those who passed on related to diabetes.

“When I was a young boy, I heard my mother talking about the relatives with diabetes. It’s right in the reservation. The Indians. It’s like the whole reservation is diabetic!” My aunts and uncles, both grandfathers, and my brothers and sisters all have it. My sister is on dialysis now. I remember watching my grandfather change the bandages on his legs. There were sores and I could see the pores”. (P13)

“My father drank too much. He was raised in the Thomas Indian School. In 1961, my grandfather came to live with the family. He was blind from diabetes. In my mother’s family, seven out of nine siblings have diabetes”. (P05)

“My aunts, I got diabetes when she was 14. The others were in their 20s. Type 2 but so early. I watched the negative side too. My aunt got a sore on her leg. I watched it get debrided. My mom lost her foot and got progressively worse. I watched my grandma boil her syringes. My sister and I had to watch and make sure her dose was right. She couldn’t see.” (P12).

“I had a long family history. My great grandmother was small and petite. She took insulin shots. Both her children were diabetic. I remember her blood sugars would go so low. She had amputations up to her knees and she died young. Dad and mom were both diabetic. Dad never really took take of himself. He was in denial. He ended up with kidney disease and dialysis for 8 years before he died”. (P14)

“I have been afraid of what it can do to a person. I remember my parents complaining of low blood sugar. Mom was in the hospital and unresponsive. She wasn’t her. She couldn’t speak. Just looked at me. It was scary to see your parent in such a state. It made me think I would be afraid for my loved ones to see me like that”. (P15)

“Fear for my loved ones to see me like that”. Given the childhood and adult memories of life in the family with diabetes, it would follow that thoughts would drift toward the possibilities of a
personal encounter with diabetes. Many of those interviewed stated they were not surprised at their diagnosis, being reminded of its prevalence in the community and their own personal family history.

“I grew up watching both my parents with diabetes. Having to do shots. No regular soda with sugar, sweet and low, diabetic foods, no real butter. Diet everything. I saw glucose tablets, lots of blood testing, syringes. It was an accepted fact that I would get diabetes and not to even fight it in the beginning. I’m gonna get it. I’m gonna get it. As an adult now, I have a better understanding”. (P15)

“I knew I was going to get it. Genetics and the way I am built. At 16 I started drinking heavy and gained 40 pounds. It was always in the back of my mind that I would get diabetes. I quit drinking at 29, smoking at 42. I was prediabetic in my mid 40’s. My aunts and uncles had it. It was part of life. I accepted it”. (P05).

“I was a gestational diabetic and I wasn’t surprised. I had a lot of friends who were also. I was fine till 2003. Mom drank, got sober and found out she had diabetes. I have watched community members within the last 5-6 years have complications and lose legs”. (P10)

“I don’t want to go down that route. It happened to a couple of my aunts, one almost went blind. It was okay. She worked at it and she lost mega weight and she maintained it. The other one not so much. She ended up losing her leg, it got amputated and she ended up going blind and then she was on dialysis. And then she passed. Flashes of her come to me a lot”. (P08)

**Thinking about why diabetes occurs.** All participants were asked their thoughts on what causes diabetes. Responses were varied, ranging from various lifestyle habits that included poor choices, lack of exercise, obesity and alcohol to genetics. Some referred to cultural changes over the last few centuries. All acknowledged the fact that there are very real factors that cause diabetes.

P04 felt that the loss of the Mohawk language to this generation was a huge contributor. “We changed when we lost our Mohawk language. Families just watch TV and don’t talk. No one moves. There is no exercise.”
“When they put the Seaway in in the late 1950s, it destroyed our community eating habits. Did a lot of fishing. We supplemented with potatoes, starches and bread. We had an abundance of fish. Lots of fish. We no longer has the fish so we filled our guts with potatoes, bread and starch instead of fish. That’s what contributed to the spike in diabetes. I don’t know if there is a study on that. Plus throw in alcohol. It is rampant. We are dealing with sugar. Alcoholics are destined to be diabetics. We got diabetics on my mother’s side and alcoholism on my father’s side”. (P05)

“Genetic, food, no exercise. There are a lot of big people here. I don’t want to be like that”. (P09)

“As a people what we used to do to stave off diabetes, we don’t do anymore. Lifestyle. Everyone’s on the go. Pizza and wings are huge here. We need to go back to old ways of cooking from the garden. Also genetics. I am a diabetic and my mother is. Alcoholism. There are lots of calories in beer and mixed drinks. People do not just drink socially. They drink a lot. Once they get sober, they get diabetes”. (P10)

“Genetics. We eat different than our ancestors. Like why do kids have so many allergies to milk? Native people did not have cows. Did not have milk. It was introduced to us. We can’t tolerate it. Also, our roles have changed. Men and women had different roles. It used to be all physical. Now is sedentary”. (P12)

“The diet around here. Cheaper food is more unhealthy. Buy lean meat and pay $20 for a few pieces. In the pasta aisle, it is a dollar for a pound of macaroni or spaghetti. Grains are cheaper. A whole meal with pasta and sauce is under $5. You can feed a whole family and it is easy to make. I saw my parents do that. We had pasta 4 days a week”. (P15)

**Getting a positive diagnosis of diabetes.** A diagnosis of diabetes can be traumatic for anyone to receive. In light of the unrelenting presence of diabetes in the Mohawk community and a personal family history of it, and in spite of any personal expectations, being informed of its arrival can wreak havoc in anyone’s life plans. All participants experienced some sort of emotion that ran the gamut from
denial and anger to immediate acceptance. These emotions would have an eventual effect on their diabetes treatment.

“What does that do? I thought it was like a cold. You catch it and then it goes. They put me on pills and a diet. Said you can’t eat this and that. I ate it anyway. Pizza, wings, spaghetti, tons of bread. I kept on drinking. All of a sudden my blood sugar was 300 then 460. I felt good”. (P02)

“When I found out I had diabetes, I thought I wasn’t going to live long. I was 25. I had seen my grandparents and other family members with it. At that time, there was not much information on diabetes. They told me I had it and just gave me pills. That was it. I wasn’t really taught anything about it”. (P03)

“There was diabetes on mom’s side and alcoholism on dads. I knew eventually it was going to happen. In the beginning, it was quick nutritional education and get exercise. No major changes, just be more aware of it. If I was offered spaghetti, I would eat it. Three plates of it. I was defiant. (P05)

“At first I said okay. Later on, I started to get a little scared. I was feeling tired”. (P06)

“A lot of it is by myself. I won’t put it off on anybody else. It is at night when I am by myself that it bothered me. It didn’t right away when I got the initial phone call. When she told me I’m like…great. I was kind of numbing in a way. Then I got home. Oh my God it happened so fast. And she was well I am going to send a prescription over and you need to do it. I went after work and picked up my meds and started”. (P08)

“I pretended not to have it. I took my medicine hit and miss. I didn’t want to change the way I was living. I thought I lasted this long. I was angry. I thought it wasn’t going to happen. After I got over the anger, I was nervous because I knew all the negative things that could happen”. (P12).

Theme one relates well to Leininger’s culture care theory in the tenet of cultural values and beliefs. Life with diabetes was deeply imbedded in the culture of the community. Mohawk community members were surrounded by family and friends, resulting in an attitude of hopelessness, resignation
and acceptance upon diagnosis. This also ties in with the group emphasis and pragmatism so common in the community.

**Theme two: Everything I am going through is brand new.** Once diagnosed with diabetes, the importance and implications of chance became noticeably relevant in their lives. This is evidenced by the three components were identified in this theme. These included *experiencing major changes in lifestyle, fitting work into the new routine, and working on diet and exercise.*

**Experiencing major changes in lifestyle.** The diagnosis of diabetes brings many changes to one’s lifestyle. Participants previously identified feelings of anger, sadness, numbness and denial. In this, most indicated that, diabetes, while somewhat expected, and experienced through the lives of other family members, was about to change their life. For some, it did not change immediately. They resumed all daily activities, both healthy and unhealthy. In some instances, it took either an event or a change in the status quo of their functioning to prompt attention.

“Well I got my toes cut off. I got 2 toes left on one and I got my big one cut off on the other. I’ll be walking fast and then I will start stumbling. But anyways, I was over to the clinic there and I says I gotta start doing something. So I started exercising. Walk around a mile. Lift up some weights. Then I noticed I was losing some weight. I just kept going”. (P02)

“I had this book. It was called Eat Right for your Type. I love that book and it did wonders for me years ago. I was about a size 26 going into a size 28 and then the next thing over time, I would say a good six months I was dropping it like crazy and I stuck with it. So now today I am trying to incorporate that what is good for my blood type with this end of it, the diabetic end. I try and pick and choose the foods that are good for me because first I’m told I gotta lose some weight which I know, and the combination thing you know. So that’s what I am doing”. (P08)

“I had to take care. People get overwhelmed by it. I will not let it rule my life. I got a referral and came here”. (P07)
“Two years in I was like this sucks. I was depressed. I checked my blood sugar three times a day. There were highs and lows. I was sick of it. Annoyed. I don’t care. Do what I want. My job situations did not help. Poor eating. My A1C was 12.4. I started doing everything right. The diabetes center, meditations, nutrition, the gym. Three months later, my A1C was 7.5”. (P10)

“I got scared when I started having vision problems. Two of my aunts were blind. My grandmother was blind. My mom, two of them were amputees. I am more focused on it lately”. (P12)

“I decided to make a change when I saw a new doctor outside the tribe. In a different town. He explained to me exactly what needs to be done in order to prevent me from developing it further. I went out of town because I felt I couldn’t get specialized care there. So many doctors go through and it takes months to get an appointment. I wanted to start that day. If I had an excuse to put it off I would. A bad habit I am trying to replace”. … I enrolled in MFH. I had been avoiding a commitment feeling I won’t be able to do this or that. I really fear trying something new. Putting myself out there. An issue I am trying to solve”. (P15)

“My dad passed away in 2016 from health problems stemming from diabetes. Seeing that made me think about if I wanted to be like that and to take care of myself better”. (P15)

**Fitting work into the new routine.** There were a few participants who were employed prior to and after their diagnosis. All experienced challenges as they attempted to blend work and the management of their diabetes. Regular meal and snack time as well as, scheduled blood sugar checks seemed to be the issue. It was unclear whether all employers were supportive of this routine or if the participants mentioned it to them.

“When I was working at the casino, lunch breaks were spread out. I would have to go in the back and eat something. Can’t eat in between and I could feel my sugar dropping. I would forget to carry stuff and would let it go. By lunch time I could kill somebody. It takes me about 20 minutes to get it back up. Now I try to carry a bar or something”. (P03)
“It also gets hectic at work and it interferes in the routine I am trying to create. I am all about my job and I don’t make the time. I am on the clock on somebody else’s dime. My boss is great though. She says do what you need to do. I am quick to be obliging to other employees, but not for myself”. (P08)

“Work interferes with a good routine. I have trouble fitting everything in. Theresa offered to write me off for just half days. I try and stop on the way to work. My boss is good but every time I want to do that, she tells me there is an 8:00 meeting”. (P12)

**Working on diet and exercise.** Ultimately, part of the lifestyle changes include a routine of exercise and nutritional balance. This involves examining daily activities and eating habits. Change comes slowly, and with many challenges. Many participants were quick to voice frustration over what they feel are large numbers of restaurants that focus on unhealthy food choices such as pizza and chicken wings. Some noted difficulty in adjusting to a diet with less starch and more vegetables.

“Before I had diabetes, I would go to work, have beer after work then eat a supper of either subs or pizza. I would eat only one meal a day. My old diet was all take out. Now I eat breakfast with 2 eggs, bacon, egg sandwiches, grilled cheese and hot dogs. I am not used to cooking for one. Short, sweet and easy. I need to eat more vegetables. My coffee at McDonalds used to be 6/6 cream /sugar. Now I get 6/2 Splenda. Baby steps.”. (P11)

“My husband cooks. Meat, salad, vegetables. Balanced meal. I like carbs. He goes to bed early. I am alone. I snack. But I read the bags of chips. On weekends I am bad if granddaughters not with me. When my A1C is good, I give myself more latitude. I am trying to walk more. I have a pedometer. The girls at work are helpful. We have a walk across Canada challenge. I aim for 10,000 on weekends and 6.000 during the week”. (P12)

“I drink diet everything. I take my medications faithfully. I try to make sure all is balanced. But I do not give up dessert. I do not exercise a lot. I hate to sweat. I eat small frequent meals. I have the occasional alcoholic drink. And I stay busy all day. My daughter is vegetarian. I am mindful of eating that way”. (P10)

“I don’t support the restaurants. Everything is salty and fried”. (P04)
“Trying to transition to healthy alternatives people can find daunting. Dad had trouble. Fried bread. The salt pork in corn soup. High salt. It is common in our community. Dad grew up in the desert. They used what they had. There were not a lot of resources. Fried bread, cooking oil. They would save the grease from the hamburger and dab the bread in it. Lots of potatoes. Mix them with hamburger and eat as a meal. Or spam or hotdogs. The generation before, that’s how they cooked”.

(P15)

In comparison of Leininger’s Sunrise Enabler, theme two relates well with both the technological and educational tenets. Here, the newly diagnosed diabetes are adjusting their lifestyle to a medication and lifestyle change that follows the ADA standards of care as outlined by Indian Health Service. This also requires much education and support. It also represents a time orientation of the present, which is very much a part of Mohawk culture.

Theme 3: Feeling like I am sinking in quicksand. Integration of healthy habits into lifestyle were evident in this theme. Sticking to and living the program, balancing body, mind and spirit, remembering, and native things.

Sticking to and living the program. All participants feel it is important to adopt habits that reflect an ongoing interest in caring for their health. With this is also the admission that change does not come easy. Once the decision has been made to take a stance and work toward health, it requires persistence and a willingness to forge ahead, even when discouragement comes. For some, there is an ongoing struggle between the should dos and should not dos, the good and bad habits. It also means being strong in the face of temptation. A few participants admitted to times in their newly required management of their diabetes when they felt frustrated and helpless, depressed and in a slump, trying to make changes but sliding back to old habits and eating patterns.
“I tend to go to food. I am like a yo yo. I go into depression a lot. I am bothered with my back and feet”. (P06).

“I get doing like, and it makes me crazy about myself because its like I know what I am supposed to be doing up here. Why am I not physically following through? At times I feel like I am stuck in quicksand or something and then I am sitting there by myself and crying and I say what is wrong with you you stupid idiot you know because I know what I am supposed to be doing”. (P08)

“My father got depressed and frustrated. He would say why bother? You try hard and still see your numbers high. So you say why bother. I watch others. They get discouraged and want to give up. They get into a slump and it feels like they are ruined for life”. (P07)

“I remember as a teenager being afraid of how destructive the disease could be. There were mixed feelings about how I have had to change habits and behaviors. As a teenager I was upset because I would have to change my eating habits. And, I had very unhealthy eating habits. My main complaint would be that would have to eat clean healthy food, instead of pizza, tacos, ice cream”. (P15)

“My brother, he passed on now. He got his leg cut off. I said brother come to the diabetes center and walk with me. He says ahhhh. I am going to eat what I want and drink what I want. I used to watch him drink 4 cups of coffee and drink a big bottle of soda. Putting chips in his mouth. Chicken wings, pizza. You want some? I would say no no no”. (P02)

“I try and take care of myself. If my blood sugar is up, I calm myself and drink fluids. I also cut down on my sugars. I check my sugar three times a day. I try to exercise as much as I can. Winter is hard”. (P03)

“Today I am not as radical as I was 15 years ago. I try to do a little better. Radical or defiant. It is part of stubbornness of not fully falling in line with a truly healthy diet. I see people eating salads all the time. I can’t do that. I was told you can eat a potato, just don’t eat a lot of them. I am 62 now. I am not as defiant as I used to be. I still eat spaghetti but once a week though”. (P05)

“I do what I should do. Taking blood, medications. It is all about food and exercise. Living with diabetes is not much of a life change because I do what I should do. If I keep on, I will be ok. Stick to the program”. (P06)
“I will start out I am like a little robot, you gotta do this. But then something comes up and I get busy and once I fall so to speak it is hard to get in that routine again. So I have kinda been bad for the last 2 weeks. I was good for the first 2 weeks for sure. I got back a little bit on track but not 100%. It’s like don’t beat yourself up anymore. It’s not a test. So that’s where I’m at with it right now. . . I do not want to be on meds. I asked my doctor point blank about getting off the meds. She says get my numbers down, work with dietician and lose weight, change eating habits. I see it very likely. There is the light at the end of the tunnel”. (P08)

“Do you want me to talk about what I should do or what I do? On good days, I am consistent with my medications and blood sugar checks”. (P12)

“I am drinking a lot more water than I used to. I used to drink diet soda, but less now. I still drink more soda than the average person but it is diet soda. I eat 3 meals a day, take smaller portions, don’t skip meals, try and exercise 150 minutes/week and drink water”. (p14).

**Balancing body, mind and spirit.** A few of those interviewed felt it was important to work toward achieving a balance in one’s life. Three areas of importance were body, mind and spirit. Balance in these areas would work to propel one forward, and provide strength during times when discouragement sets in. Body balance was referred to as taking care of self and sticking to lifestyle changes in order to keep the diabetes under control. Mind balance seemed to point to attitude and the ability to look within self, and spirit balance pointed to relationships with the Creator and with people.

“Yes, I am here every day at 3:00. Every day! At home I mow my own lawn, rake it, do everything. I wash my own cars and all that. My wife says you shouldn’t’ do that. I say I feel good and that’s why. I am 74. Use me as an example. I am off insulin!”.

“My approach is different. Do I want that? Do I need it? The attitude. I know what happens in the body. Is it a matter of getting older? I don’t know. Each year I am more aware of how old I am. My family does not have longevity”. (P05)
“I now portion my food. I used to stuff myself. I don’t do that anymore. I guess you just have to work at it”. (P09)

“Sometimes I am strong minded. I can sit with family and eat something else. Or I might take a little portion and drink lots of water”. (P03)

“It is body, mind and spirit. You can’t have one without the other. They must be balanced out right. I go into a depression a lot. When I pray, I look at my spirit and realize I am in a slump. I was brought up Catholic and I also go traditionally. It is all about love, kindness and being good to people. Honor the earth and honor people”. (P06)

“Optimistic people are the ones with all the health issues. I have changed my perception of other people. They are just whiners. I want to say to them your complaints are superficial. You don’t understand what it is like to live with a clinical condition you are trying to control and can’t. All these things people take for granted. It has made me more grateful, even more now. I can see. I can walk”. (P10)

Remembering. Life goes on every day. In all of life’s daily activities, most participants felt it was important to be mindful, to remember their responsibility to maintain their diabetes. This is underscored especially when they see a family or community member experience severe consequences from a life of diabetes.

“I put it in my mind what can happen to me if I don’t watch it. My neighbors have had toes amputated. I have high blood pressure. With the two together, I really have to watch my salt intake. Now I read labels. You get used to it after so many years. Put it in your mind that you have it and what you can do”. (P03)

“My son in law has type 1. Both of my grandkids watch. They are athletic. The doctor told them to be careful or they will jump into the pool of diabetics”. (P04)

“Keep on remembering your restrictions. I can’t have chips or pretzels. I watch my wife do it. I quit drinking. That was hard because I liked it”. (P02)
“It makes you bittersweet. I am more aware of what I eat and my lifestyle. I cut down on what I eat. Living with diabetes is not much of a life change because I do what I should do. I see how important it is with my numbers”. (P06)

“It has changed my life. I have to be conscious of what I am doing and what I put in my mouth”. (P14)

“Made me more conscious of what I am doing, eating, lifestyle. Because I did fall off that wagon when I was doing so good. Hopefully I can make something good out of something bad. Get me back on that again. I felt go great when I was doing that eat right for your type. My energy levels skyrocketed. I lost weight. I felt so good. I miss that”. (P08)

“Well keep trying to be healthy and do the best I can. I will live my life. I am not going to deny myself anything. I can’t control what will happen. I can to a certain point. I don’t go through my day saying “You are a diabetic” However every night when I take my meds I am reminded that “You are a diabetic” So you have to be conscious of that, and take some protein with that so you don’t have a sugar low. But I don’t live my life thinking about it. And I am not going to. I am going to still do what I want in moderation”. (P10)

**Native things.** Indian medicine is a large part of the Mohawk culture. All participants acknowledged its use in the community, even discussing where to obtain it. However, there were only a few who actually used it in their lives. A few felt that combining it with Western medicine would not be beneficial as they were already using Western medicine. None of them used it for their diabetes, while one had a family member that did.

“We do use some native things. Cedar and Indian tobacco for prayers and smudging to the Creator. Pine for colds. Plantain salve for sores and cuts”. (P14)

“I believe that Indian medicine is good, but it is not a treatment. When I was young, my grandmother made something. I can’t use it anymore. My husband drinks. It loses its power. Since my aunt passed away 5 years ago, I have stopped using the tea. She knew it all. I don’t know enough. I do
believe they have power, that they work. Strawberries have power. I believe in the power of false
faces. When people are really really sick, they help”. (P12)

“I have worked with traditional healers, but I don’t use any. I take magnesium and cinnamon. I
have tried teas. I am open minded”. (P10)

“Sweet flag. It’s a root and I chew it for a cold. It is picked in the fall. They put it in an onion
bag and hang it to dry”. (P13)

“There is a root. You boil it into a tea for colds and joints. The deer eat it. My nephew gave it
to my brother after he almost got his leg cut off. He walks good now. My sister in law is a medicine
doctor. My wife brought home some tea once. Holy smokes it was strong. I only took it once”. (P02)

“What was explained to me a long time ago, if I am taking clinical medicine, then Indian
medicine will not work. It is no longer pure. I am okay with that. I know of 2 people who went with
Indian medicine. The guy, it came back. The woman, not yet. I am of the opinion that clinical medicine
and Indian medicine will not work together. That is my approach to it”. (P05)

“I gave skunk oil to my kids. It helped them not to get sick. It’s just like castor oil. It helped
them. They always got better. My sister is actually using Indian medicine for her blood sugar. It is not
real high. She does not exercise and eats real good”. (P09)

“I am wanting to back in...not as much as I used to. Because I found that helped me a lot with a
lot of different things. I had heart issues and that helped me and it prevented having to have stents put
in. And that too, I fell off the little wagon cause I was doing it as a maintenance twice a year. Making a
tea for 2 weeks in spring and fall. I stopped doing it. Now I feel that is what has happened to me. Can’t
find it this time of year. I picked my own. I am going to make some phone calls and see”. (P08)

Also mentioned was the Longhouse, a traditional gathering place for Mohawk ceremonial
activities and celebrations. Three of the 15 participants actually took part in Longhouse ceremonies.
“At the longhouse ceremonies, there is always activity (dancing) before lunch. For food we have soup. It is okay. Has lots of vegetables. Many times there is wild game. Strawberry drink is medicine and is sweetened with maple syrup instead of sugar. You only take a little bit. There is fried bread...that is not as healthy. We have pieces of cake and cookies in a basket that gets passed around. You only take a piece. There is tea steeping on the stove if anyone feels they need it. Cornbread is a traditional food”. (p14)

“Longhouse foods fit with diabetic diet. In the green bean ceremony, there is beans and spices. The strawberry drink has no sugar. Hash and fried bread were not around 200 years ago”. (P09)

Theme three’s integration of healthy habits follows Leininger’s enabler tenets of cultural values and lifeways, religious and philosophical factors, and economic factors. It also is indicative of the Mohawk viewpoint of holism, patience, and religion as a way of life.

Theme four: Breaking the cycle.

All of the informants expressed the importance of change, and had clear ideas on how it should be implemented. Three components were evident in this theme. These included going back to basics, understanding, and talking and changing.

Going back to basics. Many participants voiced concern over the lack of basic skills the up and coming generations were exhibiting. These included lack of cooking and grocery shopping as well as gardening. Also mentioned here were the lifestyles of the young families and their children. Sports are a big part of life in the community, and they require a lifestyle of travel and on the go eating. These can contribute to future issues with diabetes.

“And then everybody is so busy running their kids to 4 different hockey teams and lacrosse teams. It is always on the go food. So people are not home cooking home cooked food anymore. And so it is food on the go. No homemade snacks being brought. Arena food...nachos and hotdogs. Gravy, poutine. Which is fine once in a while. I think if we had more options, like more vegetarian options, a place where sandwiches and wraps you could put healthy things on them, if it was available. Going back to the old ways of cooking food from the garden”. (P10)
“Go back to the basics of changing our eating habits. It’s a start. They have different nutrition events, you know. Cooking classes. Nutrition events. Keep hitting it hitting it. In the grade schools. Start em really young. At Mohawk school go in with nutrition events. Looking at their menu, it is not good. Canned goods, processed. In the springtime go outside and plant a garden. Kids love to be outside. Bring the vegetables in the school”. (P08)

“People need to go back to the original foods. Corn, beans and squash”. (P14)

“Everybody works. No time for cooking. We need to come back to family. Shut off the phones and the TV. Eat together. Learn about God. Talk to each other”. (P06)

**Understanding.** Many of those interviewed felt there was lack of full understanding of what diabetes is and how it affect the individual. One participant admitted to thinking it was a cold that could be cured with a pill. Others felt the disease was not taken seriously by many who are affected by it, or they allow discouragement and failure to overcome their desire to make it work. Also noted was the lack of understanding by providers. Some have observed specific behaviors by people in the community that was alarming.

“Some people just don’t care. They take their insulin to bars. They don’t understand how their medicines work. People are scared. There is lots of fear. If they let it, it can overcome their life. There is a cycle and people don’t know how to break out of it. Again, there is no education and understanding of how meds work. Doctors put you on meds and never explain the side effects. People think it will cure them. You don’t really know what they are doing in their home”. (P07)

“It’s all about options. What are my options? What choices do I have? Education of nutrition, physical activities, medication”. (P05)
“I had a cousin who lost her leg. Another customer lost her leg. They thought they could just take the shot and still eat whatever they wanted”. (P06)

“People are not really aware of the side effects of diabetes. When doctors start to lecture, I shut down. You can prescribe all you want, but if you don’t understand what I am going through, that’s a whole different thing”. (P07)

“Some people don’t understand what diabetes is. They hear it and think I’m gonna get it. Our future. It doesn’t have to be that way. Understand from a young age that it doesn’t have to be that way. You don’t have to have diabetes”. (P15)

Talking and changing. Participants noted that understanding changes if there is conversation taking place. Talk. The importance of being informed was mentioned by more than one participant. Making informed choices. Getting information about diabetes and what it can do to the body is imperative.

“It’s all about being informed to make informed choices. A lot of people don’t want to deal with that. But if somebody has the initiative to put that out there and make it available. Somebody has to step up to the plate and make it available. If someone is there and has that to offer when someone reaches out. Make informed choices. Get all the information you can. If you want to eat spaghetti it is your choice but be aware of what it does to your body. Also be aware of the people it has killed. When I was young and stupid in my twenties I didn’t care. As time went by I realized just how precious life is. So these perspectives expanding our horizon. Unfortunately some people are too busy. Ask people what they have to offer. I have experience from what works and what doesn’t. A workshop. A diabetes workshop. More in the school curriculum. Do they still have health? I don’t remember any mention of diabetes. More personalized. No generalities. Show them what diabetes does. Amputations and bodily disfigurements”. (P05)

“I just keep on telling my grandkids. I have one 17 years old. Knows it all. When I was 17 I was in jail. I say grandson, anything you want to do I have done. I have robbed, I did everything. I got drunk. I have been in jail. It’s not worth it. Get an education. He don’t want to go to college. I tell my son don’t make him go if he doesn’t want to”. (P02)

“Big need for more education on the consequences. I feel the medical doctors over there are not diabetic. We need a diabetes counselor when they are going through issues. Someone who has
been through it. I had a diabetic driver. I told her you are young. Take care of things. She went and ordered fast food at a stop!” (P07)

“Be more strict. Warn people about what diabetes can do. The younger generation. They don’t want to be told”. (P02)

Cultural tenets reflected in theme four include cultural values and beliefs, kinship and social factors and educational factors. Mohawk values of patience, present orientation and harmony with nature describe values related to culture.

**Theme five: Keeping the circle strong.** The importance of a culturally appropriate approach in maintaining a healthy thriving community was underscored by participants. Three components were evident in this theme. These included *educating families, strengthening the community, and looking to the future.*

**Educating families.** A few participants expressed concern for future generations. They noted hectic lifestyle, poor eating habits, lack of exercise and obesity as genuine issues that could impact future family health. They questioned the types of health education in the schools, wondering if diabetes and its consequences was a topic discussed there. As well, they suggested that not only children, but their parents, the whole circle of family needs to know more about diabetes. Nine out of fifteen participants expressed concern over the generations coming up. Questions arose over the youth in the community, their understanding of what diabetes is, and how it could affect them. Others voiced concern over the younger family unit and the lack of healthy dietary guidelines as well as hectic work and after school schedules. These promoted poor eating habits and a steady diet of fast foods. Still others wished for community restaurants that offered healthier choices than the standard pizza, wings,
hamburgers and fries. Education in grade school, many felt, was the key. Talking about diabetes and how it would affect them was important.

“My grandkids rely on technology. It’s not healthy. One of my granddaughters. I am really worried about her. She has indicators. She eats a lot. I push her to move. Should we focus on weight? She is only 12. I wish for a cure. It comes down to us educating the parents. Be proactive. I don’t see kids playing outside. It was different when we were kids”. (P12)

“Acknowledge it and talk about it in families, educating each other and helping people to understand….educate the youth, but older people as well. They are the ones that raise the youth. If you told me as a young person that I can change it and it’s not always going to be...how to check your sugar and all that. Take away all that fear of change”. (P15)

“Kids need to learn about proper foods to keep the body strong. They have poor food habits and no exercise”. (P06)

“Are they teaching about diabetes in high school or even elementary? It is a major problem. If nobody’s talking about it nothing changes. It’s the same thing with substance abuse. More education. There is help there”. (P05)

“The cycle is not stopping. There is a generational eating issue”. (P07)

“My brother used to weigh around 400 pounds. Diabetic, hypertension. He had gastric bypass surgery but growing up, my mother used to bring home a large pizza just for him. Or 10 hamburgers from McDonalds. Just for him. You wonder why kids are obese. You grow up and it goes on the parents. I get into this saying that cycles can be changed. Circles need to get broken. Just because your parents did it doesn’t mean you need to. Why don’t we try to teach our kids different ways? Times are changing. Respect parents, but some habits need to be changed”. (P08)

“I know a girl. She is a friend of mine’s daughter. She has a 10-year-old son. He is huge. And he is so fussy. I said, I am like his grandma. He calls me Tota G. He loves coming to my house but he wanted to stop coming because I didn’t have all the good things he likes to eat. I would give him a carrot stick. I don’t like that. Why not, have you ever had one? I go then you can’t say you don’t like it if you never had one. He would sit there and kind of pout. I said you are far from gonna be starving
here. He is huge and his mother enables him. He just sits there and plays his game. I said make him go outside and get some exercise. She shows and says and speaks the concern but there is no follow through. I said you need to change that. You are the parent. She is like my mom. She would go get McDonalds and bring it home. Here you go. And the kid doesn’t know how to eat anything good for him. He really doesn’t. I really think they need to hammer away at that level to break that circle”. (P08)

**Strengthening the community.** Community services play an important role in the provision of healthcare, support and education in any community. All participants expressed appreciation and support for the Diabetes Center, noting its positive influence, culturally appropriate provision of care, and impact on strengthening their community.

“The diabetes center has helped me a lot. I get all my supplies there. Classes. Programs and speakers. Workshops”. (P03)

“There is nothing like this on other reservations. People here are lucky. This is unique. Diabetes is an epidemic. This is helping with the epidemic. It gives us an option over just doctor visits. It is needed”. (P07)

“I am glad it is here. You don’t have to pay”. (P09)

“Model what you are teaching people. Use me as an example. They took me off insulin”. (P02). “Number one they are so welcoming, so welcoming. When you come in they are like hello how are you. They care, and you can tell they care and it’s not fake. That’s one thing. That’s what makes me come back. We should be grateful as a community to have this place. This place has been given to us by the creator to make us well. I like coming here.

I prefer to come here than go to the clinic. It feels more comfortable and I know everybody here. I have worked with some of them. Community functions. And you can always like drop in. If you are having a rough time you can say I need an appointment with the nurse practitioner and they are right on it. No questions asked. And the fact that she comes here twice a month and sees her diabetic patients”. (P10)
“They are supportive here. The Mohawk word for naughty is *Kawiluxan*. They don’t make me feel naughty”. (P12)

“The diabetes center helped a lot of people understand their situation with diabetes. People are coming forward and starting to try and take care of themselves a little more. I didn’t always understand the concepts of what it does to your body. I am learning more and being aware”. (P14)

**Looking to the future.** As the interview process wound down, participants were asked about their future and the future of their community. Many were optimistic. Some had suggestions for program improvements.

“I would like to see a camp for new diabetics. A boot camp to help them get started with their diabetes. Get through to the employers. I felt alone. My husband doesn’t have diabetes. My family is mostly gone. It would be a good thing for the people. Especially a community like the reserve. Maybe even a health program in the summer for all the kids”. (P12)

“I have a feeling I will be on insulin”. (P11)

“What they do now affects what happens to them in the future. What their parents feed them definitely will affect their future. I think we will see more diabetes with the 1990-2000 generation. They are turning mid 20s now”. (P10)

“I want to see my great grandson grow up. They say they talk about seven generations and projecting six more. I can remember my great grandfather. Now I feel I am in the middle of those generations. Now I get to meet my great grandson. My great grandfather said to our children. I wish I could see you grow up. I feel the same way”. (P12)
Cultural implications of theme five include political and legal factors, economic factors, kinship and social factors, and educational factors. Mohawk tenets change to a more futuristic orientation, with a continuing family focus. Holism, partnership and cooperation are also evident here.

Summary

Diabetes affects American Indian/Alaska Native populations at rates beyond any other group in the US (IHS, 2014). The results of this study provided a glimpse into one tribe dealing with this disease, heretofore, not described in the literature. A qualitative ethnographic approach was used in this study to explore, describe, and develop a cultural understanding of how 15 American Indians from the St Regis Mohawk Tribe perceived and managed Type II diabetes. The aim was to understand how the Mohawk culture affected adjustment and acceptance to a life with diabetes, as well as the interventions associated with diabetic care from a Mohawk perspective. Men and women who met the criteria were eligible for participation in the study: above the age of 18 years, self-identified and tribally enrolled as Mohawk Indians, and previously diagnosed with Type II diabetes mellitus.

The data analysis and findings of the study resulted in the identification of five major themes relevant to the topic and research questions: (1) It’s like the whole reservation is diabetic, (2) Everything I am going through is brand new, 3) Feeling like you are sinking in quicksand, (4) Breaking the cycle, and (5) Keeping the circle strong. Participants expressed a strong connection with being Mohawk and being diabetic. They had seen tremendously destructive health outcomes as a result of the disease in the form of blindness, amputations, dialysis and death. Each participant had such a story and with multiple members and generations of their families. Their concept of diabetes seemed imbedded in the knowledge that diabetes was strongly evident in their community and the experiences they had either
seen or heard about from their family members. This concept also framed their expectations regarding personal risk potential and reactions upon diagnosis. There was a certain inevitability and at times hopelessness before, during and after diagnosis. In thinking about what causes diabetes, they returned to the connection with community and family, as well as looking at lifestyle issues. These lifestyle issues included alcohol use, genetics, inactivity and poor eating habits.

Once diagnosed with diabetes, participants acknowledged the newness of their situation, expressing and acknowledging how in spite of their connection with family history and community, their situation was unique to them requiring personal adjustment and focus. As they progressed in their journey with diabetes, fear, frustration, anger, and sadness were replaced with acceptance and the knowledge that they were able to take control of their illness and slowly begin to move toward a comfortable new normal always within the security of the community.

Many participants identified the issues surrounding diabetes as a cycle. These issues included the necessity to return to a basic lifestyle, developing an understanding of what diabetes is and is not, and learning how to safely and appropriately care and advocate for self. The provision of accurate information was identified as essential to make informed and appropriate choices. Finally, in a look toward the future of the community, emphasis was placed on the importance of family and health. Concern was expressed over the lack of understanding young families have regarding healthy eating, available food and exercise. This seems to be tied in with both parents working and a busy schedule with sports and after school activities. Suggestions included educating family units on diabetes, nutrition and a healthy lifestyle, and supporting and strengthening the community through provision of solid programming. This is accomplished at the diabetes center, located at the heart of the Mohawk community.
Chapter 5 continues with an in-depth discussion, recommendation, and conclusion of the study.

The individual themes will be discussed and findings interpreted relevant to the literature review.
Chapter 5: Conclusions and Recommendations

The purpose of this focused ethnographic study was to explore, describe, and understand how American Indians from the St Regis Mohawk Tribe perceive and manage Type II diabetes.

The overarching research questions of this study asked:

1. How do the members of the St Regis Mohawk Tribe living with Type II diabetes define and describe the disease?

2. What cultural factors influence the management and health maintenance of Type II diabetes among the American Indian Mohawk?

To address the first research question, participants responded to several interview questions. From these responses, several major themes emerged. Themes include but are not limited to the following: It’s like the whole reservation is diabetic, Everything I am going through is brand new, Feeling like you are sinking in quicksand, Breaking the cycle, Keeping the circle strong.

To address the second question, in addition to the interview, the investigator spent many hours on site observing and interacting with MFH participants and staff during both scheduled exercise time and special events. Visits were also made to community businesses and cultural centers in order to capture a sense of community life.

Chapter IV presented the results, procedures, and summary of findings. The current chapter provides an interpretation of the findings previously revealed in Chapter IV. Information presented in Chapter 5 includes: interpretation of the findings, conclusions, limitations, implications for nursing practice, and future research recommendations.
Discussion of Findings

Analysis of the interview data obtained from the 15 interviews resulted in thick description of each individual’s definitions and descriptions of their life with diabetes. In addition, the researcher, while functioning as an information gatherer with a Western medical perspective and work background (etic), was also a member of the tribe. This characteristic enabled the researcher to add an emic perspective to the gathering and analysis of data, as well as promoting an atmosphere of acceptance and trust in the building of relationships and gaining entrée. While each participant’s viewpoint was individual and personal, there were many similar thoughts and feelings. Additional findings, adding to the informant’s accounts were the field notes on various educational activities, community observations, and descriptions of the physical environment within the diabetes center.

“It’s Like the Whole Reservation Is Diabetic!”

Perhaps one of the most powerful statements uttered during the interviews is the title of this theme. It reveals the sheer magnitude of the impact diabetes has had in the American Indian population, specifically the St Regis Mohawks of Akwesasne. Fourteen out of the 15 interviewed acknowledged the presence of diabetes and its impression on them from a young age on up, referring to diabetes as “right in the reservation”. This presence was manifest in the lives of their immediate family – mothers, fathers, aunts, uncles, grandparents and siblings and all recounted stories of how diabetes had affected their life. Considering this, diabetes programs should incorporate mental and emotional support to anticipate and care for feelings of hopelessness, depression, anxiety and anger that surfaces around familial and community histories and outcomes of diabetes, especially in high-incidence American Indian communities.
The seeming omnipresence of the disease appeared to have an impact on their beliefs in causes of diabetes as well as the variety of their reactions over their own personal diagnosis with diabetes. Many felt diabetes was caused by genetics, stating it “was in the families”, while others noted lifestyle, obesity and poor nutrition as potential causes of diabetes. Two persons felt diabetes was caused by either excessive drinking or stopping drinking. One woman said she stopped drinking and got diabetes, while another recounted that her mother quit drinking, was working on her health, and was diagnosed with diabetes. These mistaken disease etiologies point to not only a need for education, but targets specific areas, that of how one actually acquires the disease and why.

Feelings upon diagnosis ranged from shock and disbelief, denial and anger to immediate acceptance. The overwhelming assumption in all was the inevitable expectation of a positive diagnosis at some point in their life.

This sense of inevitability was identified in previous work. Struthers et al (2003) conducted a phenomenological study of Lakota and Winnebago tribes to investigate their diabetic experience. A prevailing theme was life surrounded by diabetes, being all through the community. Gregory (1999) described diabetes as an all-powerful ever present disease among the Cree of Winnipeg and Manitoba Canada, stating everyone has it and all feel at risk for it. In addition, watching how the disease affected others in their community invoked a sense of fear for themselves. Many of the St Regis Mohawk participants echoed these sentiments.

Previous studies confirmed the belief of genetics and lifestyle in the American Indian population. Jacobs in a 2014 study of the Lumbee Indians in the southeastern portion of the United States reported a reference to immediate relatives with diabetes, and a belief that lifestyle (lack of exercise and poor diet) were contributors to diabetes. Satterfield in a 2003 qualitative descriptive study of tribes
throughout the United States refers to “American lifestyle” (stress, obesity family history, little activity, and poor eating habits) as causes of diabetes. Other studies by Lautenschiager & Smith (2006) and Cosby & Houlden (1996) reaffirm these findings.

Some of the feelings identified by St Regis Mohawk participants at diagnosis were those of anger, shock and denial. These feelings were concordant with findings by Struthers et al (2003) and Hernandez (1999). Gram et al (1996) noted grief, sadness and lack of hope. These were also identified in the interviews with Mohawk participants. This again supports the need for and importance of diabetes programming that is sensitive to and proactive in response to the emotional adjustments occurring with diagnosis in the American Indian.

Everything I Am Going Through Is Brand New

A positive diagnosis of diabetes in any individual presents challenges as the individual strives to make and adjust to changes in lifestyle. For the individuals of Akwesasne, this was no different. Many experienced a period of denial and refusal to adjust their previous habits and lifestyle. In some instances, adjustment and compliance came on the heels of a life altering change in health status such as amputation or vision loss.

Those in the workforce also experienced the added stress of diabetes management in a work environment that was not always conducive to new diabetic management. In addition, the whole process of medication adjustment along with new diet and exercise routines often resulted in blood sugar highs and lows, as well as concern for potential medication side effects. This often resulted in sentiments of frustration, depression and a sense of “sinking in quicksand”. In all of this was a striving to adjust to and comply with the changes diabetes had wrought in their lives.
Iwasaki (2006) in a study of tribes in Western Canada identified the daily stress related to day-to-day managing of diabetes as a major theme, sharing comments on the impact diabetes had on the daily lives and routines of the people there. Also identified was a feeling of helplessness, which was inferred in many of the Mohawk comments. Tiedt (2013) noted a feeling of vulnerability along with a “why bother” attitude and lack of self-care, which was similar to the findings in a 1999 study by Hernandez. This study reported the notion that life was too busy for diabetes, with no time to learn. This was partially identified in the St Regis Mohawk. Barton (2005) found the changes in diet and instructions on weight loss and exercise were difficult to accomplish among the Nuxalk in British Columbia, and many there found themselves “cheating”.

Denial and anger, along with the notion of noncompliance was a common theme noted in much of the literature found. Hernandez (1999) described a pattern of skipping medications and avoidance of routine, along with an attitude of minimizing diabetes and trying to live a normal life. In many instances, it took a threatening event of some sort to change the person’s direction and put them on a path toward health. This was also discovered among the Mohawk interviewees. In one instance, amputation was the triggering change in behavior.

While the present study identified a few participants with work struggles relating to diabetes management, Iwasaki (2006) noted lack of job opportunity related to the disabilities created by a life with diabetes.

“Feeling Like You are Sinking in Quicksand”

Most participants indicated that the diagnosis of diabetes and the changes it brought to their life required an adjustment that became easier over time. Many also stressed that a positive attitude was imperative. This included trying to maintain a balance in “body, mind and spirit”, and to keep on
remembering that diabetes is an ever present part of their life. All stressed the importance of diet, exercise and proper nutrition, as well as compliance with their medications in maintaining body balance. Mind balance referred to having the proper attitude toward their disease and the changes necessary for the best health. Spirit balance referred to relationships with the creator and other people. Three of the participants stressed the importance of positive relationships with others, valuing respect, love and honor for others.

Mind, body and spirit was also mentioned in the literature as an important aspect in diabetes care. Grams (1996) noted the importance of a balance in these areas, while Struthers (2003) spoke of traditional ways (prayer, medicine man and healing dreams) to balance, and Tiedt (2014), Shaw (2013) and Hernandez (1999) all mentioned the role spirituality can play in promoting balance. Barton (2005) discussed the inclusion of ceremonies.

Informants also acknowledged that the whole process of diabetic management is not an easy one. Many referred to other community members either in their family or in the periphery of their life who have had struggles, or continue to struggle with the complications diabetes brings on. These reminders spur them on to keep remembering to continue to manage their diabetes correctly, or as one Mohawk elder states, “Stick to the program”. This also keeps them mindful of the part diabetes plays in the Mohawk community.

Hernandez (1999) also described the process of integration of diabetes into one’s life immediately following a turning point moment. Diabetes would finally become a part of one’s life. This involved an inner knowing that promoted a taking care of self. Sherifali, in a 2012 study of First Nations people, determined a time when the people finally came to terms with their diabetes and its management. Iwasaki (20026) noted a desire to look after self with diet and exercise, Struthers (2003)
spoke of the people taking a personal role in their disease, Tiedt (2014) mentioned the importance of a routine, and Grams (1996) stressed the knowledge of the need for control and regulation of lifestyle and activities. In all of these, the thoughts and actions of the people of Akwesasne were similar.

More than half of those interviewed used traditional Indian medicine, though not for their diabetes. Many mentioned teas that were gathered in the fall. These teas were used for joint pain and for colds. Another person referred to plantain leaves, which were crushed and made into a salve for cuts and sores. Skunk oil was also noted to be commonly used in a way similar to castor oil. All participants knew where to obtain specific medicines. Of those not using Indian medicine, one participant expressed the thought that Indian medicine was powerful, but she would not use it as a treatment. In addition, her husband drank alcohol, so even though she was not taking in alcohol, the very fact that her partner in the home was, for her the medicine would lose its power and not be effective to help her. Another felt she would not want to mix “clinic” medicine with Indian medicine. Clinic medicine would be the Western medicine that is prescribed from physicians at the tribal health clinic and dispensed from the clinic pharmacy. One man preferred to use “Western” medicine, although he was familiar with others who had both success and lack of success with Indian medicine. Important to note here is that informants referred to allopathic medicine in different ways. “Western medicine” as used by this man refers to allopathic or “clinic” medicine.

While those interviewed stated they did not use Indian medicines in the treatment and control of their diabetes, they were familiar with its use in other areas. Barton (2005) noted the use of both Western and Indian medicine among the participants along with regular checkups and monitoring. This was supported by Lautenschiager (2006). Jacobs (2014) recorded a realization of the importance of adhering to medication.
Three of the persons attend Longhouse and participate in ceremonies there. One person reports being Catholic, but also periodically attend the Longhouse. They report the foods at the gatherings do not interfere much with their diabetic diet, mentioning wild game and corn soup. However, the fried bread and bits of dessert could be alluring. There is activity and dancing along with meals.

**Breaking the Cycle**

Over half of the participants mentioned concern for the future of the community, noting the frenetic lifestyle of most reservation families, and expressing the need to “go back to the basics” and break the cycle of diabetes in the community. There is a strong interest in sports in the community, specifically hockey and lacrosse. This involves year round activity and much travel, as children play on more than one team. As a result, families are in transit much of the time. Thus, home cooked meals at the dinner table are being replaced with fast food at restaurants or arena concession stands.

In addition, given the universal need for both parents to work, there is a tendency to replace home cooked meals with takeout to save time and energy. Many would like to see more community restaurants offering healthier choices. Another area of concern is the replacement of exercise and play with sedentary activities such as video games and television. As one Mohawk elder states ‘when TV came in, it took over the whole household. Now nobody moves”. Other suggestions involved a return to traditional ways that included gardening and homegrown food as well as, family values and a respect for all persons.

At least half of those interviewed mentioned the importance of understanding what diabetes is and how to correctly manage the disease. This would include education on how diabetic medications work, and the importance of nutrition and activity. Many feel the perception in the community is that medications will cure diabetes, and in taking them, there is freedom to do and eat whatever is desired.
One participant stressed the necessity of making informed choices. He commented that if no one is talking then nothing will change. Other issues mentioned were those of provider communication. It was felt that a culturally appropriate provider approach is imperative, as well as someone who is an example in word and deed. This would include an understanding of and respect for the specific culture in question as evidenced by knowledge of communication, traditional healing methods, and actual interest in the persons treated. One participant referred to shutting down when doctors lecture as well as, lack of explanation about their medicines. It is apparent that focused education around the need to change diet and take medications and exercise and rest and decrease stress are all needed and not just one or the other. Other areas of potential educational benefit and/or exploration would be diabetic etiology, specifically as it relates to the perceived link to alcohol, and potential uses of Indian medicine in conjunction with Western medicine in the treatment of diabetes.

Diabetes education in the literature included stress management, nutrition and healthy eating, as well as exercise (Barton, 2003, Berry, 2009, Shaw, 2013). The literature also spoke to the importance of peer support. Many felt nondiabetics lacked the understanding necessary to educate new diabetics, valuing shared experiences (support groups), and wanting to learn from other diabetics (Gregory, 1999, Hernandez, 1999, Barton, 2005, Iwasaki, 2006).

Rural Oklahoma Indians in Parker’s (1994) study voiced a fear for the next generation and a loss of cultural traditions. Grams (1996) noted the desire to return to more traditional (old) ways of life – gathering, healing, foods, and to reclaim cultural heritage. The Nuxalk in Barton’s study (2005) suggested a need to break life cycles. These sentiments were all echoed in Mohawk comments about the future of their community.
Satterfield (2003) also makes note of the lack of time as well as the fast food issue and adds cost of nutritional food and environmental restraints (no place to walk). Lautenschliager (2006) refers to a lack of healthy affordable food as a barrier. Grams (1996) also pointed out differences between a sedentary and active lifestyle in the management of diabetes. Mohawk respondents agreed regarding the added expense of nutritional foods, stating persons with limited incomes have a much easier time feeding their family pasta and meat rather than fresh fruits, vegetables, and leaner cuts of meat or fish. Mohawk informants also spoke about inactivity and the importance of exercise for healthy living, weight control and their diabetic management.

The importance of understanding diabetes in terms of dietary control was mentioned in the literature. Boston (1997) referred to a poor shared understanding in regards to nutrition, the right foods to eat and the right ones to avoid, suggesting the need for nutrition teaching. Barton (2005) spoke of less understanding of how Western medicines work. The First Nations people in Sherifali’s study (2012) stressed the need for timely and ongoing education and counseling. Struthers (2003) noted the importance of educating the young people.

Interactions with providers proved to be a frequent topic in the literature. Reactions were both positive and negative. Boston (1997) spoke of poor provider and patient communication while Cosby (1996) mentioned provider inconsistency. Gregory (1999) noted negative experiences with providers who pushed “rules and regulations” as the feeling of being rushed with no explanations. Many in his study felt pamphlets were not the ideal way to get information. Barton (2005) spoke of provider words being hard to understand, and Tiedt (2013) described tension related to provider relationships and poor provider approach. Others had good experiences from the providers. However, all desired respect, and a friendly interested partnership with their caregivers.
Keeping the Circle Strong

Communities are comprised of families. Keeping the circle of community strong involves investing in the components of the circle itself. These components include Mohawk culture and identity, respect for all members of the family (elders, women, children and youth), unity in government, family and environmental wellbeing, and lifelong education. The educating of families about diabetes was an important factor that most felt would improve the outlook for future generations. This could occur through health education in the schools but could also be accomplished as a community wide educational program. In remembering their own experiences as youth and watching their elders contend with diabetes, they wanted to see young families taught about healthy eating and lifestyle, as well as develop an understanding of what diabetes is and how they can work to prevent its occurrence, even at a younger age. One woman was concerned for her grandchildren, mentioning the concept of 7 generations (future generations are built and influenced by the behavior and choices of the previous generations), stating she remembers her great grandfather and now she is in a position to have her great grandchildren remember her. This is an important cultural concept that should frame all culturally appropriate approaches to change.

All participants had strong praise for the work done at the diabetes center, applauding their quick, friendly and courteous service, nonjudgmental attitude and the quality and availability of the programming there. There is appreciation in the fact that this center is not the norm on other reservations. All feel the community is aware of the services offered there. It was felt the diabetes center is a major influence in the strengthening families in the community. A few had suggestions for improvement. These included peer counseling and a diabetes boot camp for new diabetics. Summer programming for children that would focus on healthy eating and diabetes prevention was also mentioned. While most felt diabetes would always be a challenge for the St Regis Mohawk community,
they applaud the enduring strength of the Mohawk people as they contend with this all-encompassing
disease. A strong community circle requires strong residents. This Mohawk belief was mentioned in
one study as Grams (1996) referred to the view of ancestors as a strong people.

The literature strongly referred to community education. Boston (1997) noted that each
community is individual with different needs, and community buy-in is necessary for any type of
programming to be successful. Cosby (1996) refers to an understanding of each tribe’s understanding of
health/illness and disease causation, also mentions community buy-in and stresses the importance of
looking at the whole family when teaching. Hernandez (1999) and Barton (2005) speak to program
design that respects Native tradition and ways. Struthers (2003) and Satterfield (2003) speak to
community oriented culture based education.

According to Tiedt (2013), families and the community working together is essential with
community leaders as role models (Satterfield, 2003). Shaw (2013) stresses the importance of
community awareness of the diabetes problem, which could be accomplished with simple, respectful
prevention messages targeting the community. Satterfield suggested combating fatalism and the
appreciation of “the old ways.” A lack of appropriate facilities for diabetes managements was
mentioned in a few of the studies. Crosby (1996) and Satterfield (2003) noted inadequate exercise
facilities, which limited the ability to exercise. Barton (2005) and Berry (2009) voiced the desire for a
diabetes clinic.

**Seven Generations**

From a cultural standpoint, the Seventh Generation philosophy exemplifies the Mohawk value
of community and the responsibility for future generations to come. Participants envisioned a
community of healthy families armed with the knowledge and tools to combat a disease, which has burdened past generations of Mohawk people.

The Peacemaker taught us about the Seven Generations. He said, when you sit in council for the welfare of the people, you must not think of yourself or of your family, not even of your generation. He said, make your decisions on behalf of the seven generations coming, so that they may enjoy what you have today." (Oven Lyons (Seneca); Faithkeeper (Onondaga Nation).

The most important thing learned about being a Haudenosaunee is the idea of being connected to a community that transcends time.

We’re connected to the first Indians who walked on this earth, the very first ones, however long ago that was. But we’re also connected to those Indians who aren’t even born yet, who are going to walk this earth. And our job in the middle is to bridge that gap. You take the inheritance from the past, you add to it, your ideas and your thinking, and you bundle it up and shoot it to the future. And there is a different kind of responsibility. That is not just about me, my pride and my ego, it's about all that other stuff. We inherit a duty, we inherit a responsibility (Rick Hill Sr., Tuscarora, Chair, Haudenosaunee Standing Committee on NAGPRA).

Summary

Research question #1 stated, “How do the members of the St Regis Mohawk Tribe living with Type 2 diabetes define and describe the disease?” This question is best answered by theme #1. “It's like the whole reservation is diabetic!” Diabetes has been described by Mohawk people as “right in the reservation”. They grow up in a community that is inundated with diabetes. Young children watch their parents, grandparents, aunts, uncles and neighbors either struggle to achieve a healthy balanced
lifestyle managing their disease or totally disregard its treatment and eventually experiencing long term complications resulting from their noncompliance. Mohawk people assume an air of expectation, an attitude of inevitability that stems from a lifetime of watching diabetes in those around them. They are not surprised when the diagnosis finally arrives, although some experience emotions ranging from sadness and shock to anger and denial.

Acceptance was the general reaction by many. All viewed diabetes as a disease, but some lack the understanding of what it is and how it can affect them in the future. It was not until they personally experience complications affecting their own health that they begin to understand the seriousness of diabetes. This is similar to that of the general population and is noted in the literature (Hernandez, 1999).” Most understand that diabetes is caused by elevated sugar in the blood and that genetics plays an enormous role. This is exemplified by the comment “it is right in the families”. Also understood is the role that diet, activity and lifestyle play in putting people at risk for the development of the disease.

Cultural Factors Influencing Management and Health Maintenance

Research question #2 states “What cultural factors influence the management and health maintenance of Type II diabetes among the Mohawk? Management and health maintenance of diabetes involves acceptance of the diagnosis and a plan to modify lifestyle in such a way that blood sugars are maintained at a certain level, and there is some sort of stability. This would include nutrition, exercise, lifestyle changes, weight control, and regular appointments with providers. Mohawk responses to these issues were not different from the mainstream population, and similar to responses noted in the literature. These included the desire to look after self, the importance of a routine, and control and regulation of lifestyle and activities (Grams, 1996; Iwasaki, 2006; Tiedt, 2014).
It seems the cultural factors lie in each person’s solid link to the Mohawk Community. There is one Indian Health Clinic and one Diabetes Center that provides almost all of the cultural based care to the community, including the diabetic community. The clinic and center, although based on the reservation, are still allopathic, Western models of care. This was only one arc of the circle. A factor that was more culturally bound was in the importance of balancing body, mind and spirit. Mohawk people accomplish this balance in different ways. The health clinic offers stress management, mental health services, adult and pediatric health care, dental care, massage, and chiropractic care. Some attend Longhouse ceremonies while others may attend church. Some use Indian medicine for personal health maintenance, while some do not. All informants, however, agree on the use of Western medicine for their diabetes treatment, preferring not to combine them. This may be due in part to a belief in the importance and effectiveness of Western medicine in their diabetic management. It could also be reflective of a holistic and traditional respect for the earth and its plant life, and a preference to keep all traditional medicine separate and pure by not using it concurrently with Western medicine. Most will attest to the importance of a positive attitude in order to maintain balance within the mind and body, inclusive of a strong spirit. The positive attitude is maintained through enriching and focused relationships within the community and adherence to healthy lifestyle choices. A strong spirit is culturally linked to the preservation of future generations. Grams (1996) refers to the Mohawk view of their ancestors as a strong people.”

Seventh Generation Principle

Another factor that was strongly linked to community was that of the family. The health clinic supports family health in the provision of age related health care, covering all seasons of life from prenatal to elder care. This was culturally significant as it relates to the longstanding history of the Iroquois Confederacy and the Seventh Generation principle. In this, all community and individual
decisions must be based on the future generations of Iroquois who will follow. Seven generations flow from the past and into the future with each person a part of one generation or another. Decisions made by earlier generations affect those that follow, up to and including seven generations (Sweeney, 2012, Wilkins, 2015). Thus, health maintenance and diabetes management are of great importance in order to influence those to come. Keeping a strong circle would include family and community education on diabetes.

**Culture Care Theory**

The basic assumption of the Culture Care Theory (see Appendix C) is that an individual’s health care practices, cultural care values and beliefs, religious and spiritual viewpoints, language, and social attitudes shape the worldview of the individual cared for (Clarke et al, 2009). The findings indicated that being Mohawk is directly related to being diabetic. The worldview of St Regis Mohawk people as it relates to diabetes was that of expectation.

This worldview was shaped by their past experiences with family and community members with diabetes. It appeared to have affected their responses to diagnosis and had a bearing on the adjustments needed to develop and maintain a lifestyle of disease management.

Madeline Leininger’s Sunrise Enabler proved to be a valuable tool in the categorizing and explanation of the five themes resulting from data analysis (see Figure 1).
The following discussion is a summary of the findings of how each tenet relates to the themes and data.

**Technological Factors**

Technology in the St Regis Mohawk data appeared to be connected to the health clinic and its adherence to the American Diabetic Association standards of care as endorsed by the Indian Health Service. All clinicians as well as the diabetes center were in cooperation with these. As well, all Mohawk patients were given glucose meters for blood glucose testing. These meters were brought in to the nurse case managers who downloaded all values into tables reflective of monthly results. These meters were even able to calculate an estimated A1C. The use of Western medicine could also be included here. Mohawk people rely on Western pharmaceutical medicines to control their diabetes.
Religious and Philosophical Factors

Many of the Mohawk responses reflected the importance of a connection with body, mind and spirit/soul. This would be reflected in a mindful attitude of positivity, the importance of healthy body, and a connection with The Creator, either through religious activity (a strong Catholic presence) or the Longhouse (traditional religious activity). Threaded through all of this is a connection and oneness with nature. This oneness includes the use of traditional herbs and blends for medicinal use, although not for diabetes.

Kinship and Social Factors

It was clearly evident from all data that the family holds much weight in the Mohawk community. Young families join together for sports and parents as well as grandparents are deeply involved in sharing these activities. The Seventh Generation principle discusses the importance of activities in the present that can affect the generations to come. The community itself is closely knit together, with everyone being connected in one way or another. In this then, it can be said that diabetes affects all generations. There was concern voiced for the younger people to learn about diabetes and how to prevent it.

Cultural Values and Beliefs

The Mohawk belief of holism and connection with nature is seen here. Indian medicines play a role in many Mohawk families. However, medicine to treat diabetes is not noted in the collected data. The concept of body, mind and spirit/soul would also fit here. Additionally, there were references to a desire to “return to the old ways” – family meals, gardens and fresh fruits and vegetables homegrown.
Political and Legal Factors

The St Regis Mohawk Tribe is responsible for governance and policy making. Monies are received from Indian health Service for the funding of the health clinic. The diabetes center is funded in part from a federal grant (SDPI), and in part by the tribe. All tribal policies are in place at both facilities.

Economic Factors

From a funding standpoint, the SDPI grant funding of the diabetes center also fits here. Any limitations or cuts in funding will have an effect. The cost of eating healthy is also worthy of mention here. Mohawk respondents noted the cost of healthy eating can be prohibitive and a barrier in the attempt to make healthy lifestyle changes. Also, there are no grocery stores on the reservation, just convenience stores. While they carry a variety of food, the cost is higher than at a conventional grocery store.

Educational Factors

Talking and understanding were key ideas in the data analysis. Education in a culturally appropriate setting was important, as was the desire for young families to be taught healthy eating and lifestyle in order to avoid developing diabetes. It was also felt there should be more education to make sure that those with diabetes truly understand how diabetes works.

In summary, of the ten imbedded tenets, kinship, social factors, and education appeared to have the highest impact. The influence of the community and culture were important facets. The Mohawk community is made up of families and concern was expressed for the future of the family as it relates to diabetes.
Conclusion

Ethnography was used to examine and describe the concept of diabetes, its management and understanding among the St Regis Mohawk people of Akwesasne. This process included immersion in the daily activities of the diabetes center as well as in depth conversation with multigenerational diabetic Mohawks. The findings of this ethnographic study can be used to provide an emic understanding of the Mohawk view of diabetes, its causation, views regarding treatment and a look at the future of diabetes in the Mohawk community. It can then be used to strengthen present diabetic programming and provide a basis for ideas for future interventions and changes.

Diabetes in the American Indian population continues with epidemic force (Barton, 2005; Berry, 2009; Jacobs, 2014; Tiedt, 2013). With the present population aging, and an increasingly younger generation beginning to experience health problems and potentially diabetes, the community must focus on strategies that will provide culturally relevant services that will be accessible and accepted by younger Mohawk recipients of healthcare.

In summary, the Mohawk Community of Akwesasne are no strangers to the ravages of type 2 diabetes. Generations of Mohawk people ranging from young children to elders have seen and experienced the damage this disease inflicts upon family, friends, and neighbors who live with it, leaving layers of impression that shape future actions and viewpoints. In this telling environment, surrounded daily by visual reminders such as blindness, amputations, dialysis, heart disease, and much more, it has been easy to develop a fatalistic, expectant, and inevitable attitude toward personally acquiring this potentially debilitating disease. This outlook is not something that is seen in the general population, is seen in the American Indian population, and can hinder the effectiveness of successful diabetic treatment and outcomes. This fatalistic expectation was seen in other qualitative studies of various
tribes across the United States and Canada (Gregory, 1999; Jacobs, 2014; Satterfield, 2003; Struthers, 2003). It is of interest to note the lack of large shopping centers on the reservation. There is however, a free standing diabetes center, a true testimony that speaks to the need for appropriate treatment in this community. It also speaks to the St Regis Mohawk dedication and interest in healthy generations to come. For these people, diabetes treatment extends beyond the usual standards of care and must also include such unique cultural factors as viewpoint (a change of attitude from one of hopeless and vulnerable fatalism to that of strength and positivity), accurate causation of the disease, incorporation of Indian medicine, and seven generations ideals, with an eye to future generations of Mohawk people.

Understanding Mohawk ideas on the causes and treatment of diabetes will provide a springboard for innovative educational programming on causes of and risk factors for type 2 diabetes. It can promote the ideas of early screening which can then lead to early identification and treatment of diabetes. It can also act in the prevention of or delay in its onset in a younger population that prior to this might not have been aware of diabetes or its consequences.

In spite of an active successful diabetes center and programming, blood sugars are alarmingly high. This could speak to the need for an increased attention to the cultural components noted in Leininger’s Sunrise Enabler. In this, care is tightly woven into all activities – kinship, religion, community, culture, and beliefs (Weager, 1995). There are many more who experience weight problems, a sedentary life style, and eating habits that line them up for a future of diabetes and its accompanying health disparities. There are generations of families rising up who lack understanding of diet, exercise and health prevention. It is within this context that educational efforts need to be focused.

The information gleaned from this ethnography supports the necessity of cultural understanding by the nursing profession in not only the importance and acceptance of education by the community,
but also in the understanding of healthy living and disease management in the Mohawk population. This will enable them to institute culturally relevant programs that will have a positive impact on the community and its future.

**Limitations**

This was a study encompassing a sample population from the St Regis Mohawk Tribe of Northern New York. The findings cannot be generalized to any other tribe in any other region. Each tribe has its own traditions and practices as well as regional and socioeconomic differences that are unique to itself and the region. All persons enrolled in the study voluntarily reached out to the researcher for participation. There may be differences between those who participated and those who did not. For example self-selected in or out.

The St Regis Mohawk reservation sits on the Canadian border and has territory on both sides. While they fell under the umbrella of St Regis Mohawk, each has its own administrative system that managed tribal activities. Each fell under a different set of governmental regulations, those who participated and those who did not, i.e. self-selected in or out. Study participants were not recruited from the Canadian side of the reservation. Also, there were tribal members from both sides of the border living off the reservation. Sampling of these may have offered more in the way of information and understanding.

While all participants are tribal members receiving services at the St Regis Mohawk health center, not all were utilizing services at the diabetes center. This fact challenged the process of member checking. Of 15 interviews, only 3 returned to the diabetes center to participate, and their feedback was considered in the final analysis.
There was a possibility of bias in that the researcher is also a member of the St Regis Mohawk Tribe and familiar with the operations and activities of the diabetes center. This was controlled by discussion with nurse educators and case managers directly involved with diabetes care at the center.

**Implications of the Study**

The findings from this study have direct and indirect implications for nursing. The areas within nursing discussed include research, education, practice and policy.

**Implications for Nursing Research**

The knowledge gained from this study adds validity to previous nursing research findings of Indigenous definitions and descriptions of diabetes, this time framed within the St Regis Mohawk population. The knowledge gained from this study supports the importance of understanding and working within specific cultural frameworks in order to provide culturally relevant care and programming in the treatment and management of type 2 diabetes as it relates to the St Regis Mohawk people. This would include age appropriate diabetes education that could be adapted and taught for understanding in all generations. Important also is the development of an accurate idea of the risk factors and actual causes of diabetes. Nutrition education that could be adapted using traditional foods and ceremonies, and healthy ideas for eating out at sporting events would be useful for young families. The Mohawk tradition is that of an oral one. Talking, between generations, could add credence to the reality of what diabetes can do to a generation.

Additional studies aimed at other diabetes related issues within this population such as gestational diabetes, obesity in American Indian youth, health education in schools, and family nutrition and lifestyle could prove beneficial and be a catalyst in the development of culturally focused programs
to strengthen the community circle and educate upcoming generations of Mohawk youth. In addition, it would allow transferability of this study to other areas in need of understanding within the American Indian or other culturally diverse population. Other areas of interest could include community based participation research in grass roots exploration of various nutrition programs, the exploration of trauma informed care both current and historical, fatalism, and the seven generations concepts.

**Implications for Nursing Education**

Education has been noted to be of the utmost importance in strengthening the community and preparing for its future. In this, nursing, as it prepares for future culturally relevant programming must look to the educating of the family unit to bring a clearer understanding of what diabetes is and how it affects future generations, seven generations, of Mohawk people. This study reinforced the importance of cultural competency in the care of diverse populations. Because of the increasingly multicultural society within the United States, professional nurses need expertise and skills in the delivery of culturally appropriate and culturally competent nursing care to diverse populations. This would involve an understanding of how culture assists the individual to define and describe their life with diabetes, or any other disease. This study demonstrates the importance of nursing education that will teach about cultural diversity, provide opportunities to experience the provision of nursing care services to American Indian or other diverse populations, promote a foundation for cultural based nursing, and advocate for culturally appropriate care for patients.

**Implications for Nursing Practice**

This study has broad implications for the field of nursing regarding the challenges the American Indian faces with the progression of type 2 diabetes. The results of the study will provide insight for improving care and management in adults living with type 2 diabetes. In practice, nurses have a vital
role in the initial management of Type 2 diabetes in primary care, which is largely directed towards assisting patients to understand the nature of the disease and becoming self-managing within their culture. As a health care professional, the ultimate aim is to be able to provide guidance and culturally specific diabetes education for fostering change in the care of the American Indian.

Members of one of these populations are the St Regis Mohawk Indians with diverse traditions and practices. The goal of the nurse professional is to provide the best possible care for these clients. In addition, the nurses must have expertise and skill in the delivery of culturally appropriate and competent nursing care.

The findings of this research study will add to the present body of nursing knowledge regarding American Indian people living with type 2 diabetes. It will provide cultural relevance and assist in the ongoing development of new strategies designed to increase positive outcomes for diabetes prevention and management. It will offer fresh understanding of the daily challenges faced by those American Indian people living with diabetes, thereby enabling nursing to respond in culturally appropriate ways of knowing that can promote an atmosphere of healing and hope, with meaningful, insightful care. In relation to the Mohawk cultural worldview, this would include the suggested provision of anticipatory emotional and mental support as newly diagnosed Mohawk people deal with feelings of anger, denial, hopelessness and depression. This could take the form of community support groups that would focus on community and individual strengths that would encourage and empower Mohawk diabetics to take charge of their health and behaviors in their journey with diabetes. It would also provide the rationale and support for design and implementation of innovative educational programming that would span all Mohawk generations bringing a true vision of hope for the future health and wellness of the community.
Implications for Policy

The information gained from this study can be used by members of the St Regis Mohawk Tribe to increase understanding of the long-range effect diabetes has on the community and all of its members. It can also assist in policy revision when examining the present policies concerning health care, elder care, educational services and the incorporation of traditional medicine along with Western medicine in the treatment of diabetes. In regard to nutrition, looking at government accountability in provided food and the provision of more healthy options could be of benefit. This may lend credence and support to the importance of securing funding for innovative programming that will look to education of future generations of Mohawk individuals in order to control diabetes and keep the circle strong.
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Appendix A: Coding Themes and Categories

Diagram:

- *Making it better*
- *Facility*
  - "Blessed to have the Diabetes Center"
- *Programs*
  - Be aware of lifestyle changes
    - Health maintenance management - "Something you gotta do"
    - Diet
    - Exercise
    - Noncompliance - "I don't care, I do what I want"
- "Taking care of self"
- "You're Mohawk, You're Diabetic"
  - Personal experience
  - Diagnosis - "they just found it"
  - "I knew it would happen"
- Community full of diabetes
  - Causes
    - "as a people, we don't do what we used to, to stave off diabetes"
    - "fishing community, seaway changed that. We eat different than our ancestors"
- *Families On the go "rind food"*
- *Not Knowing how to cook*
- *Education*
  - "When I was young I heard my mother talk about relatives that had died from diabetes"
Appendix B: Adult Informed Consent Form

Title of research study: Diabetes in the St Regis Mohawk: A Focused Ethnography

Version Date: 8/23/17

Investigator: Pamela McDonald-LaChance

Why am I being invited to take part in a research study?

You are being invited to take part in a research study because you are an American Indian type 2 diabetic receiving services at the St Regis Mohawk health clinic or diabetes center.

What should I know about a research study?

- Someone will explain this research study to you.
- Whether or not you take part is up to you.
- You can choose not to take part.
- You can agree to take part and later change your mind.
- Your decision will not be held against you.
- You can ask all the questions you want before you decide.

Who can I talk to?

If you have questions, concerns, or complaints, or think the research has hurt you, talk to the research team at 315-358-9667. You may also contact the research participant advocate at 716-888-4845 or researchadvocate@buffalo.edu.

This research has been reviewed and approved by an Institutional Review Board (“IRB”). You may talk to them at (716) 888-4888 or email ub-irb@buffalo.edu.

if:

- You have questions about your rights as a participant in this research
- Your questions, concerns, or complaints are not being answered by the research team.
- You cannot reach the research team.
- You want to talk to someone besides the research team.
• You want to get information or provide input about this research.

Why is this research being done?

Diabetes has been a long standing problem among American Indian people. This includes the St Regis Mohawk of Akwesasne. This research is being done to find out more information on how diabetes impacts our community. More understanding is needed on how this disease impacts the people of this community physically, emotionally, culturally and spiritually. It will offer a fresh understanding of the daily challenges faced by community members living with diabetes, as well as provide input for maintaining and improving the programs at the diabetes center.

How long will the research last?

We expect that you will be in this research study for a one hour one time interview. However, you may be contacted at a later date to verify the accuracy of the questions answered and transcribed.

How many people will be studied?

We expect about ___20___ people in this research study

What happens if I say yes, I want to be in this research?

If you agree to participate in this study, Pamela McDonald-LaChance, a registered nurse, member of the community, and a doctoral student at University at Buffalo will meet you at the diabetes center at a time of your choosing. She will ask you questions about your life with diabetes including those issues that help you in your daily routines and those that make life more difficult. She will also ask about how diabetes has affected your family, financial, spiritual and cultural habits. Finally, she will ask how the present diabetes care you receive could be improved to fit community needs. With your permission, she will tape record the questions and your answers. If you do not desire to be audio recorded, the answers to your questions will be hand written. The questions and answers will then be typed and all identifying information will be removed. The interview will be approximately 1 hour long and will be for 1 session only. However, you may be contacted at a later date to schedule a face to face appointment to verify the accuracy of the questions answered and transcribed.

What happens if I do not want to be in this research?

Your participation in this research study is voluntary. You may choose not to participate in this study. Whether or not you participate will have no effect on the care you receive from either the clinic or the diabetes center.

What happens if I say yes, but I change my mind later?

You can leave the research at any time it will not be held against you. It will not affect your participation in any programs or services.

Is there any way being in this study could be bad for me?

There are no known risks associated with participation in this study.
Will being in this study help me in any way?

There are no benefits to you from your taking part in this research. We cannot promise any benefits to others from your taking part in this research. However, possible benefits to others could include contribution to nursing knowledge regarding diabetes and the American Indian as well as information useful for the improvement of provision of programs and services at the diabetes center.

What happens to the information collected for the research?

I understand that the information I give in my answers will be confidential. My name will not be attached to the data. A study identification number will be attached to all of my transcribed materials. My name and phone number will not be released to anyone for further research purposes. In addition, all recorded information will be permanently erased. It is possible that the research results may be published.

What else do I need to know?

If you agree to take part in this research study, you will be given a $20 gift card for your time. This is a onetime payment upon completion of the interview.

Before beginning the interview, the researcher will ask you to respond to the following questions:

1. Have you had a chance to read through the consent information sheet?
2. Do you have any questions?
3. May I audio record this interview?
4. May we begin?
A Research Study about Diabetes

My name is Pam McDonald LaChance and I am a registered nurse working on my Doctoral degree from University at Buffalo. I am conducting a research project called Diabetes in the St. Regis Mohawk: A Focused Ethnography. This research is being done to find out more information on how diabetes impacts our community. It will offer a fresh understanding of the daily challenges faced by community members living with diabetes. I would like to hear your story.

This research study would be a good fit if you are a type 2 diabetic over age 18 and are an enrolled member of the St. Regis Mohawk Tribe receiving services from the clinic and/or the diabetes center.

If you decide to participate in the study, we would meet at the Diabetes Center at a time convenient for you and I would explain all parts of the project. Your participation would include answering questions about your life with diabetes as well as offering suggestions on how diabetes care could be improved not only in our community, but all over. The time involved would be about 1 hour.

As a thank you for participation and your valuable time, a $20 gift card will be offered when the interview has finished.

To take part in the research study or for more information, please contact Pamela McDonald-LaChance at the Diabetes Center for Excellence at 313-338-3667.
Appendix C: Culture Care Model

Leininger's Sunrise Enabler to Discover Culture Care

CULTURE CARE

Worldview
Cultural & Social Structure Dimensions

Kinship & Social Factors
Cultural Values, Beliefs & Lifeways
Political & Legal Factors

Environmental Context, Language & Ethnology

Religious & Philosophical Factors
Economic Factors

Technological Factors
Educational Factors

Influences

Cultural Expressions, Patterns & Practices

Holistic Health / Illness / Death

Focus: Individuals, Families, Groups, Communities or Institutions in Diverse Health Contexts of

Generic (Folk) Care
Nursing Care Practices
Professional Care-Care Practices

Transcultural Care Decisions & Actions

Culture Care Preservation/Maintenance
Culture Care Accommodation/Negotiation
Culture Care Repatterning/Restructuring

Culturally Congruent Care for Health, Well-being or Dying

Codes: (Influencers)

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- Credit must be properly given to this work, but not in a way that suggests endorsement by the author, copyright holder, heirs, or assigns.

**Document:**
Leininger’s Sunrise Enabler Guide

**Original Source:**
http://www.madeleine-leininger.com/cc/sunrise.pdf
Appendix D: University at Buffalo’s IRB Approval Letter

University at Buffalo Institutional Review Board (UBIRB)
Office of Research Compliance | Clinical and Translational Research Center Room 3048
175 High St. | Buffalo, NY 14208
UB Human Subjects Assurance D# 10520311

STUDY EXEMPTION

September 29, 2017

Dear Pamela McDonald-LaChance,

On 9/29/2017, the University at Buffalo IRB reviewed the following submission:

<table>
<thead>
<tr>
<th>Type of Review</th>
<th>Initial Study</th>
</tr>
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<tbody>
<tr>
<td>Title of Study</td>
<td>Diabetes in the St. Regis Mohawk: A Focused Ethnography</td>
</tr>
<tr>
<td>Investigator</td>
<td>Pamela McDonald-LaChance</td>
</tr>
<tr>
<td>IRB ID</td>
<td>STUDY0000172</td>
</tr>
<tr>
<td>Funding</td>
<td>None</td>
</tr>
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<td>Grant ID</td>
<td>None</td>
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<td>IND, IDE, or HIDE</td>
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Documents Reviewed:
- HRP-503-Template%2520Protocol1.docx
- Recruitment.pdf, Category: Recruitment Materials
- Interview Guide.docx, Category: Other
- HRP-502-Template Consent Document1.pdf, Category: Consent Form

The University at Buffalo Institutional Review Board has considered the submission for the project referenced above on 9/29/2017 and determined it to be Exempt.

In conducting this study, you are required to follow the requirements listed in the Investigator Manual (HRP-103), which can be found by navigating to the IRB Library within the Click system.

UBIRB exemption is given with the understanding that the most recently approved procedures will be followed and the most recently approved consenting documents will be used. If modifications are needed that may change the exemption determination, please contact the UB IRB Office. Also see the Worksheet: Exempt Determination (HRP-312) for information on exemption criteria and categories.

As principal investigator for this study involving human participants, you have responsibilities to the SUNY University at Buffalo IRB (UBIRB) as follows:

1. Ensuring that no subjects are enrolled prior to the IRB approval date.
2. Ensuring that the UBIRB is notified of:
   - All Reportable Information in accordance with the Reportable New Information Smart Form.
Hi Pamela,

Your project is very minor in scope, so I are making the decision myself to give you the approval to proceed with your project from the Akwesasne Task Force on the Environment. I approve this with the understanding that you will share your results and make recommendations to the Medical Clinic and the Lets Get Healthy Program.

Craig Arquette
ATFE Chairman