SURVIVING THE PERFECT STORM OF DIABETES

IN THE WORLD OF THE SCHITSU'UMSH

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DEDICATION

I would like to dedication this work

to the people who have given the most to make this happen:

To my husband Cliff for introducing me to the Native American culture,

for walking this journey with me, and helping to keep me in balance.

To my sons Logan and Tyler for sacrificing mom-time so I could write.

To the people of the Coeur d'Alene tribe for allowing me into their world

and sharing their lives and stories.

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support over the last four years. It has been a long journey and I miss you all. I look

forward to reconnecting with you all again.

ABSTRACT

Jane A. Tiedt

SURVIVING THE PERFECT STORM OF DIABETES
IN THE WORLD OF THE SCHITSU'UMSH

Diabetes is a significant health problem in the United States and disproportionately affects Native Americans. Despite many new prevention and intervention programs, there has been a prolific increase in the incidence of diabetes among Native Americans. The purpose of this qualitative study was to explore the experience of Coeur d'Alene tribal members living with type 2 diabetes using a Heideggerian hermeneutic framework.

Participants were recruited through the local diabetes educator at the tribal clinic using purposive and snowball sampling. Individual interviews were conducted with ten Coeur d'Alene tribal members whom had type 2 diabetes and were willing to share their stories of about living with diabetes. Participants ranged in age from 26-86. Interviews lasted from 25-90 minutes and focused on gathering stories about their daily life with their diabetes, and barriers and supports to their diabetes self-management. These became the data for hermeneutic interpretations. Individual transcripts were read and reread for initial themes. Next, comparisons between and across transcripts were done through interpretive emersion into the texts. Emerging themes and patterns were brought before a group of qualitative nurse researchers and doctoral students as a means of cross-checking and validating interpretations.

Perseverance was the overarching pattern in the stories of living with diabetes in the world of Schitsu'umsh. The four themes that emerged under the umbrella of

perseverance were valuing tribal traditions, being inattentively caring, struggling with disease burdens, and experiencing tensions in patient-provider relations. Living with diabetes in the world of the Schitsu'umsh was always a tenuous balancing act. There was an ever present dialectic tension between strengths and barriers underlying their daily struggles for balance.

By increasing our understanding of Native American experiences of living with diabetes, collaborative partnerships can be developed with the tribes to address these barriers to diabetes self-management and to develop culturally relevant diabetes education programs. There is also a need to address cultural competence by the health care community and to work at eliminating biases and prejudice in our healthcare system. This work brings new cultural understandings of what it means to live with diabetes in one Native American group.

<div align="right">Rebecca S. Sloan, PhD, RN, Chair</div>

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Abbreviations	Terms
ACCORD	Action to Control Cardiovascular Risk in Diabetes
ADA	American Diabetes Association
BIA	Bureau of Indian Affairs
BMCWC	Benewah Medical Center and Wellness Center
CDA	Coeur d'Alene
CDC	Centers for Disease Control and Prevention
CHR	Community Health Representative
DCCT	Diabetes Control and Complication Trial
DM	Diabetes Mellitus
DPP	Diabetes Prevention Program
DSME	Diabetes Self-Management Education
ER	Emergency Room
HgbA1c	Glycosolated Hemoglobin
HHS	Health and Human Services
IHS	Indian Health Services
NDEP	National Diabetes Education Program
NG	Naso-gastric Tube
NHANES	National Health and Nutrition Examination Survey
NPAIHB	Northwest Portland Area Indian Health Board
REACH	Racial and Ethnic Approaches to Community Health
TB	Tuberculosis
UKPDS	United Kingdom Prospective Diabetes Study
USCCR	United States Commission on Civil Rights
WHO	World Health Organization

CHAPTER ONE

Introduction

In life there is sadness as well as joy, losing as well as winning,
falling as well as standing, hunger as well as plenty, bad as well as good.
I do not say this to make you despair, but to teach you…
that life is a journey sometimes walked in light and sometimes in shadow.
Grandfather says this: keep going. (Joseph M. Marshall III, 2006, p. 124)

Frey (2001) described the world of the Native American people as a merging of

two great rivers because their traditional ways of life have been influenced by Euro-

American contact. From first encounters with fur traders to westward migration and

government interactions, their landscape has permanently changed. To add to this image

of two merging rivers is a great flood brought on by disease epidemics that have ravaged

the landscape and the people (Jones, 2004). The most recent epidemic wave was diabetes.

The incidence of diabetes among the Native American population is higher than that for

any other racial or ethnic group. Additional, the effect of diabetes on morbidity and

mortality is disproportionally higher for Native Americans than the general population

(National Diabetes Education Program [NDEP], 2008). Although there are national

efforts to address this disparity through culturally-based diabetes education, health care

and community-based prevention programs, the epidemic persists and the affected

numbers continue to climb.

As a diabetes educator, I have witnessed firsthand a lack of sensitivity and a

paternalistic approach to Native American beliefs and cultural values within the

healthcare arena. I have heard the term "lazy" and "fatalistic" used by healthcare

professionals as they interact with clients from local tribes. I have had colleagues express

their dislike for working with Native people because "they're always so non-compliant."

These suggest a lack of cultural competence in health professionals and an inadequate level of knowledge about the Native American experiences of living with diabetes from the tribal perspective. The majority of studies about Native Americans with diabetes focused on tribes in Arizona and New Mexico where the prevalence of diabetes runs as high as 25-50%. Very little is known about the experiences of living with diabetes for Native Americans from the Columbia Plateau tribes of the interior northwest region of the United States.

The purpose of this study was to explore experiences of Coeur d'Alene (Schitsu'umsh) tribal members living with type 2 diabetes. I examined their experiences of diabetes as individuals embedded within the time and culture of the Coeur d'Alene tribe, rather than through a detached, "objectified" Euro-American lens. As part of that experience of diabetes, I investigated self-management challenges facing the Schitsu'umsh people with type 2 diabetes. The long term goal of this project is to use this information to develop culturally relevant tools for diabetes self-management and diabetes education programs with the Coeur d'Alene tribe. Before these tools can be developed, though, there was a need to identify what it means to Schitsu'umsh people to live with diabetes on a daily basis within the context of their social, historical, and cultural beliefs and values.

The specific aims of this study were to:

- Describe Schitsu'umsh experiences of living with type 2 diabetes.

- Explore the concept of diabetes self-management within the context of the Schitsu'umsh tribal culture and history.

- Identify barriers to diabetes self-management for individuals in the Schitsu'umsh tribe with type 2 diabetes.

- Identify sources of support for diabetes self-management for individuals in the Schitsu'umsh tribe with type 2 diabetes.

- Discuss the implications for culturally appropriate nursing care based on the experiences of Schitsu'umsh people with type 2 diabetes.

Background and Significance

Diabetes

Nearly 8% of the U.S. population lives with diabetes, but in some Native American tribes the prevalence is as high as 25-50% (NDEP, 2008). Diabetes is a chronic metabolic disease that requires on-going medical care and patient self-management to prevent acute and long-term complications. Type 2 diabetes is the most common form of diabetes, accounting for over 90% of cases. Diabetes results from defects in insulin production in the presence of insulin resistance, leading to abnormally elevated blood glucose levels (American Diabetes Association [ADA], 2007). If untreated, diabetes can cause serious macro- and microvascular complications, including heart disease, kidney disease, stroke, peripheral vascular disease, nerve damage, and blindness (Pooley, Gerrard, Hollis, Morton & Astbury, 2001).

Diabetes Self-Management

Diabetes care involves an interdisciplinary team composed of primary care providers, dieticians, pharmacists, nurses, and certified diabetes educators who collaborate with the patient to develop an individualized self-management plan and goals for self-care (ADA, 2007). The interdisciplinary team provides treatment regimens and

diabetes self-management education (DSME). Educational interventions may include meal-planning, physical activity, blood-glucose monitoring, medication administration, and motivational strategies for life-style changes. The intent of DSME is to empower individuals to maintain their blood sugar levels within normal ranges in order to avoid short and long-term complications through adherence to diet, exercise, and medication plans. Unfortunately many diabetes self-management regimens are complex and very challenging to maintain over time (Watkins et al., 2000). Dietary modifications are the hardest to maintain, followed by exercise programs. The least difficult activity to adhere to is medication administration (Glasgow et al., 1999). In one large clinical trial, only 20% of participants were able to achieve an ideal self-management regimen (Diabetes Control and Complication Trial Research Group, 1993).

Diabetes is often asymptomatic so, for many patients, the greatest burden is the treatment and not the disease itself (Hart, Redekop, Bilo, Berg & Meyboom-de Jong, 2005; Woodcock, Julious, Kinmonth & Campbell, 2001). The burden of treatment falls upon the patient and family, who must juggle daily regimens of blood glucose testing, meal planning, physical activity and medication administration (Ford, Havstad, Brooks & Tilley, 2002). The burden of diabetes and daily self-management has been associated with decreased quality of life. More recently, one arm of the ACCORD (Action to Control Cardiovascular Risk in Diabetes) clinical trial was stopped 18 months early when participants in the intensive control group had greater mortality rates than participants in the control group (National Heart, Lung and Blood Institute, 2008). Although several major studies have found that intensive diabetes regimens decrease the incidence of diabetes-related complications (Diabetes Prevention Program Research Group, 1999;

United Kingdom Prospective Diabetes Study Group, 1999), it is unclear how these large clinical trials translate into practical application in the experiential world of those living with diabetes. Cross-cultural implementation of these best practice approaches to diabetes care in Native American communities has had very limited success (Chino & DeBruyn, 2006).

<p style="text-align:center">Native Americans</p>

Diabetes is a significant health problem in the United States and disproportionally affects Native Americans. The prevalence of type 2 diabetes in Native Americans is two to three times that of the non-Native population. Furthermore, the prevalence of diabetes is higher in Native Americans than any other racial or ethnic group (NDEP, 2008). Prevalence rates have soared from 12.8% in 2003 to 15.1% in 2005 and to 16.3% in 2007 (Indian Health Services [IHS], 2007a). Most alarming is the Centers for Disease Control and Prevention (CDC) report (2003) showing a 71% increase in diabetes among Native Americans under the age of 35 and a 68% increase in diabetes among Native American adolescents. There also is a growing number of Native American children who are being diagnosed with type 2 diabetes.

Diabetes is associated with costly and debilitating complications and decreased quality of life that disproportionally affects Native Americans (CDC, 2003). Chronic kidney disease develops six times more often and lower limb amputations are three to four times more common in Native Americans with diabetes than for the non-Native diabetic population (NDEP, 2008). The final review of the Healthy People 2000 initiative indicates that diabetes-related deaths and end-stage renal disease remained unresolved health disparities for Native Americans (National Center for Health Statistics, 2001) and

continued to be high priority areas by the Healthy People 2010 initiative (U.S. Department of Health and Human Services [USDHHS], 2008). The sources of these health disparities are complex and deeply rooted in historical, social, and economic causes (Smedley, Stith, Nelson & Committee, 2003).

The federal government established community-based efforts to address these disparities through the Racial and Ethnic Approaches to Community Health (REACH 2010) campaign. Target groups for the REACH campaign include Native American, Alaska Native, African American, Asian, Pacific Islander, and Hispanic populations. The six priority areas for health disparities are diabetes, cardiovascular disease, immunizations, HIV/AIDS, infant mortality and screening for breast and cervical cancer (CDC, 2006; Ma'at et al., 2001). The goal of REACH 2010 is to address, reduce, and eliminate health disparities through community coalitions and community-based programs (Satcher, 2006). A shift in paradigms is needed to insure that Native American healthcare is delivered from the perspective of what is needed and how these needs can best be met (Lechky, 1991). For Native American communities, this means integrating programs into the cultural context in which they live (Pender, Murdaugh & Parsons, 2006). We need a better understanding of the historical, social and cultural context of living with diabetes from a Native American perspective quite simply because past and present strategies for diabetes education and management have been ineffective (Struthers & Lowe, 2003). Before we can develop better diabetes education and prevention programs, we must examine the health beliefs embedded in the historical and cultural values and beliefs of the Native American people (Airhihenbuwa, 1995; Brugge & Missaghian, 2006).

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CHAPTER TWO

Review of the Literature

Cultural Values and Practices of the Coeur d'Alene Tribe

To understand the values and practices of the Schitsu'umsh people, one must

understand the landscape as it was created by *Amotqn* (the creator) and the animal people

who were here before human people came to this world. The animal people prepared the

world for the coming of human people by bestowing the landscape with gifts. Gifts from

the landscape included berries, roots, trees, deer, elk, fish, birds, and so forth. All gifts

were intended for the human people to use, in order to survive and flourish. Another gift

was *summesh* – or spiritual powers. The landscape has spiritual power and all elements

are considered sacred (Brave Heart & DeBruyn, 1998). Spiritual gifts may be given to a

human in the form of a song, or protective totem, or through prayers, powwows, or jump

dances. The spiritual powers of these gifts are also present in memorial give-aways and

sweat baths. From these gifts, one only takes what is needed and the rest is shared with

others (Frey, 2001). *Amotqn* provides the gifts to the people and, in turn, it is important

for the people to be stewards of the land (Wilkinson, 2005).

Mi-yp or "teachings" is another gift given by the creator and animal people. These

teachings include ethics and social rules such as sharing. A key teaching is that of taking

only what is needed and treating each other and the landscape with honor and respect

because they are all connected. These teachings are passed on through oral traditions--

the stories told by the elders to the young ones. The landscape is alive with the stories.

They are of the animal people, such as Coyote and Crane, Coyote and the Green Spot,

and Rabbit and Hare on Tekoa Mountain. In the telling of these stories, traditions are

passed on from one generation to the next. The oral traditions of the Schitsu'umsh focus on providing for the whole community. This sense of cooperation and sharing is a part of their way. Schitsu'umsh traditions convey how to treat each other; how to treat the animals, land, plants, and trees; and how to respect the gifts from *Amotqn* and the animal people (Frey, 1995, 2001).

Competition is a value that was traditionally prized by the Schitsu'umsh people. Competition tends to be friendly among kin, but fiercer among those tribes and individuals outside of the kinship (Frey, 2001). When the tribes met and traded during seasonal rounds, there was usually an assortment of games and competitions (Doherty & Doherty, 2008). Competition between tribes in the form of pow-wow dancing and stick games was common. The stick games involved a set of counting sticks and bone markers. Team players sit across from each other and one player conceals the bone markers from the opposing team which then tries to guess where the markers are concealed. The prize for a correct guess is a counting stick. The team that ends up with all of the counting sticks on their side is the winner (Doherty & Doherty). There are often side bets wagered for each team as well. Success during the stick games is said to be based on the supernatural powers of the participants (James, 1996).

Another gift from *Amotqn* is kinship. Family is the most important element of tribal life. For the Schitsu'umsh, communal kinship is very important. The Schitsu'umsh tribe had a Hawaiian kinship structure, which recognized gender and generational differences. Families consisted of intergenerational extended relations subsisting together. Work and resources were mutually shared (James, 1996). The daily lives of

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tribal community members were linked to seasonal rounds for gathering foods and other resources they needed for survival.

Although the Schitsu'umsh spent their winter months together as one large community, smaller groups traveled intermittently during the rest of the year throughout the Northwest to gather, hunt, fish, and trade. As the first signs of spring emerged, they celebrated with a first foods ceremony and then gathered the first edible greens of the seasons. The first salmon of the season also were caught during the spring. The Schitsu'umsh often traveled to the Columbia River in groups. The men caught salmon and the women and children processed and dried the fish. In the summer as the annual fish runs finished, groups traveled to the prairies of Idaho to dig camas and other roots. Gathering berries during summer was another important activity. In the fall, the men went hunting for game ranging from deer and elk, to small squirrels and rabbits. The women spent their time drying the meat, processing the hides, and continuing to gather nuts and berries in preparation for the long winter. As winter approached, these groups would return to the main village. Winter was a time of reconnecting with family and community. Long hours were spent around the fire telling stories as others weaved baskets, made clothes, and prepared and repaired fishing or hunting supplies (Doherty & Doherty, 2008; Frey, 2001).

The Euro-American notion of individuality contradicts the Schitsu'umsh concept of community and kinship. When you meet a Native American, they want to know where you are from and who you are related to – who are your kin. The Euro-American way is different: when you meet a white person, it is not uncommon to want to know where the individual is from and what his/her occupation is. This reflects the Euro-American value

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of individual status and importance. What this indicates is that the world of the Schitsu'umsh people is different from that of Euro-Americans. In order to provide culturally competent diabetes care, diabetes education and management needs to be grounded in the cultural topography of the Schitsu'umsh people. For example, it may be useful to incorporating the tradition of storytelling as a way of teaching about diabetes or health promotion. Likewise, when developing diabetes self-management plans, it is crucial to understand the importance of family and kinship and how that affects the self-management plan. Are there implications of telling one family member to eat differently from the rest?

Historical Influences

Fur traders, horses, and disease are among the early outside influences on the Schitsu'umsh people. The fur traders were particularly interested in trading goods for beaver pelts, which were in high demand in Europe at the time. Traders introduced the Schitsu'umsh to trade goods – such as beads, pots and pans for cooking, hunting equipment, and guns. The Schitsu'umsh became so adept at trading that they earned their name "Coeur d'Alene" - which means "heart of the awl," because they were tough negotiators. By the time Lewis and Clark reached the Columbia Plateau region, regular contact with European trading vessels, and regular visits to the fur trading posts provided ample opportunities for the Schitsu'umsh to trade goods and services. The traders introduced tribes to the concept of commodities and market economy. The Native American concept of sharing was at odds with the U.S. economic system of materialism and individualism (Wilkinson, 2005). The traders also introduced the Native Americans to European diets high in grains such as wheat, oats, barley, and rye, with very little meat

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or protein. This was very different from their traditional diet, which was high in protein, roots, berries, and contained very little starch or grains (Barreiro, 2004; Garritty, 2004).

Although it is unclear when horses were introduced to the Schitsu'umsh, they have had horses since the mid 1700s. The introduction of horses did not change the need for seasonal rounds to gather food, but it did make the process easier. The Schitsu'umsh were able to cover more ground faster and the horses lightened the load as well. It took less time to travel to the plains of Montana for buffalo hunting (Cebula, 2003; Frey, 2001). Horses also fostered trade and further contact with whites because it was now possible to travel greater distances to the Plains tribes (Reichwein, 1990). This had implications for the fur traders as well. Trapping fell to the wayside as large parts of the tribal community traveled eastward for the buffalo hunts and few tribal men remained in the local area to trap and hunt (Palmer, 1998).

Another "gift" brought by the traders and early European contact was smallpox, which could virtually eliminate most of a village in a few days. Because the Native people did not have any direct contact with the disease in the past, they had no immunity and were very susceptible to the ravages of the disease. The young and old were most vulnerable. This tragedy resulted in the loss of many oral traditions as most of the elders died from the disease. In some cases, villages were given smallpox-laden blankets in an effort to annihilate them (Jones, 2004). In other situations, the tribal people were altruistically given blankets from dead soldiers stricken by smallpox to provide warmth from the bitter cold only to result in the infection and death of the village population (Frey, 2001). Smallpox epidemics caused the population of the Coeur d'Alene tribe to

decrease from approximately 3000-4000 members during the 1780s to 494 by the turn of the 20th century (Palmer, 1998).

The Louisiana Purchase, travels by Lewis and Clark, the white man's desire for land, and westward migration caused the world of the Schitsu'umsh to change rapidly. As the American population expanded, the demand for land grew. To address this need, by the late 1700s the federal government entered into treaty agreements with Native American tribes. The tribes would cede their land to the federal government in return for providing for the health, welfare, and education of their people in perpetuity. As a sovereign nation, each tribe entered into an agreement with the federal government through either treaties or executive orders. The difference was that Congress had to ratify presidential executive orders (Frey 2001). Sadly, many of these treaties and executive orders were ignored or modified, further limiting the size of reservation lands and shrinking their boundaries (Davis et al., 1999).

An 1873 executive order by President Grant gave the Coeur d'Alene tribe a reservation with boundaries that included all of Lake Coeur d'Alene and approximately 600,000 acres of land, plus $150,000 for the 2.2 million acres of land ceded. This order, however, was not ratified by Congress. In another attempt in 1877, Chief Seltice renegotiated the reservation boundaries, reducing the reservation by an additional 150,000 acres and including only part of the lake. This was also not approved by Congress. A third executive order in 1889 included significantly less of the lake and fewer acres than the first agreement. This order called for ceding three million acres of land to the federal government for a price of $650,000 (approximately 22 cents per acre). Each tribal member was to receive a payment of $960. The final reservation deed

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included 598,000 acres and was ratified by Congress. In addition, the executive order included provisions to construct a lumber mill and to pay for the services of a doctor, blacksmith and carpenter; but these funds were never appropriated (Palmer, 1998).

This settlement history has set the tone for many of even current interactions between the tribe and the U.S. government. It has created a general sense of distrust toward the federal government because their written word was often broken (Brave Heart & DeBruyn, 1998), and helps explain some of the health disparities that exist today for the Native American people (Davis et al., 1999). This history translates today into continued mistrust of white authority figures: not only government officials, but also healthcare professionals and researchers (Moreno-John et al., 2004).

After the American Civil War, the federal government implemented a new policy to address growing tensions between the native tribes and encroaching settlers. The federal government adopted a military approach to "deal with the Indian problem" and annihilation became the rule of the day. There are several military battles of particular significance to the Schitsu'umsh. The 1858 Battle of Steptoe was the first. Lieutenant Colonel Steptoe, led by a group of Nez Perce scouts passed through Coeur d'Alene lands. The Nez Perce scouts goaded the Schitsu'umsh people as they traveled through, fostering hostility and tension between the two, and a skirmish broke out between the Schitsu'umsh and Steptoe's troops. Other tribes in the area joined in battle. By the end of the day, Steptoe's defeat was imminent. During the night, in consultation with the Jesuit, Father Joset, the Schitsu'umsh allowed Lt. Colonel Steptoe and his men to escape through their lines unharmed. Unfortunately, this was a huge point of embarrassment for the U.S. military (Frey 2001).

The second major battle affecting the Schitsu'umsh people was the Battle of Four Lakes. Colonel George Wright fought against the Schitsu'umsh people and other regional tribes in retaliation for the Battle of Steptoe. Both sides suffered losses. After the battle, Wright gathered over a dozen Native men from the area tribes and had them hung as part of his punishment. As further retribution, Wright implemented another campaign of destruction. His soldiers travelled over the reservation lands, destroying everything in their path. Whether the Native people had anything to do with the battles or not, they received the wrath of Wright's scorch-the-earth policy. The Native people's buildings, food stores, animals, and livestock were destroyed (Frey, 2001).

Another significant historical influence was the arrival of the Jesuit missionaries to the Coeur d'Alene reservation in the 1840s. The missionaries, supported by the federal government began efforts to assimilate the Native Americans into the dominant Euro-American culture. Ironically, several hundred years before their arrival on the reservation, the coming of men in black robes wearing crossed sticks on their waists was foretold in a vision by their leader, Circling Raven. After several Algonquin Indians converts who were traveling with the fur traders told the Schitsu'umsh of the great white man's book and promise of being saved by the great spiritual leader, the tribe sent representatives to St. Louis to ask the Jesuits to come. The wish was that the Jesuits would bring with them a new kind of spiritual medicine to overcome smallpox and other diseases ravaging their people. One Jesuit priest, Fr. Pierre Jean DeSmet, responded to the "call in the wilderness." He was found wandering the prairies around Rathdrum and was brought to the Schitsu'umsh people. He worked with the tribe to build a mission on the banks of the St. Joe River in 1842 (Cebula, 2003). Built on a flood plain, it was replaced in 1845 on a

point overlooking the Coeur d'Alene River. The mission was moved to DeSmet, Idaho in 1878 (Frey, 2001).

The priest learned the native language and ways of life and tried to integrate the tribal way of life with Catholicism. The Jesuits did not like the transhumance pattern of existence of the Schitsu'umsh, so they taught them up-to-date farming methods in hopes of keeping the tribal people nearby so they would attend mass regularly. This was a very successful strategy. Many families had farms of up to 2000 acres and had two homes. They would have the farmstead and then a second home in DeSmet where they would go on the weekends to attend church services. Often they hired non-Indian people to help work the farm (Frey, 2001). Gradually the tribal people began to reject Catholicism and grew discontent with the Jesuits. Relations grew strained as some tribal members saw how the Jesuits were suppressing their traditional ways of life (Cebula, 2003).

The Jesuits and the Sisters of Charity of Providence in Montreal built boarding schools. Children were forced to attend boarding schools by withholding a family's rations or annuities (Wilkinson, 2005). In the boarding schools, the children were given Anglo names. In addition, the nuns cut off the children's long hair--which, in the Native American tradition, was done when they lost a parent or close family member. Losing their parents through physical separation was another outcome of attending boarding. The nuns and priests destroyed their traditional clothes and spiritual objects. The children were forbidden to speak their native tongue or practice their traditional religion. The nuns were very strict and children were sometimes brutally punished for not complying with these rules (Frey, 2001).

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These policies were implemented in the larger community as well. Many tribal members viewed the actions of the Jesuits as punitive. A group of tribal members, still supportive of the Jesuits, were given policing powers to punish tribal members caught violating the rules of the mission church. These rules banned tribal members from practicing any traditional beliefs, or rituals, wearing traditional clothes, or speaking their native language. This group, called the Soldiers of the Sacred Heart turned into vigilantes. They would beat, whip, incarcerate, or fine offenders for the slightest infraction of rules (Frey, 2001). Today, a strong Catholic influence exists among the Schitsu'umsh and there are still factions within the tribe based on current and historical affiliations to the Jesuits (J. Gordon, personal communication, October 9, 2008).

Laws at the time which only giving voting rights to landowners, led people westward to pursue the American dream of land ownership. In addition, the discovery of gold and silver in the mountains around the Coeur d'Alene reservation sped the influx of Euro-Americans into the region. This resulted in increased competition for land and settlers staking land claims on the reservation (Brave Heart & DeBruyn, 1998). In 1854, Congress appropriated funds to build the Mullan Road directly through the Schitsu'umsh reservation land. This made it easier for miners to travel westward to the mineral-rich area around Lake Coeur d'Alene and fueled the growing tensions between the tribe and white people (Reichwein, 1990).

A greater effect on the tribe was the Dawes Act or the Allotment Act. To address the growing need for land for settlers and in an effort to make the Native Americans self-sufficient, the government took reservation lands and allotted 160 acre parcels of land to each tribal member. The remaining land was considered left over and was opened up to

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settlers. This was tribal land that was supposed to be held in trust by the federal government (Brave Heart & DeBruyn, 1998). In 1907, the Dawes Act was implemented on the Coeur d'Alene reservation. The result was that tribal members with very successful farms were being removed and allotted small tracts of land in a patchwork fashion throughout the reservation, and white lumber companies were allotted lands favorable toward their financial gains (Reichwein, 1990). The Coeur d'Alene tribe was never compensated for the land taken by the government in the allotment process (Palmer, 1998). Moreover, the Native Americans had no concept of land ownership and frequently were taken advantage of by corrupt white men. Essentially the Dawes Act resulted in "a generation of landless Indians with no vocational training and almost total demoralization" (Bullough & Bullough, 1982, p. 97).

Conditions on the reservation were bleak because much of the allotted land was useless for farming. Tribal members became dependent on the Bureau of Indian Affairs (BIA) for food and basic necessities. As the area was inhabited by settlers, the ability to travel for their seasonal rounds was restricted, thereby cutting off sources of traditional foods such as berries, roots, camas, fish, and game. The tribe was often prohibited from hunting or gathering on non-reservation lands. Many of their traditional foods were not available or not able to be grown on their allotted land parcel. Unable to sustain themselves, the tribal members essentially became wards of the government, turning to them for their basic survival needs (Wilkinson, 2005).

Tribal members suffered unrelenting oppression by the BIA. Food and clothing rations were slashed or withheld by the BIA officials if members did not comply with BIA rules and expectations. The government openly supported the church's efforts to

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civilize the natives and prohibit the traditional heathen practices of the tribal members.

These efforts took a significant psychological, emotional, and spiritual toll on the tribal

people (Wilkinson, 2005). The ultimate result of the Dawes Act was to force the federal

government to assume full responsibility for the Native Americans. The alien

environment and confining conditions on the reservation caused a dramatic decline in the

health status of the Schitsu'umsh people (Trennert, 1998). The predominant foods they

were given included lard, white flour, and white sugar. The food subsidies significantly

altered their traditional diet and continued to include highly refined and processed foods.

The inability to engage in traditional levels of physical activity required to hunt and

gather their daily subsistence, as well as the type of food provided by the government

commodities, contributed significantly to the changing health status of the Native

Americans (Brugge & Missaghian, 2006). Less physical activity, sedentary lifestyle, and

a westernized diet have all contributed to the rising epidemic of obesity and diabetes

(Gohdes & Acton, 2000).

In the 1920s things improved slightly for Native Americans. John Collier, an avid

supporter of Native Americans and social worker with the southwest tribes, advocated for

an investigation into the deplorable conditions on the reservations. Because of his efforts,

the Brookings Institute released the Merriam Report, which highlighted the need to

reform government Indian policies. Collier was appointed head of the Bureau of Indian

Affairs and he helped initiate policies to stop further allotment. Under his guidance, the

Indian Reorganization Act was passed. This gave tribes the right of self-governance and

was an effort to promote self-determination. Tribes passed their own tribal constitutions,

developed business development plans, and established their own governing bodies such

as tribal councils or executive councils. At the time, conditions on the reservations were very impoverished, infectious diseases were rampant and Congress consistently underfunded Indian Health Services (Wilkinson, 2005).

Another detrimental policy passed by the US government was the Termination Act in the 1950s. The government was tired of being in the business of caring for the Indians and decided it would be better to terminate the tribes and assimilate them into cities. The common sentiment of the day was that if the Indians wanted education, health, roads, and better conditions they should help pay for it (Wilkinson, 2005). As a result, over 100,000 Native Americans were relocated to urban areas. It was assumed that they would find jobs and assimilate into the American melting pot (Snipp, 2000). The outcome was to move the impoverished native people into city slums, where tribal members faced discrimination and racism. In addition, loss of federal tribal recognition meant loss of access to resources and services through IHS (Weaver, 1998). The Termination Act did little to improve the status of the Native American people (Wilkinson). The Coeur d'Alene tribe did not go through termination, but had to fight to prevent this from happening. For those tribes that underwent termination, the results were a devastating rise in poverty, depression, and suicide as they were alienated from their people, native lands, and traditional ways of life. A long term result of the termination policy is that many children of terminated tribal members are now a part of the growing segment of Native American middle-class professionals who are helping to revitalize Native American life (Wilkinson).

In the 1960s, the federal government established the Office of Economic Opportunity to carry out the war on poverty. This provided increased funding for

community-action programs and supported tribal self-determination by funding new community initiatives to improve conditions on the reservations (Wilkinson, 2005). Under the Nixon administration, several more policies were passed to promote self-determination and sovereignty among Native American tribes. Sovereignty means that the people rule and govern themselves rather that some outsider or outside political system tells them what to do. They govern themselves as they see best serves their people and their culture. Some describe it as self-preservation through conservation of the language, culture, and religious freedom (Weaver, 1998)

The Indian Self Determination and Education Act and the Indian Health Care Act in particular had a significant effect on health care for the Coeur d'Alene tribe. These acts gave them the right to run their own clinic. The tribe currently receives a yearly allotment of funds for their healthcare and they decide how to use those funds to best meet the needs of the tribal people and the larger community. In addition they have sought grants to support and improve their health services especially in the area of obesity, diabetes, and diabetes prevention. Using grant money, the Coeur d'Alene tribe has built a wellness center that serves native people and local community members. This supports the need for self-determination and tribal sovereignty (G. Carpenter, personal communication, July 20, 2007).

Health and Diseases among the Native People

Early Health Concerns

Pre-Columbian health conditions for the indigenous people of North American included infectious diseases, traumatic injuries, and malnutrition. Undernourishment and bacterial pathogens were the most common contributors to morbidity and mortality.

Other common ailments included dysentery, pneumonia, insect-born viral diseases, round worm, and food poisoning (Martin & Goodman, 2000). The arrival of Europeans to North America brought a host of "old-world" diseases such as measles, smallpox, diphtheria, chicken pox, mumps, typhoid, and influenza. The Native Americans had no acquired immunity, which led to huge epidemics in many tribal villages and camps (Trennert, 1998).

Infectious Diseases

The health status of the Native American people declined dramatically after confinement of tribes to reservations. The reservation conditions were harsh and foreign to the native way of life. Poor sanitation, improper food preparation and handling, school over-crowding, and lack of adequate medical care all contributed to increased morbidity (Trennert, 1998). By the early 1900s, TB and trachoma (a highly contagious eye disease that caused blindness) were epidemic among Native American tribes. According to the Indian Commissioner at the time, "The TB scourge is the greatest single menace to the future of the Red race" (F.G. Luepp, as cited in Trennert, 1998, p. 99). Throughout the early to mid 20th century, health and sanitation conditions remained poor and Native Americans experienced higher morbidity and mortality rates than the general US population. During the 1950s, conditions began to improve on the reservations. The health status of Native people began to improve when the Indian Health Service was transferred to the Public Health Service. Over time, infectious diseases have declined, but the incidence of chronic diseases has significantly increased (Mail, 1978).

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The Rise of Chronic Diseases

While infectious diseases have decreased and stabilized among Native Americans, data indicate a rapid rise in chronic diseases due to quickly changing social, culture, and economic conditions (Young, 1996). Challenges facing Indian Health Services [IHS] include the rising prevalence of diabetes, cardio- and cerebro-vascular diseases and continued elevated rates of accidents and suicides (IHS, 2007a). Most research suggests that the causes of these conditions are rooted in social issues such as racial discrimination, residential segregation, poverty, lifestyle choices, and cultural barriers (Tashiro, 2005). Access to healthcare continues to be an issue. A report by the Institute of Medicine found that discrimination of Native Americans persists in the US health care system and continues to deprive them of access to health care that is equivalent to what is provided to the vast majority of Americans. The report found that even when controlling for education, income, and insurance, whites were more likely to receive better diagnostic workups and treatment (Smedley et al., 2003). A study comparing access and utilization of healthcare for Native Americans and whites concluded that the Native Americans had less insurance coverage, less access to care, and less utilization of services than whites (Zuckerman, Haley, Roubideaux & Lillie-Blanton, 2004). Furthermore, over half of Native Americans in the lowest income brackets did not have access to IHS care. Although IHS provides some care to those living in service areas, access remains limited (Kaiser Family Foundation, 2004). Those with IHS care receive less preventative care than the white population (Zuckerman et al.).

Overall, healthcare for Native Americans has improved since the 1950s. Life expectancy has increased from 51.3 to 69.1 years for Native American males and from

51.9 to 77.5 years for Native American females (Young, 1996). Native Americans still, however, have a lower life expectancy than any other racial group (USCCR, 2003). Mortality rates from cancers have remained relatively unchanged. Deaths from TB and gastroenteritis have significantly decreased. Rates for suicide, homicide, and accidents have declined some, but remain higher than for the general population (Young). Table 1 compares the ten leading causes of death among Native Americans in 2006 to those for the general US population and the population of Idaho.

Table 1. 2006 Mortality Disparity Rates

Leading Cause of Death: Percentage of Total Deaths	Native Americans[a]	General US Population[a]	State of Idaho[a]	Benewah County[b]
1. Heart disease	19.1	26.9	22.6	16.9
2. Cancers	17.7	23.0	21.7	24.7
3. Unintentional injuries	11.7	4.8	6.4	4.5
4. Diabetes	5.9	2.8	3.0	3.4
5. Strokes	4.5	5.8	6.8	13.5
6. Chronic liver disease	4.3	1.1	1.2	1.1
7. Chronic respiratory disease	3.7	5.8	6.1	10.1
8. Suicide	2.8	1.4	2.1	1.1
9. Influenza/Pneumonia	2.5	2.6	2.1	2.2
10. Chronic kidney disease	1.9	1.7	1.2	1.1

(Source, [a]National Center for Health Statistics, 2009; [b]Idaho Vital Records, 2006)

Of greatest concern is deaths related to alcohol abuse, diabetes, cardiovascular disease, violence and cancer. Although cancer diagnosis rates are similar to the U.S. population, Native Americans have lower survival rates after diagnosis (Johnson & Rhoades, 2000a).

The high incidence of diabetes is of particular concern because it is associated with lower life expectancy and poorer quality of life.

Health Disparities

These disparate mortality rates for Native Americans are due to multiple interrelated factors. Health disparities, and subsequent mortality disparities, are rooted in a complex web of access issues, socio-political, economic, and racially driven factors. Often we are not even aware of these issues because of our own Eurocentric biases, and the 'white privilege' of civil liberties, goods, and resources that we take for granted on a daily basis (Drevdahl, 2001; McIntosh, 1990). "Since white privilege is so much a defined part of US society, whites are not even conscious of their relationship to power and privilege. In US society, white is the norm; people of color are defined as deviating from that norm" (Gillespie, Ashbaugh DeFiore, 2002, p. 239). From a phenomenological perspective, Heidegger refers to this unawareness in our daily functioning as present-at-hand or the background of our daily existence (Leonard, 1994). For the opposing group – the oppressed or underprivileged; their daily existence is marred by constant barriers to goods, services and resources. Heidegger refers to this as "ready-to-hand." Our awareness of our present situation comes to the forefront because of the breakdown in our daily experiences (Macquarrie, 1968).

Lifestyle.

The tradition Native American diet consisted of protein, complex, unrefined carbohydrates such as the camas root and water potato, and high fiber fruits and greens (Barreiro, 2003). Historically the diet in hunter/gatherer societies consisted of 30% protein, 50% carbohydrate, 20% fat and approximately 100 grams per day of fiber

(Kaufman, 2005). In comparing this to the current ADA recommendations, the traditional diet is in alignment with those guidelines. This leads one to conclude that the quality of food in addition to lack of physical activity is a major contributing factor to obesity and diabetes. Kaufman (2005), past president of the American Diabetes Association, related the diabetes epidemic to the commercialization of food production. "We define progress in terms of quantity of food rather than quality–we define progress as the elimination of any requirement for physical activity in our jobs...and thanks to this form of progress, we've managed to devise a world designed to kill us" (p. 18).

An analysis of present day diets of Native Americans found a continued use of high fat, highly processed, high caloric food choices. In a study of Native American eating habits, the top ten foods regularly consumed were: white bread, potatoes, butter, eggs, cream, margarine, rice, milk, chicken, and hamburger. There were no fruits or vegetables included in the top ten (Kuhnlein, Receveur, Saueida & Egeland, 2004). Another study examined tribal food consumption during a 24 hour diet recall, and found that the average diet consisted of 43-46% carbohydrates, 16-17% protein, 37-40% fat with 13-14% being saturated fat (de Gonzague, Receveur, Wedll & Kuhnlein, 1999).

This is similar to the study comparing dietary intake of Pima Indians in Arizona with the Pima Indians across the border in Mexico. The group in Mexico followed their traditional diet, with a predominantly subsistence economy. Much of their physical activity was related to providing food and sustenance for their families. In contrast, the Pima Indians in Arizona farmed using tractors and trucks for most of their work. The study examined the effects of environment on diet and rate of diabetes. There was a five-fold increase in prevalence of diabetes among the Pima Indians in the U.S. The dietary

analysis showed that the Pima Indians from Arizona consumed a higher proportion of their daily calories from fat and a much lower fiber intake than the group following the traditional lifestyle in Mexico (Schulz, et al., 2006).

The current dietary recommendations from the American Diabetes Association suggests a total daily carbohydrate consumption of 45-65%, protein 10-30%, total fat 20-35% and total fiber 25-30 grams per day. In addition, the American Heart Association recommended daily allowance is less than 30% fat and less than 10% of daily diet is saturated fat. In comparing the 24 hour recall diet with the ADA recommendations, it appears that the area of greatest concern was higher than recommended daily intake of fat and inadequate fiber consumption. It does not address the adequacy of micronutrients in the diet.

Besides the marked shift in macronutrients, the long-term use of highly processed foods has led to deficits in micronutrients as well. According to the most recent NHANES (National Health and Nutrition Examination Survey) data from the CDC, most adult diets in the U.S. are deficient in vitamins A, C, and E, calcium, magnesium, potassium, and fiber. The deficits in magnesium, vitamins A and C are associated with inadequate consumption of fruits and vegetables. Calcium is reflected in low milk and dairy intake. There are limited amounts of fiber in white bread or processed breakfast cereals that are a popular food item in the commodity programs (Moshfegh, Goldman, Ahuja, Rhodes & LaComb, 2009). The U.S. Department of Agriculture made significant revisions in the food distribution program on Indian reservations to add more fruits and vegetables (U.S. Department of Agriculture, 2008). However the list of available foods for Indian reservations indicated that fruits and vegetables were only provided as canned

commodities. According to Garrity, (2004) there is a very limited supply of fresh fruits and vegetables in many rural areas.

Genetics.

Since the completion of the human genome project, there has been a growing interest in the link between genetics and disease. It is common to read articles in medical journals and healthcare newsletters about the genetic predisposition to certain diseases within certain racial groups. One example is the notion of a "thrifty gene" in Native Americans as the cause for the diabetes epidemic among this group. Conversely, genetic sequencing has failed to account for significant differences in disease patterns among or across race or ethnic groups (Smedley et al., 2002). It is important to avoid overemphasizing the genetic component of health disparities. Rather, disparities among socially disadvantaged groups most frequently suggest a gene-environment interaction. For example, diabetes is more common among those Native Americans living on reservations than those off the reservation. This suggests that socio-economic-status (SES) plays a key contributory role (Race, Ethnic and Genetics Work Group, 2005).

A greater concern is that by rationalizing diseases or attributing them solely to genetic factors, we ignore the need to examine the social determinants of health disparities (Brooks & King, 2008). We know there are specific genetic explanations for some diseases among certain racial and ethnic groups such as Tay-Sachs disease among Eastern European Ashkenazi Jewish decent, sickle-cell anemia in African Americans, and cystic fibrosis in people of white European ancestry (Craig & Dunn, 2007). However, most diseases are not caused by single gene mutations, but by multiple genes and genetic-environment interactions. The human genome project has demonstrated that the genetic

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make of humans is 99.9% the same (Craig & Dunn, 2007), which does not support the notion that health disparities are linked to racial differences in genetic makeup. Many argue that the concept of race, in and of itself, is a social construct rather than genetically-based (Gillespie et al., 2002).

Socioeconomic status.

Epidemiological measures demonstrate racial-related disparities in life expectancy, mortality, and prevalence of chronic diseases (Smedley et al., 2002; National Center for Health Statistics, 2009). Socio-economic-status (SES) is a composite measure for income, education, housing conditions, and occupation. As SES decreases, health status also decreases. Lower SES is associated with increased disease burden and shorter lifespan (Sapolsky, 2005). Research has also demonstrated that SES is predictive of cardiovascular function, metabolic measures, obesity, and levels of stress hormones. In another study, lack of homeownership was a significant predictor of depression (de Groot, Auslander, Williams, Sherraden & Haire-Joshu, 2003).

Racism.

Even controlling for income, educational level, geography, or socioeconomic factors, racial disparities in health still exist. This has led one group of researchers to suggest these disparities are rooted in racism. The researchers propose that a caste system still exists in our healthcare system today. This caste system in healthcare can be traced back to late 19th century Darwinism theory of "survival of the fittest." In essence, the prevailing societal views at the time were that "individuals with lighter skin pigmentation were ranked at the top, which in America and Europe reinforced the absolute dominance of whites" (Brooks & King, 2008, p. 13). One can examine 100 years of census records to

see how racial definitions shift with the societal beliefs of the time (Brooks & King). This reaffirms the supposition that race is a social construct by the dominant social group at the time and racism is one social determinant of health disparities.

Residential segregation.

Key factors in determining health status include access to the health care and residential segregation. Minorities live in poorer neighborhoods than whites. Those in lower SES brackets tend to cluster in the same urban neighborhoods; often because it is the only location that they can afford. This is particularly true for Native Americans and other ethnic groups since racial discrimination in the housing industry continues to force minorities to reside in less desirable neighborhoods (Gee & Payne-Sturges, 2004). Another concern related to residential segregation is exposure to environmental toxins such as air pollution and lead-based paint. When not counterbalanced by resources, stressors lead to heightened vulnerability to environmental hazards and perpetuate health disparities (Gee & Payne-Sturges).

Policy interventions.

Although Native Americans are supposed to have health care provided in perpetuity as part of their treaty agreements between the federal government and Indian tribes, 31% of American Indians and Alaska Natives under the age 65 are without health insurance, compared to 17% of white Americans (Center for American Progress, 2010). Diabetes, heart disease, cancer, and substance abuse remain significant issues for health disparities among Northwest tribes (NPAIHB, 2007a). Interventions to address these disparities require actions at several levels. National policy making should be based on an understanding of the cultural and historical influence on Native American health and

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should focus on developing strategies to address these health disparities (Olson, 2002).

Better data collection and reporting are needed to evaluation the outcomes of these

strategies (Sekhar, 2009). Recommendations to the current health care reform package

before Congress should include reauthorizing the Indian Health Care Improvement Act.

There is a need for cultural competent health care and efforts to eradicate racial biases

and prejudices within our current health care system (Russell, 2009). Policies and funding

aimed at eliminating environmental factors, promoting community resources, and

eliminating socioeconomic barriers are needed (Gee & Payne-Sturges, 2004). Enacting

effective anti-discrimination laws, raising the minimum wage, and passing legislation to

correct pay inequities also would help increase access to care and healthy lifestyle

options. As public policies are developed, it is important for tribal and healthcare leaders

to scrutinize who will gain and at what cost.

Native American Healthcare

In a move toward promoting tribal self-determination, President Nixon

recommended granting tribal control and management of federal Indian Health programs.

As a result, the Indian Self-Determination and Education Assistance Act (PL 93-638) was

passed into law in 1975, giving tribes the option of taking over management of their tribal

clinics (Kickingbird & Rhoades, 2000), In 1976, the Indian Health Care Improvement

Act was passed, outlining a specific benefits package that IHS was to provide. This

package included inpatient and outpatient care, dental care, mental-health and alcohol

counseling, and preventative health care. Services were aimed at eliminating health

disparities and promoting self-determination by allowing tribes to control and manage

their own programs (Johnson & Rhoades, 2000b). The problem was the government

assumed the current IHS system was adequate for addressing the health care problems

instead of the chronically underfunded agency it was (Johnson & Rhoades, 2006a).

Title I of PL 93-638 offers tribes the choice of managing their own health care

programs. They can contract with IHS for the services they would normally receive from

IHS. Congress amended the PL 93-638 in 1988, adding another step in the self-

determination process; this is known as Title III of PL 93-638. After three years of

success contracting with IHS for health care services, tribes are eligible to enter into a

self-governance compact with IHS. This is similar to a block grant, where tribes enter

into annual funding agreements with IHS (Dixon, 2001). This gives the tribe the

flexibility to reallocate resources and redesign programs without having to go through the

federal bureaucracy (Dixon, Mather, Shelton & Roubideaux, 2001). The challenges

inherent in contracting are that rules and regulations for tribal health care fall under

different regulations than the federal government. Under the compact agreements, tribes

became responsible for making healthcare facilities handicapped accessible and for

purchasing worker's compensation insurance for all employees. These additional

expenses are not included in the allocation of federal funds.

When government health care entitlement programs such as Medicaid and

Medicare run out of funds, Congress passes supplemental appropriations to cover the cost

overrun. This is not the case for IHS: when funds run out, services cease until the next

fiscal year (Dixon et al., 2001). Current IHS funding only provides 59% of funding

needed to provide basic health care services (IHS, 2005). According to a report by the US

Commission of Civil Rights [USCCR] (2003), the federal government budgets almost

twice as much per capita for healthcare to federal prisoners as it funds per capita to IHS

for Indian health ($3803 per capita v. $1914). For the Department of Health and Human Services, Native American healthcare remains a low priority. With IHS accounting for only 0.5% of the total Health and Human Services budget (USCCR), IHS remains perpetually underfunded and understaffed (Roubideaux, 2005).

Indian Health Services

The Department of Health and Human Services oversees Indian Health Services. The IHS headquarters are located in Rockville, MD. Services are divided into twelve designated regions: Aberdeen, Alaska, Albuquerque, Bemidji, Billings, California, Nashville, Navajo, Oklahoma City, Phoenix, Portland and Tucson. IHS regional offices manage local health care units, administer the budget, manage personnel and property, conduct program planning and implementation, oversee gathering of statistics, and maintain government contracts (IHS, 2005). Under the IHS area offices are the service units, which include hospitals, clinics, and health centers. Not all services and facilities are available in all areas. IHS funds services through four avenues: 1) IHS run facilities, 2) contracts and compacts for health care services with tribes, 3) contracted health service, and 4) urban health programs (Kauffman & Joseph-Fox, 1996).

IHS subsidizes funding for 41 urban Native programs throughout the US. Less than 1% of the IHS budget goes toward these urban health centers, so the programs tend to be predominantly referral centers and don't always provide health care (Warne, 2003). These sites provide approximately 700,000 service visits per year to the 1.3 million Native Americans residing in urban areas (Northwest Portland Area Indian Health Board [NPAIHB], 2007b). With more than half the Native American population residing in

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urban areas, access to healthcare is an ongoing challenge (Sherwood, Harnack & Story, 2000).

For those who qualify, IHS provides primary care free of charge, but access to specialty services are very limited and often delayed (Dixon, 2001). Eligibility requirements for IHS include being of Native American descent, and a member of a federally recognized tribe living within the IHS service area for that tribe. If a tribal member does not live in the service area of their reservation, they do not qualify for IHS services, nor does IHS provide funding for them to obtain care where they are residing. The only exception to these rules is that non-native women, who are pregnant with an Indian child, are eligible for pre and postpartum care from IHS (Johnson & Rhoades, 2000a).

IHS has also introduced another eligibility requirement because of rapidly rising healthcare costs for "referral" Contract Health Services (CHS). Tribal members must reside in the service area for at least 180 days before they can qualify for IHS care. They must be pre-approved for referrals to specialists or to receive funding for hospital care outside of IHS system. If the allotted funds for CHS are used for the fiscal year, they must wait until the next fiscal year to get approval for the service. In addition, for contract care services, Native Americans must exhaust all resources and be turned down for Medicaid before IHS will consider providing payment (Dixon, Lasky, Iron & Marquez, 1997).

IHS provides healthcare services to approximately 57% of Native Americans who are members of federally recognized tribes and live with the IHS service area (IHS, 2010). IHS health care is delivered through 29 hospitals, 59 clinics, 32 health centers.

IHS also provides some support to 34 urban Indian health projects. The Joint

Commission on Accreditation of Healthcare Organizations accredits all IHS hospitals and

health centers (Johnson & Rhoades, 2000a). IHS staff includes: 890 physicians, 320

dentists, 600 pharmacists, 2700 nurses, as well as physicians' assistants, dental

hygienists, nutritionists, health educators, engineers, and sanitarians (IHS, 2010).

Through PL 93-638 contracts, IHS provides cooperative management of 16 hospitals,

237 health centers, 93 health stations, and 166 Alaska village clinics (IHS, 2010). The

challenge for IHS is to remain financially solvent while addressing the growing burden of

managing chronic diseases (Johnson & Rhoades).

Portland Service area.

The Portland area office services 43 tribes in Oregon, Washington, and Idaho

(approximately 170,000 Native Americans). Seventy-five percent of Portland area IHS

allocation funds go toward tribal health care contracts and compacts. IHS only directly

manages seven tribal clinics (Yakima, Spokane, Colville [Nespelem], Makah, Warm

Springs, and Fort Hall). There are no IHS hospitals in the Portland Service area (IHS,

2005). Services for specialty care and inpatient treatment are funded through IHS

contract-care programs (United States Government Accountability Office, 2005).

In addition to the BIA Portland office, there is a Northwest Portland Area Indian

Health Board (NPAIHB), which is a non-profit advisory board formed in 1972 by the 43

tribes in the Portland service area. Each tribe appoints a delegate to the board. The

mission of NPAIHB is to promote the health and well-being of the tribes through

strategic planning, legislative and political analysis, and program development. NPAIHB

also conducts research and disease surveillance through a tribal epidemiology center (NPAIHB, n.d.).

  Coeur d'Alene tribal health.

  Benewah Medical Center and Wellness Center (BMCWC) is operated by the Coeur d'Alene tribe through grant funding and a compact agreement with IHS under PL 93-638. The clinic serves the tribal community, as well as non-natives in the community and surrounding area. The health center has served as a model for other PL 93-638 clinics around the country and received the 2005 Johnson and Johnson "Crystal Award" that recognizes outstanding excellence in providing community-wide health and wellness services and for their contribution to improving native health (G. Carpenter, personal communication, July 20, 2007).

  The clinic provides a full-range of outpatient services, including medical and dental care, pharmacy services, counseling, radiology, lab, physical therapy, community health, and diabetes education. The clinic staff consists of three full-time and two part-time physicians, two nurse practitioners, a dentist and hygienist, four mental health and substance abuse counselors, as well as a diabetes educator, a dietician and support staff. Fifty percent of the revenue for BMCWC comes from IHS, and the other 50% is a combination of patient revenue, federal grants and contracts, wellness center user-fees, and other sources (Carpenter, 2006).

  The clinic, which opened in 1994, currently serves 6,500 patients and provides 26,000 healthcare visits per year. It has outgrown its space, so a module unit was added to accommodate the growing demands for services. If resources were not an issue, the clinics would add dialysis services. BMCWC has outgrown its facility and would like to

have a new clinic as well (G. Carpenter, personal communication, July 20, 2007). Service needs identified by IHS for the Coeur d'Alene tribe include inpatient mental health, dialysis, chemotherapy, occupational therapy, urgent care, assisted living facilities and long-term skilled nursing facility (Indian Health Service, 2005). A nine-member Health Board appointed by tribal council includes seven tribal members and two non-native community members and is responsible for oversight of BMCWC (G. Carpenter, personal communication, July 20, 2007).

Community Health Outreach programs offered by BMCWC include chronic illness home care, diabetes care, nutritional services, maternal-child health, school health services, resources for communicable and sexually transmitted disease (STD), as well as health promotion and disease prevention programs. Home care services range from nursing assessments to monitor disease conditions, medication management, case management, and referral to the Panhandle Home Health for long-term home health services. The diabetes program provides one-on-one counseling with a nurse and/or dietician on diabetes self-management, life style modification, and a diabetes support group. The diabetes educator also holds a weekly foot care clinic. Maternal-child health services include prenatal home care, and postpartum home visits, as well as contraceptive education and coordination of the federal WIC (Women, Infants, and Children) program. At the area schools the community health outreach staff assists with immunizations, screenings, health education and teen-pregnancy prevention. Staff also gather and report surveillance data on STDs and offer education and resources on prevention, as well as support services. In addition to these specific areas, the outreach staff emphasizes general health promotion and disease prevention through a variety of community screening and

education classes (D. Mithoug, personal communication, Sept. 29, 2009; BMCWC, 2009).

In 1998, the Wellness Center was completed debt-free through a variety of federal, state and private funding sources. The state-of-the-art facility includes several pools, a hot tub, physical therapy and cardiac rehabilitation services, basketball and racquetball courts, indoor walking track, aerobics room, exercise equipment, day care, conference rooms and community health education and fitness coordinators (Coeur d'Alene Tribe, 2004). The use of the facility is free to tribal members and available for a monthly fee to non-Native community members.

The greatest health concerns for the Coeur d'Alene tribe are chronic diseases and obesity. Although the tribe is seeing some increase in childhood obesity, methamphetamine use in their youth is of greater concern. Denial among patients about the presence of diabetes adds to the challenge of caring for patients. The diabetes educator observes that the tribal people ignore it or forget about it until they began to have symptoms or complications (J. Gordon, personal communication, July 20, 2007). An ongoing issue is lack of tribal member participation in diabetes education programs, including support groups and diabetes classes offered by the clinic. This suggests the need to gain a better understanding of the experiences of the Schitsu'umsh people living with diabetes within the context of their cultural believes and practices. To provide better diabetes care, as healthcare providers we need to cross the chasm of history and culture to understand the Schitsu'umsh experiences of diabetes.

Tribal sovereignty needs to be respected and supported. To honor the tribe's self-determination, my role as a healthcare provider and researcher is to develop a

collaborative partnership with the tribe. The solutions to the diabetes epidemic need to come from within the community and from the tribal people themselves. "The best outcomes will be inspired by the Indian people themselves and carried out by their own institutions" (Wilkinson, 2005, p. 303).

<p style="text-align:center">The Reservation: Present-day</p>

The Coeur d'Alene reservation covers 345,000 acres of land in the Idaho panhandle, extending over parts of Benewah and Kootenai counties. It contains forest, farmland, and water. The rolling hills of the Palouse country are fertile grounds for growing wheat and legumes. The woods provide the tribe with a source of revenue through selected forestry management, and also provide access to traditional food sources. The St. Joe and Coeur d'Alene rivers offer plentiful access to fishing and water recreation. The lower portion of Lake Coeur d'Alene is located on the reservation; however, the water quality of the lake has been significantly affected by heavy metal pollution as a result of a century of mining in the Silver Valley region directly north of the lake (Coeur d'Alene tribe, 2008).

Physical environment

The current reservation area is predominantly located in Benewah County in the Idaho panhandle and extends up into Kootenai County. The data presented in this section are for only Benewah County. Because Kootenai County contains demographics for a large urban area, it does not accurately represent the present-day conditions on the reservation. As a predominantly rural area, Benewah County statistics provide a better representation. With foothills-type geography, Benewah County is primarily forest, farmland, and part of Lake Coeur d'Alene. It covers 776 square miles of land and 7.9

square miles of water. The reservation and Benewah County are located at the south end of Lake Coeur d'Alene and below the Silver Valley mining district. This has resulted in tribal exposure to significant environmental toxins and water pollutants from the mining industry, as well as a polluted watershed on the reservation. On the reservation, there are approximately 180,000 acres of timber and 150,000 acres of farmland used to produce peas, lentils, wheat, barley, and canola. The tribe itself owns a 6000 acre farm. In addition to the previously mentioned crops, the tribe also grows Kentucky blue grass, which is sold for grass seed (Citydata.com, 2009; Coeur d'Alene tribe, 2008).

Economics

Of the 9352 residents of Benewah County, 31% reside in urban areas and 69% in rural. The majority of residents (83%) living in Benewah County also work there. 22% of the residents live below the poverty line (state average is 11.8%). At the time of the most recent census data (2000) 17% of the population did not have health insurance and 16% of minors were without health insurance. The major industries in Benewah County are education, health and social services (20.9%), manufacturing (15.3%), and retail (12.2 %). The majority of jobs for men are in wood products, agriculture, construction, public administration, and trucking. The main job areas for women are health care, education, public administration, finance/insurance, hospitality services, arts and recreation, and food/beverage stores. The unemployment rate was 13.8% in October 2009, which is significantly higher than the state average of 8.3% for the same period. The median age of the residents in Benewah County is 39.2. There are slightly more males to females (51:49%). Median cost of rent is $380 and median home value is $151,926 (state average

was $183,700) (Idaho Health Stats, 2009). Tribal gaming and tourism also significantly support the local economy.

Plummer and Worley are the two largest towns on the reservation. Plummer has a population of 997; with an approximately 50% male/female ratio; and a median age of 30. The population of Plummer is 42% Native American, 54% white, and 4% other. The predominant religion is Catholic (40%). The town of Worley has a population of 219 people, with a median age of 37. The proportion of males to females is 48% to 52%. Racial breakdown includes 29% Native American, 68% white, and 3% other (Citydata.com, 2009).

With almost 1700 employees, the tribe is currently the largest employer in Kootenai County. The Coeur d'Alene tribal casino alone employs over 1400 job. The casino and resort results in $103.8 million in sales annually and contributes significantly to the regional economy. In 2009, the Coeur d'Alene tribe donated $1.8 million toward education and since 1993, has contributed almost $14 million toward education from gaming revenue (Coeur d'Alene Press, 2010). In addition, the Coeur d'Alene tribe has used casino revenues to promote economic development for infrastructure, social services, human resource development and training and creating new businesses (Peterson & DiNoto, 2002).

Transportation and Safety

There is a city link bus system available on the reservation that runs between Plummer, Worley, Tensed, Desmet, and the Coeur d'Alene Tribal Casino where riders can transfer to other Citylink buses to access additional destinations; however hours of operation are limited (Idahocitylink.com, n.d.). Additional transportation is by private

vehicle. The clinic does offer transportation to those medically in-need and the

Community Health Program also arranges transportation for their clients with medical

needs and who are unable to pay for their own transportation to medical appointments in

Spokane and Coeur d'Alene (J. Gordon, personal communication, January 19, 2010).

There are local police and fire services available in Plummer and Worley, as well

as county services. In addition, the major highway through the reservation is patrolled by

the Idaho State Police department. The county sheriff's department is located in the

county seat of St. Maries, but does not always work collaboratively with the tribal police.

Education

Primary education is available through either public or tribal schools. The public

elementary school located in Worley was condemned and the children are currently bused

to the public school in Plummer. The school district has added a number of portable

classrooms to accommodate the additional students. In addition, there is a public middle

school and high school located in Plummer. The tribal school is located approximately 15

miles south of Plummer in the town of Desmet and serves students grade kindergarten

through 7th grade. There are adult education and tutoring classes available through the

tribe to serve the adults in the community. They also have access to a computer center,

GED classes, job retraining programs, and extension courses are available through a

regional community college (Coeur d'Alene tribe, 2008).

Summary

The Coeur d'Alene (CDA) reservation lies along the southern part of Lake CDA

in the Idaho panhandle. As a sovereign nation, the Coeur d'Alene tribe has the right to

self-govern through their tribal council. This governing body consists of eight elected

tribal members, including the chair, Chief J. Allan. The tribal government oversees the operations of 18 departments. They have their own tribal police department. The justice branch of tribal government includes judges, prosecuting attorneys, and tribal defenders. The tribe owns and operates several businesses, including Berg Integrated Systems Manufacturing, a lumber mill, the Coeur d'Alene Casino and Hotel, and Circling Raven Golf Course (Coeur d'Alene tribe, 2008). The tribe has successfully in built nationally-acclaimed social programs, including an award-winning medical center and wellness center to serve the tribe and local community members. The tribe is also known for its Supreme Court victory which granted them the southern portion of Lake CDA (Andrews, n.d.) which opened the door for improving state-tribal relations (Wilson, 2002).

Despite the recent economic downturn, the tribe has most recently been recognized as the largest employer in Kootenai County, with the Coeur d'Alene tribe employing almost 1700 people (Kramer, 2010). According to the tribe's economic development plan, their future goals include improving the infrastructure within the reservation to ensure adequate water, sewer, public transportation and adequate sidewalks. The second goal was to improve community partnerships and communication channels with local city and regional governments. Third, was to maintain the open space and rural character of the reservation. The last economic development strategy was to improve the economy base on the reservation by attracting new businesses, providing support systems for existing businesses, and enhancing the arts and culture sector. Four action teams were developed consisting of community vitality, community pride, lifelong learning and communication and leadership. These teams were charged with the goals of community beautification, removal of social barriers and enhancing the economic

outlook on the reservation through community development (Coeur d'Alene tribe, 2009).

Their economic development vision states:

> Coeur d'Alene reservation communities are close-knit communities with tribal and local governments working in strong partnerships. We have open communication conversations and full participation from our citizens. We are renowned for our progressive, cohesive, and collaborative communities and self-supporting rural life. We have a strong belief in and support for education that provides lifelong learning. We have created vibrant bustling downtowns and a diverse, progressive, and innovative small business sector. We have developed an abundance of savvy business people who cater to the multitude of recreational enthusiasts and passing visitors. (Coeur d'Alene tribe, 2009, p. 4)

CHAPTER 3

Methodology

Introduction

This study was grounded in the philosophical teachings and theoretical underpinnings of Martin Heidegger's *Being and Time* (Heidegger, 1926/1962), where he explores the lived experience of individuals as "being-in-the-world" (Munhall, 1994). Heidegger's framework was applicable for studying Native Americans because it considers the phenomena of concern in the context of the person in their world. Heideggerian hermeneutics provided the method to explore the lived experience of a phenomenon within the context of their language, culture, and history. This framework fit well with the question of how Native Americans experience of living with diabetes from their own cultural perspective. In this section, I provide an overview of the philosophy of Martin Heidegger and the philosophical underpinnings of interpretive phenomenology. I explore ways of thinking and understanding the world from a Heideggerian perspective and describe the research method, which was based on Heideggerian hermeneutics.

Philosophy of Martin Heidegger

Heidegger was born in 1889 in the small town of Messkirch, Germany. During his formative years under the influences of the Catholic Church, he entered into training for the priesthood but was dismissed for health reasons. It was during this time that he was exposed to philosophical works of Franz Brentano and his protégée Edmund Husserl (Blattner, 2006). Reading the works of Brentano and Husserl led Heidegger to ponder the question "what is the meaning of being?" Heidegger was an avid follower of Husserl and even worked with him for a brief period at Freiburg University. Heidegger grew

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discontent with Husserl's epistemology-based philosophy and began to challenge Husserl's notions of descriptive phenomenology and Cartesian duality (Harman, 2007). According to Heidegger, the problem with Husserl's phenomenology is that he retained a commitment to objectifying phenomena (Harman).

In an effort to promote the field philosophy, Husserl introduced descriptive phenomenology as a research method so that his discipline was at the forefront of arriving at incontrovertible truths (Dostal, 2006), and phenomenology was considered the mother of all knowledge (Cohen & Omery, 1994). "Traditional philosophy from Descartes to Kant wanted to offer not only a definition of knowledge, but also an account of how the knower is connected to the known" (Hoy, 2006, p. 183). Husserl's phenomenology follows this philosophical framework. Grounded in epistemology, Husserl's phenomenology focuses on describing and clarifying the essence of the thing as we encounter it in our conscious world. The key question of phenomenology is, "How is this thing made known to us in the absence of preconceived notions or prejudices?" (Ray, 1994). Husserl believed that one could hold at a distance, any preconceptions or prejudices to get to the essence of the thing itself. Husserl's stance is that we can stand back from our involvement with things and reflect on them as mere objects by bracketing our preconceived ideas (Carman, 2006).

This notion of bracketing our presuppositions and the split of object and subject was the root of Heidegger's discontentment with Husserl. Heidegger's position was that preconceived notions cannot be bracketed or suspended; it is these very notions that constitute our possibilities in the world and how it is intelligible to us (Ray, 1994). Heidegger distinguishes the factual level of human existence (ontic) from the deeper

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levels that explain our existence of being (Frede, 2006). Ontology is concerned with what it is to be human and our sense of how we live in our world. The key question of ontology is, "What is our understanding of the world as we exist in it?" Heidegger makes interpretive understanding the central mode of human existence (Dasein). This was a divide from philosophy's traditional focus on phenomena that acknowledge the duality between subjective and objective (Hoy, 2006). Husserl's descriptive phenomenology sought to describe the experience as it appears or presents itself, whereas Heideggerian hermeneutics goes beyond description to deeper understanding of what is concealed (Munhall, 2007). Before considering Heidegger's approach to interpretive phenomenology, it is necessary to understand Heidegger's notion of "Dasein" or Being.

Heidegger's Concept of Being

Any qualitative research method requires an understanding of its philosophical underpinnings; therefore to understand Heidegger's approach to phenomenology we must understand his notion of being-in-the-world or Dasein, which literally means "being-there." We are Dasein by the way we exist in the world (Wrathall, 2005). Dasein refers to our own existence or "mineness." According to Heidegger, our background and history provide the basis for interpreting of being-in-the-world: "We are born into a world, whose history and culture make us who we are…we are both in and of the world" (Dostal, 2006, p. 134). As a relevant example, the traditional name of the Coeur d'Alene tribe - Schitsu'umsh literally means "those who were found here." Their experiences of living in the world with diabetes cannot be separated from their landscape and oral history. They are all connected. They are all one.

Dasein exists in a triadic world where past (facticity), present (falleness), and future (possibilities) all come together. Dasein understands itself in terms of past, present, and future possibility because "being is time and time is something never simply present, but constantly torn apart in an ambiguous three-fold structure" (Harman, 2007, p. 1). "Facticity" means that Dasein always finds itself in a situation not of its choosing. There are a great many givens based on the situations into which we are born. Facticity is the term Heidegger gives for the fact that we cannot recognize our existence without recognizing our existence in a particular world (Solomon & Gottlieb, 1999). All elements of the three-fold are a part of that "throwness" into a culture or group. The three-fold is a way of seeing and understanding being that we inherit and over which we have no control. "Falleness" is similar to the notion of "fall of man" which refers to a preoccupation with day-to-day living and the tasks at hand which distracts Dasein from its authentic self and our future possibilities (Macquarrie, 1968). It is this average everydayness that Dasein is mainly concerned with: how we find ourselves in our everydayness of being-in-the-world (Dostal, 2006). This mode of engaging with everyday existence is how the world becomes intelligible to us (Guignon, 2006). There is a horizon on which the past, present, and future unfold together; this comprises our existence as being-in-the-world.

We cannot know ourselves better than we know the world because they are one and the same. There is no duality, no subject/object, or ego/consciousness--just being-in-the-world (Solomon & Gottlieb, 1999). Parse (2001) best captures the essence of Dasein when she explains Heidegger's definition of person. Being-in-the-world is a unitary phenomenon (not a dichotomous subject/object). Hyphenating the term being-in-the-

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world demonstrates the oneness between person and world and that is why we use the term "lived experience" rather than just experience (Racher & Robinson, 2003).

The person as being-in-the-world.

The goal of Heidegger's work is to understand what it means for Dasein to exist (Dreyfus, 1991). There are five defining characteristics to Heidegger's notion of being: 1) the person as a being-in-the-world, 2) the person as a being for whom things have value and significance, 3) the person in time, 4) the person as self-interpreting; and 5) the person as embodied (Leonard, 1994). The first characteristic is the person as being-in-the-world. This definition of world is not the same as globe or environment: rather, it refers to a set of relationships, practices, language, values, and beliefs that we have by virtue of being thrown into a culture or social group and the historical significance that goes with that (Leonard, 1994). An example is the term "world of diabetes," which defines the diabetes realm through a set of relationships, values, practices, and beliefs.

There are three levels of how our background unfolds to form our understanding of being-in-the-world: 1) fore-having, 2) foresight, and 3) fore-conception. "Fore-having" is a practical familiarity with the world that is passed down from generation to generation (Benner & Wrubel, 1989). "Foresight" is the term Heidegger uses for the language and culture that already exists in the world as part of a common understanding based on our world-view. For example, a member of the Schitsu'umsh tribe will bring a different perspective than someone of the Lakota or Dine or Cherokee tradition. We bring our common background to the foreground, which helps us understand our being-in-the-world. We know in advance how particular things will appear in our world (Hoy, 2006) "Fore-conception" means that we are creating the world we live in, and at the same time,

we construct a world from our own understanding, experience, and background (Koch, 1995). The notion of fore-conception means we have some preconceptions of how we should interpret the world as we engage in it, for our worlds cannot be separated from our experiences (Diekelmann & Ironside, 1998).

The person for whom things have significance and value.

The second characteristic of Dasein is the person for whom things have significance and value. "A basic characteristic of Dasein is that things show up as mattering – as threatening, or attractive, or stubborn, or useful and so forth" (Dreyfus, 1987, p. 264). There is a connection to the things in our lives and our daily interactions with the world.

People have very different concerns and beliefs, based on their culture, language, or situation. This means, we need to study people within the context of their world in order to understand what is significant or valuable to them. In addition, the importance of something can guide our activity or our possibilities toward the future. This relates to the concept of being-in-time (Leonard, 1994).

The person in time.

Time is another essential element of Dasein and is different from the typical western linear view of time. Being-in-time means looking at the past, present, and future together (Leonard, 1994). All of this is referred to as temporality (Munhall, 1994). Past, present, and future are not separate from one another. "We exist as three temporal dimensions at once; it is being ahead of ourselves in the future, drawing on our past, while being concerned with the present that constitutes our being" (Frede, 2006, p. 64). The three-fold horizon of time is torn apart as life unfolds in special moments of caring or

in flashes of time which stand out from others (Dostal, 2006). Time is lived time or it is significant "for-the-sake-of things" that matter to us moments (Leonard, 1994). The array of understanding of triadic time influences how we interpret our experiences of being-in-the-world.

The person as self-interpreting.

The person as self-interpreting is the forth characteristic of being. Even at a cultural level, we co-create our world through self-interpretation. Heidegger refers to this self-interpreting as *existenz. Existenz* is the freedom to choose possibilities for one's self based on the how one finds himself situated in the world (Wrathall, 2005). It is this notion of free will that sets humans apart from other sorts of beings. Dasein decides its existence either by taking hold of the future possibilities or neglecting them by simply accepting a given way of life without considering alternatives or questioning why.

The authentic *Dasein* makes the question explicit and recognizes the nature of choices of existence. In contrast, others live an inauthentic life by failing to ask the question of being or how we come to exist in the world. These individuals fall captive to the world. This state of everyday inauthentic living is what Heidegger refers to as "falleness" (Solomon & Gottlieb, 1999). In this taken-for-granted mode of being, Dasein is lost in everyday existence and becomes cut off from its own possibilities (Dostal, 2006). As this is our typical existence, there are rarely moments when our true selfhood emerges (Macquarrie, 1968).

The person as embodied.

People's experiences of time tend to be embodied (Young, 2002). We are embodied through our consciousness, which is different than having a body. This notion

of embodiment is the fifth characteristic of being-in-the-world. In this unity of self and body, the world and consciousness are inseparable (Racher & Robinson, 2003). In this way, we avoid the problem of mind-body duality, it is the difference between saying 'I know my body' and 'I am my body.' The body is not just a machine, but is the core of how we exist in the world (Leonard, 1994).

Embodiment is shaped by our routines, skills, environment, and cultural understanding of our being-in-the-world, but it is through our body that we access the world in which we live (Benner, 1994). "We feel, think, taste, touch, hear and are conscious through the opportunities the body offers….for each individual a particular perspective or consciousness exists based on their history, knowledge of and openness to the world" (Munhall, 2007, p. 161). For example, when we become ill, it is more than the body that is affected. In a sense, it is a breakdown in our day-to-day existence in the world so our general notion of embodiment does not work anymore. Illness of the body is not the problem; the issue is how our embodied person is no longer able to navigate the world as we know it--and this affects our existential possibilities (Leonard, 1994). Heidegger's notion of being-in-the-world supports the need to explore the Native American experience of diabetes as it is embodied in their life-world. Diabetes is not just a disease, but a condition that affects their way of being in the world. Interpreting Native Americans' experiences of diabetes must be done within the context of their language, culture, history, and worldview.

Interpretive Phenomenology: Methodology and Methods

Interpretive Phenomenology

Martin Heidegger introduced his methodology in the 1920s, as a means to analyze experiences within their social, cultural, and historical context (Parse, 2001). Heideggerian hermeneutics is a philosophical approach to interpretive phenomenology that seeks to unveil concealed meanings of an experience or phenomena by probing the data for interpretations (Speziale & Carpenter, 2003). Heideggerian hermeneutics looks at the lived experience of a phenomenon through the lens of person in the context of their language, culture, and history. Hermeneutics comes from the Greek word *hermeneuin,* which means to interpret; therefore hermeneutics refers to the practice of interpretation (Dombro, 2007). Dilthey originally introduced the concept of hermeneutics to philosophy but Heidegger shifted the focus of hermeneutics from an epistemological to ontological one (Parse).

The aim of Heideggerian hermeneutics is to ask for the meaning of a phenomenon as it is lived out in the human experience (Crist & Tanner, 2003). Heidegger's philosophy and methods of interpretive phenomenology are particularly appropriate for nursing and studying cross-cultural issues related to nursing practice. Since phenomenology provides a method for studying the meaning human experiences as they are lived, it is an appropriate research method for the nursing profession (Ray, 1985). Interpretive phenomenology and hermeneutic methods help nurses understand the essence of experiences of individuals embodied in their physical and cultural environments rather than as isolated beings or only physical bodied (Dreyfus, 1994). The core of interpretive phenomenology "is respect for the social and cultural nature of being human. Human

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practices, skills, habits, meanings, and in particular recognize practices allow for others to be made visible" (Benner, 1994, p. xv).

Phenomenology comes from the Greek word *phenomenon* (Ray, 1994). It literally means 'to show itself,' or as Heidegger (1962) says, "to put into light or manifest something that can be visible in itself" (p. 57). The purpose of hermeneutic phenomenology is to draw out or peel away the outer layers to reveal what is obscured within (Macquarrie, 1968), not to simply depict how phenomena appear on the surface. What is drawn out or revealed is called *aletheia,* which Heidegger refers to as "truth" or "unconcealment" (Smythe, Ironside, Sims, Swenson & Spence, 2007). Heidegger's concept of hermeneutics stems from Dasein and being-in-the-world and involves searching for common meaning, interpreting parts to the whole and whole to the parts and, finally, sharing what emerges as new understanding (Parse, 2001). Language, prejudices, preconceptions, historical context, and temporal situatedness are all components of this circular interpretive process.

The importance of language.

Language is the background for interpretation and understanding (Parse, 2001). Language itself speaks and is the voice of being-in-the-world (Macquarrie, 1968). Heidegger would say that we speak by way of language or, more literally, we speak from out of language because people speak to us with the language they inherit. A person's language is a part of their linguistic culture (Allen, 1995). It is this linguistic essence that Heidegger referred to as originary language. This is not the spoken word, but rather a mode of being or identifying with the world in a certain way (Wrathall, 2005). "Language creates the possibility for particular ways of feeling and relating that make

sense within a culture" (Leonard, 1994, p. 46). Language expresses our being in the world and provides the horizon of possibilities for understanding.

Horizons of understanding.

Our interpretation of the world as we experience it is the central mode of being-in-the-world (Hoy, 2006). Our very existence constitutes our understanding and interpretation of the world in which we find ourselves. Understanding is not a simple cognitive act, but our ability to live in and navigate a world that is constantly changing. There are three levels of understanding our being in the world: the forehaving, foresight, and foreconception (Hoy). Our interpretations are based on our past, present, and future merging together on the horizon of understanding. Understanding moves in a circle.

Hermeneutic circle.

Our possibilities are hidden within the hermeneutic circle. "We genuinely take hold of this possibility only when, in our interpretation, we have understood that our first, last and constant task is never to allow our fore-having, fore-sight, and fore-conception to be presented to us by fancy or popular conceptions" (Macquarrie, 1968, p. 24). Our insights are based on what is already understood. They cannot be separated from our possibilities or new understandings and discoveries. By our very act of understanding, we become engaged in the world that we are trying to interpret (Heidegger, 1977).

This hermeneutic circle is also the method used for interpreting narrative text and is grounded in our pre-understanding. We already have some understanding of what we are interpreting; however, we expand and alter our initial interpretations in the course of analysis (Macquarrie, 1968). There is a back and forth movement between parts and the whole and, in the process, we enhance our understanding (Wrathall, 2005). We proceed

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from a naïve understanding to a deeper, more meaningful interpretation. Naïve reading is the process of reading the whole text from beginning to end to familiarize ourselves with the text. The next step is interpretive reading which entails a continuous movement between parts and the whole for the purpose of seeking meaningful patterns. Another step is comparing interpretations across texts, or looking at emerging themes and notions common to all of the experiences (Speziale & Carpenter, 2003). This is a reflective and reflexive circular process; new understandings lead to further interpretation (Diekelmann & Ironside, 1998). From a hermeneutic perspective, there is no one final absolute interpretation. Interpretations are contextual within social, cultural, historical, and linguistical perspectives (Dombro, 2007).

<center>*Research Design*</center>

Implications from a Pilot Study

The process for this study began three years ago, when I spent my summer visiting local reservations and tribal health clinics as a part of a course project. The director of the Benewah Medical Center was very open and willing to engage in a dialog about supporting my research project. After developing my pilot study proposal, the director was instrumental in bringing the proposal forward to the tribal health board and garnishing their support. The major concern of the health board was how, as an outsider, I was going to be introduced to tribal members and how we were going to recruit study participants. Initial plans for recruitment included posting flyers at the Wellness Center and co-teaching diabetes classes with the clinic's diabetes educator. Despite multiple attempts to offer diabetes classes using both traditional classroom didactics and a new approach called a conversation map, all classes were cancelled due to lack of

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participation. The most successful strategy for recruiting participants was through direct contact: the diabetes educator asked individuals if they would be interested in participating in the study and then set up the interview.

The preliminary findings from a pilot study highlighted the importance of oral traditions, respectful communication with providers, and the value of family and community. They also indicated a need for different approaches to diabetes education and care. In the pilot study, five interviews were completed. One person did not show up for their interview, and another declined to be interviewed due to concerns about someone stealing the copyright to his story!

Another concern that arose during my pilot study related to the historical connection between the tribe and the Jesuits. Not all of those memories or experiences were positive. Several of the individuals I met had strong feelings about the Jesuits and the tone of our interactions changed significantly when I mentioned that I worked at a Jesuit university. Two other issues that arose were the strong sense of competition between tribal members and how everyone in the community knew what everyone is doing. The latter has caused concerns about confidentiality when the participants went to the clinic or diabetes classes. The sense of competition was mentioned in several interviews. Participants expressed frustration about attending diabetes classes, noting there was a comparison and judgment about whose blood levels were better or who was taking better care of their diabetes. By the completion of the pilot study, some notions and ideas had emerged from the preliminary interviews, but further data were needed to explore these emerging themes in more depth. I still did not have a good understanding of

why tribal members would not attend diabetes classes or why they were uncomfortable going to the clinic for care.

Sampling

The target population for this study was Coeur d'Alene tribal members with type 2 diabetes who lived in eastern Washington and northern Idaho. Ten participants were recruited using purposive and snowball sampling techniques (Munhall, 2007; Speziale & Carpenter, 2003). Only one person recommended another individual to participate in the study. When that individual was contacted via the snowball method, she never returned my phone calls. One participant was recruited through a mutual friend of the researcher. All other participants were recruited directly by the diabetes educator.

Participants were chosen based on their willingness to share their story and commit time for the interview. Individuals eligible to participate in the study were men and women over 18 years of age who were registered tribal members of the Coeur d'Alene tribe, able to speak and understand English, and had type 2 diabetes for a duration of 12 months or more. Individuals with type 1 diabetes, those under the age of 18 years, those who were unable to communicate in English and those who have had type 2 diabetes for less than 12 months were excluded from participation. Individuals with type 1 diabetes were excluded because the pathophysiology and treatment regimens are different from type 2 diabetes. I did not choose those diagnosed with type 2 diabetes for less than 12 months because the focus of this study is on the lived experience of type 2 diabetes and those newly diagnosed may not have had time to adjust to living with diabetes. Table 2 presents the demographic profile of the study participants.

Because of the small population of the Coeur d'Alene tribe, specific information regarding age and length of years with diabetes were not included with the table in an effort to maintain participant confidentiality. Of the ten participants in the study, seven were female and three were male. Their ages ranged from 26 to 86 years old. The length of time the informants had been living with diabetes ranged from one to over sixty years. Diabetes treatments included diet, pills alone, insulin alone, and a combination of pills and insulin.

Table 2. Participant Profiles

Participant	Pseudonym	Sex	Current Diabetes Treatment
1	Delores	F	Insulin and pills
2	Leo	M	Insulin and pills
3	Casey	F	Insulin
4	Daryl	M	Pills
5	Frank	M	Insulin
6	Sandy	F	Pills
7	Carol	F	Insulin and pills
8	Mary	F	Diet
9	Virginia	F	Insulin and pills
10	Lillie	F	Pills

Procedures

Potential participants were contacted either in person or via phone by the diabetes educator at the Benewah Medical Center and Wellness Center. She explained the study

and verified they met the inclusion criteria. If they were interested in participating and met the eligibility requirements, a time and location for the interview were arranged that was convenient for them and conducive for interviewing. I provided my schedule ahead of time to the diabetes educator each month so she knew when I was available for interviews. During the initial contact between the researcher and participant, I introduced myself and verbally explained the purpose of the study in more detail. The participants were given the informed consent and allowed time to read it and answer questions. One informant was legally blind so I read the informed consent to him. After allowing time for questions and clarifications, the participants were asked to sign two copies of the informed consent; one for their records and one for the researcher. After agreeing to participate in the study by signing the informed consent and verbally giving permission, I began to record the interview using an Olympus DS-50 digital recorder.

The interviews were held in a variety of locations, including the diabetes educator's office, a classroom in the community health building, someone's car, homes, and places of employment. The interviews lasted from 25 to 90 minutes; the average was around an hour. At the end of the interview, participants were given a $25 Wal-Mart gift card as a thank-you gift for their time commitment. Field notes were gathered by the investigator to supplement the recordings. Participants were asked broad, open-ended questions that centered on the meaning of their experience living with diabetes. Probes were used as needed to focus the interview. Questions to stimulate dialogue included:

- How did you learn you had diabetes?

- How has your life changed since you've learned you had diabetes?

- What is it like for you to take care of your diabetes on a normal day?

- What have been some problems you've encountered in caring for your diabetes and how have you addressed them?

- What have you found in your experience of taking care of your diabetes that has worked especially well for you?

- What in the tribal community has helped you in taking care of your diabetes?

The researcher transcribed the digital recordings verbatim. Only the researcher and her committee chair had access to identifiable data. During the transcription process names, locations, and facilities were de-identified using pseudonyms. De-identified transcripts were transferred to a compact disk. Only de-identified and/or aggregate data were used during the analysis process or appear in the report of the study's findings.

Protection of Human Subjects

Permission to conduct this study was obtained from the Institution Review Board at Indiana University Purdue University-Indianapolis (IUPUI), from the Coeur d'Alene tribal health board, Benewah Medical Center director, and the Coeur d'Alene tribal council. The risks and benefits of participating in the study were outlined prior to conducting the interview during our initial face-to-face meeting. Written informed consent was obtained by the researcher prior to the start of the interview. The risks associated with the study were mild anxiety or distress evoked by reflecting on their experiences of living with diabetes. Participants were informed they could choose not to answer any questions or could withdraw from the study at any time without penalty. The benefit of participating in the study was being able to share their story about the experience of diabetes from a Native American perspective.

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All data was kept in a locked file cabinet in the researcher's office. Participants' names were not attached to their data. Efforts to assure confidentiality included use of pseudonyms. HIPAA guidelines were followed throughout participant recruitment, data collection, storage, analysis, and dissemination process.

Data Analysis

Data analysis began during the fieldwork process and was ongoing throughout the interview, transcription, and interpretation processes. Sloan's (2002) three step research method was used to interpret the narrative data from this study. These steps are in-the-moment interpretations during the interview process between the researcher and participant, reading and interpreting individual transcripts for emerging themes, and then interpreting between and across all transcripts for themes and common patterns (Sloan, 2002).

"In-the-moment" interpretations occurred at several points during the course of data collection. Essentially, data collection and analysis occurred concurrently between the researcher and participant. There is always a play on conversation as the researcher becomes immersed in the participant's story as it unfolds. The interviewer remains present to what is being shared and this leads to new questions and probes (Smythe, Ironside, Sims, Swenson & Spence, 2007).

The second step in data analysis was reading and analyzing each individual transcript. This occurred after each audio recording was transcribed verbatim, and identifying data were removed. The transcript was rechecked against the original recording for data accuracy and also compared with field notes (Speziale & Carpenter, 2003). Notes about vocal intonations, facial expressions, and gestures were also added to

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the transcripts (Crist & Tanner, 2003). The transcripts were read and reread for emerging themes, then new insights, and patterns began to emerge (Sloan, 2002). This was an inductive process that began with describing the details of the experience and then looking for more general image of the phenomena of interest at it emerged (Speziale & Carpenter, 2003). Using a narrative approach, the researcher began by reading and rereading the transcripts and then wrote reflections about central themes that emerged. As the analysis process evolved, new notions were revealed. These initial interpretations led to new questions and probes for subsequent interviews (Crist & Tanner). Some of the first interviews indicated that being ridiculed for getting diabetes by other community members was a reoccurring theme. Analysis of pilot interviews also revealed the importance of family, struggles among themselves and/or family members with addictions, and communication barriers at the clinic. This gave me new questions to explore in the subsequent interviews.

The last phase of interpretation was to look for themes and patterns across all the narratives: texts were read and reread for shared meaning common across all interviews (Diekelmann & Ironside, 1998). It is important to note that different interpretations are plausible, so the transcripts were offered to a group of qualitative nurse researchers and doctoral students for critique and interpretation through a secure on-line Macromedia Breeze® electronic classroom portal.

This hermeneutic research team composed of PhD nursing and social work students and faculty experienced in Heideggerian hermeneutic philosophy and methodology reviewed de-identified transcripts and assisted in interpreting the data (Sloan, 2002). Team members identified and reflected on common themes as they

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emerged. They wrote reflective summaries of their interpretations and then shared these with the researcher during biweekly online sessions with the hermeneutic team.

There often is an 'ah-ha' moment when you spend time dwelling, thinking, reflecting and letting the process happen rather that forcing interpretation. My epiphany came when I began to integrate some of Heidegger's work into my narrative writings. The concept of Heidegger's fourfold world was introduced to me and I was immediately drawn to the similarity between the fourfold world and the Native American four directions which are often represented as the medicine wheel. I then wrote exemplars for each of the participants which described their experience of living with diabetes as they dwell within the fourfold world. These exemplars or paradigm cases were beneficial in providing a new mode of understanding about the participants' experiences of living with diabetes from the Schitsu'umsh worldview (Benner, Tanner & Chesla, 1996). It was from those exemplars that the four main themes and an overarching pattern of perseverance emerged across the stories told by the study participants.

I kept a record of themes, notions, and ideas in a journal throughout the interpretive process. During the regular meetings with my on-line hermeneutic research group I reviewed the latest ideas and notions with them to validate my interpretations (Sandelowski, 1986). Sometimes my ideas and notions were disregarded by the group. This led me to spend more time reading and rereading the transcripts and using their guidance and suggestions to find new meanings within the data.

Issues of Rigor

Although qualitative research has been an integral part of nursing scholarship for the past 30 years, it has been historically viewed as "soft" research, with questionable

reliability and validity (Koch, 1995; Paley & Eva, 2005). Many qualitative nursing scholars question the use of the terms validity and reliability. Although the terms are relevant to quantitative research methods, they are not consistent with the paradigm of qualitative research. The issue is that qualitative research is fundamentally different from quantitative and should not be held to the same criteria for establishing methodological rigor (Rolfe, 2006a). This raises the question of by which standards do we judge the quality of qualitative research?

There are numerous methods to judge the 'goodness' of qualitative research (Emden & Sandelowski, 1998). The standards for judging the quality and value of study are found in the analysis, interpretation, and presentation of the findings (Rolfe, 2006b). For this study, I used the standards outlined by Sandelowski and Barroso (2002). These quality criteria are: truth value or credibility; consistency and dependability; usefulness or applicability; and neutrality (Sandelowski, 1986).

Neutrality referred to the ability of the researcher to avoid becoming so enmeshed in the stories that the participant's narrative is corrupted with researcher's personal perspectives. The researcher needs to make sure that the voice of the participants comes through in the data. Too often in Native American research misinterpretations have led to broad, value-laden, and subjective generalizations based on biases of the Euro-American researcher perspective (Oberly & Mecedo, 2004).

Truth value looked at whether the findings spoke to those who have lived the phenomena (Sadelowski, 1986). The truth or meaning is in writing and how it resonates with readers' understanding of the phenomenon of study (Speziale & Carpenter, 2003). Credibility considers how believable the results are to readers and to members of the

research team (Speziale & Carpenter). Credibility was supported through the on-line hermeneutic research team concurred with the interpretations. In addition, the members of the hermeneutic research team added insights and reflections to ensure credibility of the interpretations. Credibility is concerned with the truth value or what we learned that we did not know before. Heidegger would say credibility is found in the 'truth of unconcealment' (Ray, 1994).

Consistency and dependability meant that the parts were compared against the whole and the whole against the parts of the text and across other texts (Allen, 1995). Consistency occurred when patterns and themes emerge across transcripts until saturation was reached. In addition, "consistency is part of identifying the historical and linguistical context: it's the meaning and structure of the text understood in ways that are consistent with the historical [and cultural] period in which it was produced" (Allen, 1995, p. 179).

Applicability or usefulness refers to goodness of fit. Did the study findings and conclusions fit within the context of situations outside of those in the study? Does the audience view the results "meaningful and applicable in terms of their own experiences" (Sandelowski, 1986, p. 29)? Several scholars argue that the real test of rigor lies in the reader and how the final report speaks to the reader (Smythe et al., 2007). Rolfe (2006a) suggests, "Quality judgments entail a subjective reading of the research text and the responsibility for appraising research lies within the reader rather than with the writer of the report" (p. 309).

There are several strategies I used to help ensure rigor in this study. To ensure credibility, I maintained a relationship with the tribe by attending cultural events, language lessons, and through community health clinical experiences. I also asked new

questions in each interview as notions and ideas emerged, allowing participants to clarify, support, or refute emerging themes. I kept an on-going journal of thoughts, ideas, and associations as they emerged during the reading and rereading of the texts. As themes and patterns emerged I compared them across transcriptions and to the whole to ensure consistency. A peer research group consisting of nursing faculty and doctoral students familiar with interpretive phenomenology assisted with data analysis for interpretations of themes and patterns within and across transcripts. This helped to ensure that neutrality was maintained in the study. In addition, I frequently shared emerging themes and notions with my husband, who is Native American, to ensure I was accurately representing the tribal world-view. He gave feedback and suggestions when these ideas and notions were not consistent with his understanding of the Native American culture. The final test of rigor will be judged by the Schitsu'umsh people themselves when I present the results back to the health board and tribal council.

Ethical Issues

The study of Native Americans with diabetes is a sensitive issue. There has been an extensive history of researcher abuse while conducting studies among Native American tribes for the sake of science; this has left long-lasting scars and a legacy of distrust and regret (Biolsi & Zimmerman, 1997; Oberly & Macedo, 2004). Cecil King (1997) described this experience profoundly in the following excerpt:

> We as Indian people, have welcomed strangers into our midst. We have welcomed all who came with intellectual curiosity…we have honored those whom we have seen grow in their knowledge and understanding of our ways. But unfortunately, many times we have been betrayed. Our honored guests have shown themselves to be no more than peeping toms and rank opportunists, interested in furthering their own careers. (p. 115)

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Research involving Native Americans necessitated working within the tribal communities to study diabetes in a way that was meaningful and beneficial to them and respects their sovereign rights and goals for self-determination (Christopher, 2005). According to the Code of Ethics of the American Anthropology Association, issues of risk and reciprocity must be considered, as the needs of the individuals and tribes come before the interests of the researcher (Bentz, 1997). I have an ethical obligation to assess for any potentially positive or negative consequences resulting from the research and publications of their study (Lipson, 1994)

In addition to risks and benefits, the issue of reciprocity must be considered. Research within Native American communities must benefit the community (Christopher, 2005). For many cultures, reciprocity extends beyond the immediate here and now and is considered a long-term investment into the tribe or culture (Lipson, 1994). Collaborative efforts between academia and the tribal communities are needed to bring about changes in the healthcare status of this long-underserved population (Grobsmith, 1997). "Abundant research opportunities still exist, but many Indians do not want to be bothered with studies that have no potential for benefiting their community in some substantial way" (Bentz, 1997, p. 130). The goal of developing prevention and diabetes education programs that are culturally relevant for the tribe is the ultimate intent of focusing on this issue; the tribe supported this study because of the potential of improving quality of life and outcomes for the Coeur d'Alene tribal members.

The third issue to address is the right to tribal sovereignty. All studies within a tribe or about the tribe need to be approved by the tribe. In addition, before the results of this study are distributed, tribal officials will be asked to review the findings and approve

how the findings will be disseminated (Oberly & Macedo, 2004). When I presented the pilot study proposal to the tribal health board, they gave their approval by consensus to conduct the study and there was general agreement that I would share the findings with professional colleagues in professional conferences. I went to the tribal council and obtained permission to continue the study and also obtained their approval for a poster and presentation at two professional conferences. This provided an opportunity to catch mistakes in cultural interpretations and correct any misunderstandings and helps ensure that the study reflects the eyes of the Schitsu'umsh people rather than through the Euro-American lens of the researcher (Brugge & Missaghian, 2006).

The core of the matter was to respect the tribe's rights as a sovereign nation to control distribution of information about them (Struthers, Lauderdale, Nichols, Tom-Orme & Strickland, 2005). The final study results will be presented to the full tribal council. Although I am not familiar with specific issues regarding research with the Coeur d'Alene tribe, I have read research articles in which a tribe requested that aggregate data about them not be published (Macaulay et al., 1997) or that the tribal name not be used in the manuscript (M. Isaacson, personal communication, October 24, 2008). The Coeur d'Alene tribal council gave permission for the tribal name to be used when the pilot study results were presented at two professional conferences last year.

Heidegger himself was controversial. One of the greatest criticisms of Heidegger, and therefore his works, is his association with Hitler and the Nazi movement. Some scholars have attempted to link his works with anti-Jewish semitism and therefore attempt to discredit his contributions to philosophy. The greatest ethical concern was that Heidegger never apologized or showed remorse from his ties to Nazism (Blattner, 2006).

Critics of Heidegger often cite the difficult in understanding his works and, unless one has a background in philosophy, it is easy to miss the depth and nuances of Heidegger. His original book *Being and Time* was in German and, even when translated into English, the vocabulary remains difficult. Heidegger created new vocabulary to articulate his ideas about being in time because he believed the language did not adequately embody his definitions of being, time, or existence (Dreyfus, 1991). Another issue was that the original translations into English missed some of the nuances of his works in the process of translation. Macquarrie and Robinson's translation (1962) is considered the best by many philosophy scholars because they went directly to Heidegger to explicitly validate their translation of *Being and Time* (Solomon & Gottlieb, 1999). Heidegger wrote *Being and Time* as a result of pressure to publish by the chair of the Philosophy Department at the university where he was teaching (Dreyfus). In the rush to have his book published, Part II was more of a rough draft of notes. Many of his ideas were not fully developed until later publications and professional lectures (Dreyfus, 1991; Solomon & Gottlieb, 1999).

CHAPTER FOUR

Data Analysis and Interpretation

Introduction

The purpose of this study from a Heideggerian perspective is to ask how does this "thing" called diabetes show up in the Schitsu'umsh world. What is the "thingness" of this thing diabetes? The "thingness" of diabetes in the Schitsu'umsh world is perseverance. Those tribal members with diabetes juggle a dialectic tension of burdens and strengths to persevere in their journey with diabetes. Strengths and burdens are not opposites, but they belong mutually together as one. They are two facets of perseverance. Heidegger refers to this as "enowning." "Enownment thus is two things that are one and the same...the letting-be-own-to-one-another of all that belong together...appearing, disappearing, staying in presence or absence. It lets all this come to be" (Hofstadter, 1976, p. 373). Enowning is the great mystery that shows and hides itself in mutual belonging. It is through being in Heidegger's fourfold world of earth and sky, mortals and divinities, that we experience enowning. "This socio-cultural Being is constantly vibrating as a clearing in the total world-fourfold, in and through enownment that lets it be and that it lets be" (Hofstadter, p. 375). It is only by thinking of enowning do we see how diabetes takes shape as a dialectic tension in the dwelling between earth and sky, mortals and immortals. It is in a nondualistic relationality that the nearness and remoteness of strengths and burdens show up as perseverance (Heidegger, 2006).

The burdens and strengths produce discord in the daily struggles with diabetes for the Schitsu'umsh people. This dialectic tension creates "strife within a being that is to be brought forth only in such a way that the conflict opens up in being, that is, this being is

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itself brought into the rift-design. The rift-design is the drawing together, into unity" (Heidegger, 1971, p. 61). The Schitsu'umsh people struggle to keep their world in balance by persevering through the burdens with available strengths and resources from within themselves, their family, and the tribal community. This concept of balance aligns with the Native American medicine wheel and circle of life (Dapice, 2006; Lowe, 2002). These four directions provide the foundation for balance in one's life and when they come together, they create a sense of sacred oneness (Fontaine, 2000).

At critical points in the circle of life when there is upheaval at the brink of chaos or crisis, these four directions need to be stabilized in order to walk in balance within the four domains of health: mental, emotional, physical, and spiritual (Coyhis & Simonelli, 2005). Imbalance leads to discordance, tension, and illness. For Heidegger, the four directions to keep in balance are the fourfold world of earth, sky, mortals, and immortals. They belong together, "they are the same single nature" (Heidegger, 1971, p. 59). They are united "primally in being toward one another, a fourfold...the unitary fourfold of sky and earth, mortals and divinities, which is stayed in the thinging of things" (Heidegger, 1971, p. 61). That is how this thing called diabetes comes out in the fourfold world.

Heidegger's Fourfold World

As I spent time dwelling with the data, Heidegger's concept of the fourfold emerged as a means for interpreting the experience of being-in-the-world with this phenomenon called diabetes. Each interview was interpreted using Heidegger's fourfold world to understand being-in-the-world as a Schitsu'umsh person with diabetes. Although each component of the fourfold is discussed separately, they are intertwined within the one entity of the fourfold.

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The first dimension of the fourfold world is earth. It is characterized as life and community. "The earth is our Grandmother and Mother; she is our mother in the immediacy of her giving and our grandmother in her ancientness" (Gustafson, 1997, p. 110). The earth is where we come from, our roots, background, and heritage. For the Schitsu'umsh people with diabetes, earth is displayed in their tribal traditions. The dialectic tension of tribal traditions is manifest in valuing heritage, respecting kinship, and sharing wisdom, with loss of traditions, family obligations, and being stigmatized.

The sky represents the second facet of the fourfold. A common image of sky is open, infinite and endless, therefore it symbolizes possibilities. Sky refers to the horizon of time consisting of past, present, and future possibilities. The dialectic tension between being inattentively caring through risk taking and denial, and turning points toward caring compose the dimension of sky within the fourfold world of the Schitsu'umsh person with diabetes.

The mortals are the Schitsu'umsh people living with diabetes. By virtue of their humanness, they are aware of their mortality. To dwell in the fourfold world as mortals is to be uniquely cognizant of death as the ultimate possibility (Dreyfus & Spinoza, 1997). The Schitsu'umsh people with diabetes are only too aware of death as they struggle with the daily burdens of diabetes self-management. They try to balance feelings of vulnerability and being overwhelmed by seeking knowledge and accepting diabetes as a part of their lives.

Heidegger (1971) describes the immortals as gods or divinities: "The gods provide the standards for which we are judged" (p. 198). In the fourfold world of the Schitsu'umsh, doctors and other health care professionals are thought of as playing the

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role of gods. This created tension in patient-provider interactions. Despite an awareness of what good care is like, the experiences of the Schitsu'umsh people within the fourfold realm of the immortals reflects unsatisfactory client-clinician relations. Figure 1 depicts Heidegger's fourfold representation of the dialectic tensions of dwelling within the Schitsu'umsh world with diabetes.
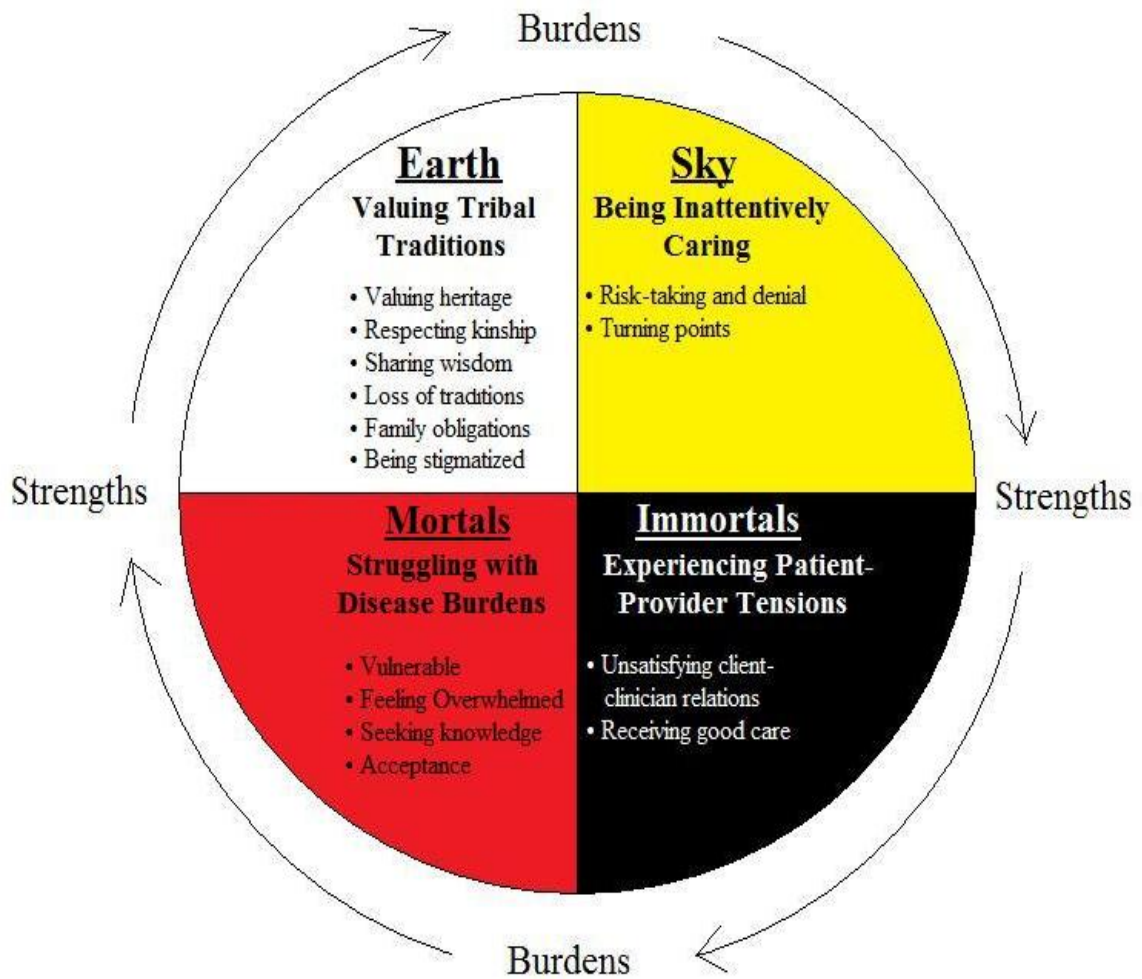
Figure 1. Medicine wheel representation of the dialectic tensions in the fourfold world of the Schitsu'umsh people with diabetes.

Dwelling in the Fourfold World

As I immersed myself into the stories of the Schitsu'umsh people and their experiences with diabetes, I heard repeatedly about the strain of trying to exist in two worlds – the Native and the "Wal-Mart" world, as one elder referred to dominant white culture. This was more challenging for some than others because some participants viewed themselves as part of the "melting pot." In both situations, it created discordance. In the book, *Keep Going: The Art of Perseverance* (Marshall III, 2006), Old Hawk explained the role of this dialectic tension:

> Life wears two faces and one is no less real than the other. If everything were the same all the time, there would be no variety, no excitement, and no balance. There would be no black to offset white, no sunset to finish the day that began with sunrise, and no warmth to chase away the cold. But that which gives your journey balance throughout life also brings difficulty. In the end, it also brings the gift that we often do not see. (p. 9)

There was always an underlying sense of perseverance in the participant stories. Although diabetes created angst, ridicule, and vulnerability; these challenges were countered by the strength the Schitsu'umsh people received from their tribal resources, traditions, family, church, and community. These were the things that keep them afloat on their fourfold world with this thing called diabetes. To gain a sense of the dialectic tension of dwelling in the world with diabetes, it is important to explore how this thing called diabetes reveals itself in the participant's stories. Below is a brief synopsis of each participant's experience of dwelling in their fourfold world of diabetes.

Delores was retired and spent her days doting on her grandchildren. Siblings, adult children and friends supported her when diabetes threatened to overwhelm her. Her husband struggled with his own addictions and was unavailable to help Delores. She

struggled with other health concerns as well. Recent bouts of respiratory disease were pivotal in her decision to quit smoking, but those experiences with disease and the healthcare system left her disheartened. Disease burdens were like a ball and chain for Delores and she missed the freedom and spontaneity that she once enjoyed. Delores relied on family, friends, and religion to cope with her daily challenges.

As an elder, Leo maintained many traditional practices that are grounded in a strong tribal heritage. Leo tried to live in balance and harmony despite the many burdens that diabetes has brought into his life. Although Leo's body has experienced the ravages of diabetes complications, he continued to seek balance in his life. Leo relied on his traditions and values for strength and guidance.

As a young woman, Casey was diagnosed with diabetes during her first pregnancy. She did not realize the seriousness of her diabetes until she miscarried during her second pregnancy. In the depths of grief, she returned to the reservation to be with her family and reconnect with her roots. Casey's return home was a double edged sword of valuing kinship and yet feeling judged by family and community for having diabetes and living differently than the rest of her kin.

Daryl spent much of his youth going between orphanages and foster homes. Without a sense of connectedness to his family and heritage, Daryl felt angry and abandoned. In addition, Daryl has struggled most of his adult life with addictions. Having been taken away from his family at an early age by the BIA, Daryl was very mistrustful of the healthcare system. In the past, he was judged as "just being another drunk Indian" when he sought out healthcare. Currently, he has one doctor he likes and feels connected with. Other clinicians focused too much on labs values and reading the

medical chart and not enough on listening and hearing how he was coping with diabetes. The current healthcare system has left Daryl feeling very unsatisfied and frustrated.

As a former war veteran, Frank epitomized the brave, strong warrior. He represented the Marine Corp motto *Semper Fidelis*--always faithful. Frank was always faithful to the warrior code, to be strong and brave in the face of the enemy. The enemy in his life was diabetes. In his bravery, Frank scoffed at the enemy. As a result, Frank was nonchalant in his self-care. He embraced all of life with enthusiasm and gusto and diabetes was not going to stop him from enjoying anything. Living life to the fullest, as long as he awoke to see a new day, he embraced it. Frank's motto was "don't let diabetes pull you down, seize the day."

Sandy was aware very early in life of the association between eating fatty foods and obesity. She made it her life mission to eat healthy and try to stave off diabetes as long as possible. She was very disappointed when she was diagnosed with diabetes and has struggled to cope with both the diagnosis and the judgments associated with diabetes on the reservation. She has made a concerted effort to learn as much as possible about diabetes and to care for herself and diabetes. Unfortunately, the demands of work and single-parenthood have stymied her attempts to eat healthy and exercise. Sandy has always considered herself a healthy eater, but she has tried to be more vigilant so that she might delay the development of diabetes complications and prevent premature mortality.

A skunk represented diabetes in Carol's world. The first words Carol said when we met were: "Diabetes stinks, it just stinks." Diabetes has taken away many of the joys in her life. Unstable blood sugars have left her wary of when low blood sugar levels might strike again and Carol was fearful that she would go to sleep one night and never

wake up again. Diabetes has taken her spontaneity away, she always has to prepare and plan ahead. Carol had difficulty making sense of the diabetes education or treatment plans. It was all too confusing, so Carol went to family and friends for guidance and advice instead--the very same people who judged her when she ate differently or tried to modify the family diet. This caused tension between Carol's need for family support and being ridiculed for being different.

Mary lived in a world that values the tribal tradition of caring and honoring elders, a world that emphasized community and family over individualism. As a result, Mary has been the family caregiver all of her life. In respect to her mother, she has been caring for her since she was a child. Mary also raised her sister's three children. Demanding family obligations left no time for diabetes self-care. Mary was overwhelmed and exhausted. Another issue of significance for Mary was the experience of being stigmatized for having diabetes. She even ridiculed herself for getting the disease.

Despite growing up on the reservation, Virginia was situated in a world filled with possibilities. She has always felt empowered to do whatever she could to support herself, her family, and the tribe. She promoted the tribe's efforts toward self-determination and actively supported the clinic and wellness center. She was very proud of those facilities. Virginia was raising grandchildren on her own and she was very concerned about the health of these young people. Although she tried to offer advice and guidance to change their eating habits, they just did not listen or they ridiculed her for eating differently from the rest of the family. Her family was the foundation to her world and gave her the perseverance to keep going despite the challenges of living with diabetes. Virginia used

humor, storytelling, religion, and traditional healing practices to help her survive in the world with diabetes.

As a child, Lillie was diagnosed with diabetes by the doctors who were visiting the Native children at the Indian boarding school on the reservation. She had to take insulin shots regularly to control her diabetes. Because she was such a sweet child, teachers, nuns and family stepped forward to take care of her. Like a porcelain doll, Lillie has spent her life, loved and cherished by her family. Although she felt that others have always taken care of her, she tried to help them as well. As a well-loved doll, Lillie was starting to show some wear and tear from years of alcohol use. A long, challenging life has taken its toll on Lillie–her short-term memory was fuzzy and she had difficulty with mobility, but she was still loved and revered by her family.

The Earth: Valuing Tribal Traditions

> You did not ask to be born, but you are here.
> What you are comes from the blood of those who set you on your journey.
> That is unchangeable.
> What you see in the reflecting pool of truth is who you are.
> You cannot change that, so it is wise not to curse it.
> The wiser choice is to embrace it and make it your strength.
> ~ Old Hawk, Lakota. (Marshall III, 2006, p.124)

The earth represented how one is situated in the world. It encompasses the traditions and values we have by virtue of the culture and family into which we are born. The earth is the grounding of our being. As Chief Joseph of the Nez Perce said, "The earth and myself are of one mind. The measure of the land and the measure of our bodies are the same" (Curtis, 1994). We are rooted in the earth and in the values and traditions from where we have come. These things show up as mattering to us (Heidegger, 1977, p.72). In this study, valuing tribal traditions was how diabetes was experienced within the

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fourfold dimension of earth. "Connecting to nativeness was not a choice or decision they had come to as adults; it was a part of their being from birth" (Canales, 2004, p. 28-29). Family and roots helped the study participants persevere in their turbulent world of diabetes. The participants received help and support by valuing heritage, respecting kinship, and sharing wisdom. Dialectic tensions within tribal traditions included being overwhelmed by family obligations, being stigmatized by other tribal members, and struggling with the loss of traditional practices as a result of developing diabetes.

High levels of traditionalism have been associated with disease protective behaviors (Coe et al., 2004). Tribal traditions for this study's participants provided numerous lifelines of support. The value of heritage was shared from generation to generation through their oral histories and storytelling. The elements of heritage via storytelling and humor came out in the interviews. Several participants used stories to explain their experiences with diabetes. Leo told a story about using a huckleberry basket to cope with his diabetes journey:

> I have a huckleberry basket. It's all nice, grandmother made it. I stand at the bottom of this hill and look at this beautiful hill, huckleberries all over it. Before I start up the hill, I pray, I ask for strength to make it to the top of the hill. I fill this little basket and each berry I picked is a piece of wisdom, is a piece of truth, is a piece of strength. At some point in time I can take that berry after I get to the top of the hill, or in a year from now, I can reach in there and pull that berry out. Oh, I remember that. Oh, I remember that piece of knowledge. Each one of these berries is like a person I've talked to or a thing I've done or a thing I've learned. So, I've got something to nourish me on my walk.

Another dimension of valuing heritage was the use of spiritual practices, both traditional and Christian, as sources of support. Delores and Virginia turned to their priest

for guidance when they were struggling. Delores also said her rosary and prayer. Leo integrated both in his healing journey:

> I don't forget my teachings from my father and mother about being a good Catholic boy, but the Indian medicine is just as strong. It's just two things I keep in balance....For me and the walk with diabetes has been a form of keeping in balance with the cultural and traditional and spiritual medicine ways and applying those where I feel necessary. And the other world of maintaining medicinal applications of good health with what health you have left; maintaining and protecting what you have. That's been my creed.

Respecting kinship was another supportive element of tribal traditions. The reverence for kinship was evident in the photos of relatives proudly displayed in the participants' homes and offices. The respect for kinship also was heard in the stories participants told, especially grandparents talking of their grandchildren. In their stories, the participants often used traditional names for grandmother and grandfather. The elders fondly recounted memories of living with extended families. "We didn't have much but it was always happy" (Virginia). Frank continued to embrace life with great enthusiasm "because of family." He shared how spending time with his kids was a significant motivator to keep going. "You know when you've got kids like that – what are ya gonna do? I've got diabetes and I've gotta live with it. No, like hell! It's get up off your butt and get moving, enjoy life!"

Respect for kinship also emerged in all of the interviews as a strong sense of duty to family and community. Respect was demonstrated by caring for kin. Lilly mentioned that when she was first diagnosed with diabetes, her family reassured her that "we'll take care of you and you'll be alright." Sixty years later, she is still taken care of by her family. Leo shared a story about helping his mother. She had bilateral below-knee

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amputations from diabetes. Although she was wheel-chair bound, she still liked to go for car rides. Leo and his brother would take her out for a drive and, when they stopped for a meal, she refused to go into the restaurant, not wanting to be a bother. Leo and his brother ordered meals-to-go and they sat in the car and ate with their mom. Being together as a family was very important.

The kinship bonds between community and family often provided a life line when challenges arouse. Carol noted, "When it comes to family, I'm all there." Several participants expressed profound gratitude for their own caregivers as they experienced the ravages of diabetes. "My wife is not only my wife and best friend...but she's also an excellent caretaker....I am very fortunate" (Leo). Delores shared that her son and younger brother take care of the lawn for her. Her sister also stopped in to check on her regularly. Respecting kinship bonds was an enduring source of support for the participants as they struggled through the world of diabetes. Respect for kinship was also demonstrated in the efforts by parents and grandparents to influence their children's and grandchildren's choices about diet and physical activity.

Sharing wisdom with others was another valued tribal tradition. As the diabetes wisdom-keepers, all this study's participants had advice for others about diabetes and prevention. The participants would like to make the journey smoother for others by sharing the wisdom they have gained about diabetes:

> I started thinking, okay, I need to do something because a lot of the people
> I was taking care of had diabetes and you can't change your diet, you just
> have to change how much you put in your mouth. So that's what I started
> telling the people to do because they was saying they can't afford it....and
> I told them what I did. Get a smaller plate, eat what you eat – eat your fry
> bread, don't deprive yourself of the things that you grew up with. Just

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have a smaller portion. Eat more vegetables, eat more salad, eat more fruit. (Delores)

Leo recognized how the changing world has made it harder for today's tribal youth:

We have the future of our children, our grandchildren, and great-grandchildren; to make sure that they have a better life than we did and if there is somewhere in there that you can play a part with your feeling about diabetes, do it, don't hold back. For the young people have it pretty hard, the pressures that they live in at age 14 now is a hell of a lot more than when I was age 14....recognize how brave they are and courageous they are to be able to go forward. (Leo)

By sharing their wisdom, the participants hoped the youth will heed their advice to avoid going down the troublesome path of diabetes altogether. Carol told her grandkids to "watch what you eat and stay away from the candy." Mary advised them to "just keep active." Sandy noted "I always shared with my kids about how they can prevent it [diabetes] and what I was doing to keep it at bay." Delores and Virginia noticed unhealthy eating habits in their grandchildren and warned them about diabetes and the risks of eating junk food.

I tell Sarah that I have diabetes, my mom had diabetes, my dad had diabetes, and from your other side...your great grandmother had diabetes, so it's in the family, but you need to protect yourself and watch what you eat. (Delores)

Sharing wisdom also demonstrated valuing tribal traditions by connecting families and supporting family cohesion. In the literature, family cohesiveness is noted to provide a protective effect in the physical and emotional health of tribal members. Cohesiveness and tradition have played significant roles in promoting resiliency, academic success, substance abuse prevention, and health maintenance and promotion (Teufel-Shone et al., 2005). Therefore, a sense of belonging and relatedness to family

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helps maintain traditional values and beliefs and is important for the promotion of health and holistic healing (Hill, 2006; Lavallee, 2007).

Loss of tribal traditions was one source of stress for this study's participants. One area of lost tradition is the value of community connections. Virginia remarked about how traditional community-focused values have changed: "Back then everyone visited everybody, we came together and shared...then we started getting money and we lost the visiting people on the porches." Loss of tradition has also affected the children: "the jobs came and the kids started losing both parents to jobs. We got a lot but we lost a lot too" (Virginia). Leo pointed out how difficult it has been for tribal people today to connect to their roots as a source of balance as they have become immersed in the Wal-Mart world. "You have to heal from the inside-out, but a lot of Indian people who've heard about the inside out, they're more outside...the traditional, cultural, and those kind of things are secondary in their life now."

Loss of traditional practices and ceremonies was another source of stress. Some participants mourned the loss of their ability to participate in traditional ceremonies. Both Virginia and Delores lamented about their inability to go into the sweat lodge anymore or dance at powwows:

> When I first got diabetes I noticed in my dancing that I couldn't dance as long or I had to eat more...Then it kind of stopped me on my dancing and my late nights of doing the stick games because you need to give yourself a rest...you had to do a regular meal...I couldn't do a lot of Indian culture stuff that I was used to doing. (Delores)

Another concern over loss of traditions relates to diet changes in the tribe. Many participants expressed concern over the loss of traditional foods. The participants recognized that the loss of their traditional diet and transition to a westernized lifestyle

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had contributed to the increase in diabetes among their people. Virginia remembered eating traditional roots, berries, and venison when she was young. She joked that now she just goes to the grocery store to "kill" her meat. She also remembered going camping with just a piece of canvas for a lean-to and a jar of flour for breading the fish. They'd catch their own fish or pheasant. She lamented that camping with her family today include hotdogs, hamburgers, potato salad, and chips. Many participants remarked that "good" foods were the unhealthy choices that taste good and make you feel comforted; such as fry bread, potatoes, pasta, and fried chicken. Traditional healthy foods from past generations of hunting and gathering were no longer perceived as "good" foods:

> We were gatherers and hunters...we did both so in the past it wasn't a problem because we were nomadic, we would go here and there, they got plenty of exercise and ate pretty healthy. With the introduction of government intervention, giving them foods they weren't accustom to, became a staple for survival and they still continue to do that with commodities. (Sandy)

Casey noticed how diets have changed and remarked that now what is viewed as "traditional" foods are high calorie fried foods. "It probably started from my great, great-grandmother; you know their tradition that has been passed down – the greasy fry bread, the hamburger stew, and the fatty foods." The salads are "potato salad, macaroni salad, and fruit salad...you hardly ever see green, and it's all carbs!" (Virginia). Carol concurred that their diet now consists of starchy foods, especially fry bread. Virginia joked that "all of our guys look like fry bread when compared to the non-Indians...Our guys eat fry bread and they eat peanut butter on fry bread, and peanut butter and honey on fry bread, and they put bacon on it."

There is some evidence to suggest that the diets of the Native people changed significantly with implementation of government commodities on the reservations and this change is responsible for the diabetes epidemic. Through government actions, the tribes lost access to traditional food. As Native communities became restricted to reservations, they were unable to do seasonal rounds. In addition, environmental contamination from mining and other sources have altered the availability of food supplies. On the reservation, commodities were given and withheld as a means of reward and punishment. With little to do on the reservation sedentary lifestyles set in; there was limited ability to hunt, fish, or gather (Powers, 2008). The situation on many reservations still violates the basic tenets of food security: access, availability, utilization, and stability of food supply (Powers).

There is also some speculation that the introduction of grains into the Native American diet by Europeans has contributed to the prevalence of diabetes. Garrity (2004) hypothesized that the traditional Native diets did not consists of grain, except for corn. The Native diet consisted primarily of game, augmented with roots, berries, and greens. The addition of grain to the Native American diet precipitated chronically elevated sugar and insulin levels, and eventually led to diabetes. Kaufman (2005) also noted that introduction of agriculture and grains led to a huge dietary shift.

Loss of traditions became a burden for participants when there was a lack of kinship support for diabetes self-management. It was difficult for participants to try and manage their diabetes by themselves. Leo mentioned that "there are a lot of people who don't have anybody...and they have to learn by trial and error." Casey noted that there

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was no help for her parents. She mentioned that there was a lack of support for people

with diabetes on the reservation. Casey explained:

> The worst thing now is stress, it's the only thing that's affecting my
> diabetes...I don't see the support...if someone comes to you and says they
> have cancer it should automatically make a difference and you should care
> and you should want to help them and do what it takes. But on the
> reservation it's really far and few in between that people take care of their
> kids. And people get older and you have these unfortunate diseases and
> there's no one there to help...My mother drank and did drugs for however
> long and my father did too, and now she's going through a lot-seizures,
> and she's had part of her toe amputated.

Sometimes the lack of support was caused by physical ailments, and for others it

was addictions. In either case, the lack of support only added to the sense of being

overwhelmed and abandoned. Delores shared how her husband's drinking affected her

blood sugars:

> When I think I am in control and then my family member goes out and
> starts drinking, I notice my sugars go up. Then I think, well I'll eat less. I
> can't do that. I'll get rid of the stress, but it comes back...I can handle it
> without him, but he can't handle it without me.

Another source of tension for participants was trying to find time for self-care

when family obligations had priority. Some participants felt stressed when expectations

to care for others competed with the need for diabetes self-management. Mothers found

themselves caring for their grandchildren as their own adult children struggled with

addictions. Adult siblings stepped in to care for their brothers, sisters, nieces, and

nephews. Others found the challenges of caring for family members with health issues

and special needs more burdensome than what they had the time to give. Consequently,

their own diabetes self-management fell into the background. They described the

exhaustion they felt at the end of the day: between work and family obligations there was

no time or energy left to exercise or focus on their own diabetes care.

> It was frustrating really, in my particular situation there would be house
> parties and you couldn't sleep, you couldn't do your homework, it was too
> loud and you'd wake up in the morning...your mother laying there sick
> asking you to help, "give me this, I need that, call this person," and it
> wears you out over time. (Casey)

A lack of support systems contributed to participants feeling overwhelmed by

family obligations. Family members were unable to provide assistance because of their

own health issues. Both Carol and Delores remarked about the lack of support from their

spouses. Mary, Casey, and Sandy were single parents raising their children on their own.

In addition, Mary cared for her elderly mother, and Sandy had a child with a disability.

They were all overwhelmed by their family obligations. Sandy told of her struggle to

manage her daughter's condition:

> I have a daughter with lots of medical problems...but they [the doctors]
> just glide right over what it is. They're trying to tell me and then knowing
> there is so much I want to know besides that – I just let it go and look it up
> myself.

Being stigmatized was another burden that arose from tribal traditions. Getting

diabetes was associated with weakness and participants were stigmatized because they

had diabetes. The participants were also stigmatized for being different, by going against

tribal norms when they chose to eat differently from the rest of the tribe. For many on the

reservation, diabetes was a taboo subject, which caused those with diabetes to feel

stigmatized for being different. Diabetes represented weakness and vulnerability. Sandy

acknowledged that people were aware that you had diabetes, but nobody talked about it.

Participants attributed being stigmatized for getting diabetes to showing vulnerability by

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succumbing to the enemy known as diabetes. Other tribal members just did not want to hear about the disease. Sandy mentioned, "In the back of their minds they're thinking this could happen to me, so everybody kind of ignores it." Diabetes revealed one's weakness. Casey was afraid to tell people when she was having symptoms related to her diabetes. It showed her weakness and she was afraid of being ridiculed or stigmatized.

Participants also felt stigmatized for being different from other tribal members. This included eating differently and acting differently because of their diabetes. Delores thought the stigma was related to people feeling uncomfortable around her or being afraid of needing to cater to her because she ate differently. Casey related it to people "milking the cow for all its worth" when they had diabetes—being very demanding and always wanting a hand out. When going to community gatherings to celebrate cultural traditions, all of the "wrong" foods were served because those with diabetes were not supposed to eat those foods. So the participants were judged if they did not eat what was served. Carol said she felt stigmatized when she went to potlucks or other large gatherings. If she didn't eat all of her food she said she was dieting rather than acknowledge she had diabetes. Family and friends asked her, "How come you're not eating all of your food, what's wrong with you?" Even Lilly told of being isolated from others in boarding school so the nuns could keep an eye on what she ate and made sure that she took her medicine. For Casey, having diabetes made her different because she ate differently from her family or other tribal members. She shared how difficult this has been:

> It's like a union decision about everything. There's one way of how we do it – for a funeral this is what we make; for a prayer, this is what we do. It's a union thing and if you go against it there's a lot of ridicule...I am labeled, I am different, I am not like everyone else...just knowing that I had it [diabetes], I was labeled.

Daryl explained, "If you didn't belong to the system...you were looked down upon." To be different was not acceptable. Having diabetes made the participants different from other tribal members.

Tension arose when participants went against tribal norms by not eating all of their food or putting their diabetes care first. It was perceived that individuals were putting themselves before the community or family and such behavior was considered taboo and was grounds for punishment from the tribe. As a result, the participants felt judged and ridiculed by the tribe. Deviating from accepted tribal norms could result in public admonishment, ridicule, or ostracism (Frey, 1995). A sense of angst arose for these tribal members with diabetes because they did not share the cultural norms and their familiar world shunned them. Heidegger would ponder: does the dialectic tension of being-in-the-world with diabetes cause those stigmatized individuals to become non-beings or negative beings (Kess-Gardner, 2004)?

Going against tribal norms included not following tribal rules, as a result, some participants felt stigmatized for not following the rules. "Those who transgress may be subject to group sanctions. Consumption of these foods is part of what distinguishes 'us' from 'them' and to consume the food may lead to dis-inclusion from the group" (Gittelsohn & Vastine, 2003, p. 4037s). Paradoxically, family and friends became the diabetes police and the participants found they were scolded for eating anything that was not considered "diabetic food." Mary complained that her friend "was gonna tell my kids on me for what I was eating." Anything not conforming to tribal values and traditions caused judgment. "Every cultural setting maintains multiple concepts about how food

should be categorized...making a particular food appropriate or inappropriate for consumption" (Gittelsohn & Vastine, 2003, p. 4037s).

In the native tradition, identity is closely linked to the tribe, so being stigmatized by the tribe affects one's sense of belonging and connectedness to their tribal roots (Weaver & Brave Heart, 1999). In this study, being stigmatized was associated with going against cultural norms and being different. Schitsu'umsh people with diabetes were marginalized within an already marginalized group. The labeling associated with diabetes caused them to experience a sort of "double jeopardy" and devaluing of personhood as they coped with multiple disparities (Johnstone & Kanitsaki, 2009). In Hill's (2006) study on belonging and connectedness within an American Indian worldview, tribal members who felt stigmatized and disenfranchised were noted to have a lower sense of belonging and social support. One strategy used to counterbalance this experience is seeking knowledge and using that knowledge as a tool to change beliefs and prejudices.

There are other examples in the research literature about being labeled or stigmatized because of a disease. This notion of labeling was brought up in a story about how health care professionals and families treated people with Alzheimer's disease. The authors contended that being stigmatizing deny that person or individual their personhood (Fletcher, Silva & Sorrell, 2002). Similar accounts of becoming labeled as a disease rather than a being experiencing life with an illness are found in Frank's (1991) description of his journey with cancer. In his book, *At the Will of the Body*, Frank tells about being stigmatized because of his cancer. These experiences resulted in being dehumanized because of a disease. "Failing to acknowledge individuals as persons

influences our view of their moral status and makes them vulnerable to oppressive and demeaning behavior" (Fletcher et al., p. 37).

One way of reconnecting with tradition is through storytelling. Historically, Native American traditions were passed on orally, so stories were used as a means of connecting the past to the future (Lavallee, 2007; Struthers, Lauderdale, Nichols, Tom-Orme & Strickland, 2005). Using such strategies to promote cultural connectedness may facilitate social support and a sense of cohesiveness. Research studies have found that both of these factors have a buffering effect on stress responses (Bowman, 1996; Krieger, 2001; Levav, 1998). Canales (2004) reported that the degree of connectedness to native traditions influenced women's healthcare decisions for themselves and their families. Several authors suggest using ceremonies to help rebuild a sense of self and foster interconnectedness with the tribal community and culture (Krech, 2002). Having ceremonies to promote forgiveness also may have beneficial effects for the community (Lawler et al., 2003), as those communities can also be a source of stress and loss.

The Sky: Inattentively Caring

> Mortal man has not the power to draw aside the veil
> of unborn time to tell the future of his race.
> That gift belongs to the divine alone.
> But it is given to him to closely judge
> the future by the present and the past.
> ~Simon Pokagon, Potawatomie. (Curtis, 1994)

The sky provides direction to navigate by and suggests a future of possible actions. Earth and sky are interconnected. How one is grounded in the earth gives context to the future possibilities in the sky. "When a focal situation is happening, one feels certain actions are appropriate-what is appropriate in this situation? What particular

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possibilities are relevant is determined by the situation itself" (Dreyfus & Spinoza, 1997, p. 7). As the participants told their stories, they told of death and destruction meted out by the diabetes epidemic. In their practical familiarity with the world of diabetes, the participants recognized the situation at hand as something that could destroy their hopes and dreams. Refusing to confront their future, the participants cared for their diabetes in an inattentive way through risk taking and denial.

In their state of denial, some participants adopted a "why bother" attitude, which resulted in healthcare providers labeling patients as non-compliant (Schultz, 2007). Denial has been noted to be a common reaction to the initial diagnosis of diabetes (Garay-Sevilla, Malacara, Gutierrez-Roa & Gonzalez, 1999; Gazmararian, Ziemer & Barnes, 2009; Livneh & Martz, 2007). Garzmararian et al., (2009) noted that denial was a major obstacle to self-care in diabetes self-management. In another study, denial was associated with poor glucose control, but there were no correlations between denial and level of social support, knowledge, or perceived stress (Garay-Sevilla et al., 1999).

One aspect of denial and risk-taking for participants in the current study was neglecting self-care. Too many other burdens were in the foreground or present-at-hand. Inattentively caring reflected this breakdown in the participants' everyday world. Situated within the fourfold world with diabetes, the participants saw few possibilities – only death and destruction. Virginia was overwhelmed when her mom died; she shared that:

> I didn't care about nothing, so I didn't take my medicine, didn't watch anything, didn't do whatever...But I did go to the doctor and told 'em, it wasn't anything they did, it's what I did – I didn't care. I took some time now and I'm back on it again.

There was no sense of the sky opening up a world of possibilities beyond the here and now. Virginia explained that her family members with diabetes just did not care so they neglected their self-care. They were not making appointments with the doctor, they drank regular pop, and they still ate their dumplings and other starches. Mary shared how she always drives her car now instead of walking since she has to drive her mother everywhere and she "just got lazy." When her friends threatened to tell her kids that she was not eating properly, Mary responded, "Go ahead and tell my kids, I don't care." Her life has been too focused on caring for others; there was no time to think about her needs or what she was doing to her own health. Sandy had a similar situation. She said she wanted to schedule in physical activity and her employer even allowed time for everyone to exercise, but she always worked through her lunch break instead. Even though Sandy's doctor ordered EKG and vision tests, she had not scheduled them; there was not enough time. The participants were all so busy with work and family, that they inattentively forgotten their own self-care.

Heidegger suggested that one's affective state was related to being caught up in facticity– the everyday world and trying to escape this everyday existence. These moods and states of angst reflect Dasein's tendency to be absorbed in the world as a fallen being (Cohen & Omery, 1994; Macquarrie, 1968).The literature describes this as psychological and emotional adjustment to diabetes. Studies about the psychological challenges associated with the daily burdens of living with diabetes are prolific. Issues affecting psychological adjustment include struggling with changing health status, worries about the present and future, and being overwhelmed by multiple obligations to self and family, impact on relationships (Penckofer, Ferrans, Velsor-Friedrich & Savoy, 2007).

Frank was so busy enjoying life that he often drove off and forgot his insulin or syringes. He just didn't have time to bother with that diabetes stuff. Despite the directions by his doctor, Frank did whatever he wanted to with his diabetes:

> I know there are a lot of things over there [at the clinic]...but at this point, I don't want no help....I want to do it on my own. I've got a life, I'm busy, I don't have time for that bullshit....I adjust my insulin to however I want to do it. I eat breakfast, go to work and just before I go to bed at night, I take my insulin....I check my sugar once a day and think about it before I take my shot at night, because I think, hey have you had a lot of sweets today, have you done this, have you done that? I take more insulin. If I haven't then I take a little less....The doctors go, how can you do that! You can OD [overdose] on insulin.

Another facet of risk-taking and denial were grief reactions. Common grief responses toward diabetes included feelings of sadness, depression, hopelessness, and anger (Grams et al., 1996). In the chaos of caring for her family, trying to manage her diabetes, and a lack of support from her husband, Carol told about getting so depressed that she just gave up, saying "what the heck." Then she stopped taking her diabetes pills. After that, her blood sugars started running between 500 and 600. Leo has also struggled with depression, which made it hard to do anything. Leo was not consistent about going to the clinic. He said, "My walk through the clinic has been an experience of going often-to not going. And then I'd say, what's the matter with me, I'd better get my blood work done and get checked over, so I go back." Grief reactions to a diagnosis of diabetes are frequently reported in the literature. Grief also is related to loss of health. Factors that affect the grief response include age, expectations, complexity of diabetes management plan, social stigma, and loss associated with the disease (Brown, 1985).

A common grief response is denial, which contributes to risk-taking and rationalizing behaviors. The basic tenet of being-in-the-world is one of practical

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familiarity with it. Heidegger referred to this as ready-to-hand. When a person is not

cognizant of it, the phenomenon remains in the background (Blattner, 2006). While in a

state of denial, participants were not aware of their diabetes; it was too much to cope with

and so it became a part of the background. They went through a grieving process

reminiscent of Kübler-Ross's stages of death and dying: denial, anger, bargaining, and

rationalizing. This observation is congruent with findings from other research studies.

Frequent responses to diabetes are denial, shock, depression, despair, a sense of pending

doom, shame, embarrassment, and loss of normalcy (Kaufman, 2005). Casey clearly

explained why denial is so prevalent:

> You imagine to yourself that diabetes isn't anything. So when I was
> diagnosed, I thought it was fine and it wasn't a big deal because I had seen
> so many people live their favorite lifestyle, but also live with this disease.
> So, you don't take it seriously.

Even though Carol was on pills for her diabetes and attended diabetes class, she

persisted in believing that she did not have diabetes. "I was in denial...and sometimes I'd

go off my pills cause I'd get tired of taking pills." Many participants thought their

diabetes was just "borderline" or temporary. Delores shared how after several years of

hearing she had borderline diabetes, she confronted the doctor and asked, "I am or not,

which is it?" He then confirmed that she had diabetes. In hindsight, she realized a lot of

her actions during those first years were out of a sense of denial. She thought if she just

dieted, her diabetes would go away:

> I would skip breakfast, eat a little lunch, and have a big dinner and I did
> that for years...when I first got diabetes I thought, okay, I'll control my
> diet and it'll go away....That doesn't happen, you can control your diet and
> feel a lot better, but you still have diabetes, you still have it.

Several participants thought the symptoms they experienced before they were diagnosed with diabetes were due to other medical conditions such as hepatitis, the flu, and respiratory disease. They did not associate them to diabetes. Daryl said, "I had other things going wrong with me at the time, I didn't think it was diabetes related, I thought it was just the way I was at the time."

Although it was alluded to in the previous section, another dimension of risk-taking and denial concerns substance abuse and addictions. Feeling overwhelmed and lacking adequate social support to manage their diabetes or other life burdens, some participants were unable to find the resources within or outside of themselves to cope. As a result, they turned to drugs, tobacco, and alcohol. According to trauma theory, self-harm such as substance abuse, is often a coping mechanism to manage the feelings of hopelessness and powerlessness and anxiety from historical trauma. Psychological distressed can be manifested through addiction (Estefan, McAllister & Rowe, 2004).

Daryl spoke of his struggles with alcohol and how he finally quit when it almost killed him. Both Delores and Carol quit smoking because they realized it had affected their health. Lilly was horrified when she had to start taking insulin shots as a young child. Health care providers told her that she needed to clean off her arm with alcohol first. When she heard the word 'alcohol,' she was mortified. She had seen what alcohol had done to others on the reservation. The diabetes educator mentioned that Lilly had on-going struggles with alcohol during her adult life, when she stopped drinking; she no longer needed insulin to manage her diabetes. Casey shared the struggles her family had with addictions:

The addiction cycle is hard to break. Any cycle that anyone has in their family no matter what it is – it could be lying, smoking cigarettes, or doing drugs; they're all hard cycles...you get addicted to being overweight, you get addicted to food and it's a hard thing to battle.

With risk-taking and denial, there was an underlying recognition that family members would not support addictive behaviors. Carol mentioned that she would not help her daughter who is addicted to drugs. Her son also refused to give her money, recognizing that doing so, just perpetuated the problem. Ultimately each individual is seen as responsible for their own actions, based on the principles of free will, self-determination, and the ethical principle of autonomy. Virginia argued that anyone who blamed others for their situation was just using that as a cop-out. She accepted the choices she had made. "I know I caused it, not anyone else. You can't blame anyone else for what you stick in your mouth." Although some tried to blame others, the elder participants tried to hold them accountable for the choices they have made.

As they travel through the fourfold world, some participants soared to the heavens and others were struck down to earth, broken and scarred. Those who were felled by this thing called diabetes, may have succumbed to the disease; others tried hard to persevere through the difficult times; and yet others sailed through unscathed. The differences in responses were related to the pivotal moments in time, which revealed possibilities and offered to alter the course of diabetes. Awareness of possibilities and limitations on the horizon of time may have influenced the participants' psychological adjustment to diabetes. Livneh and Martz (2007) studied the relationship between grief and time orientation for people with diabetes. The daily demands of diabetes heightened the awareness of the time commitment required for self-care. The past was symbolic of life

before diabetes. The present was the daily regimen of diabetes self-management and the future represented anticipation of complications, health crises, and uncertainty. Pivotal moments may have helped the participants cope with the psychological adjustment to diabetes and helped them look toward a positive future rather than one of death and destruction.

For some participants in this study, there was an epiphany or turning point when diabetes became a part of their consciousness and these turning points became a source of strength in their sky of possibilities. Heidegger referred to this sudden awareness as "mindfulness." In the startled moment of wisdom, beings are set free from their state of falleness (Heidegger, 2006). This revealing of sky is known as "kariology time"--when one's life changes evermore because of some significant event. The event might be a sudden death or loss in the family, an emergency or life-threatening illness. The crossroad for Leo was toward the end of his mother's life, when he saw how she maintained her pride and dignity despite her double-leg amputations. This made him realize how important it is to find balance in his life.

> That was a turning [point]...they not only showed us how to live, but they showed us how to die. They were very dignified in their lives right to the very last breath. They were doing everything they could in this world to do what they felt that they were supposed to do before going to the next world – to keep in balance...to heal from the inside out. (Leo)

For Casey, the decisive moment was when she miscarried during her last pregnancy. "The guilt of losing my baby, of not caring for myself enough, and not realizing that I wasn't taking care of myself...was the biggest thing." For many others, a health crisis triggered behavioral change. They quit smoking, quit drinking, or accepted

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their diabetes and began to eat healthier. These health crises made them see their own mortality, or that they would not be around for their children or grandchildren.

Mortals: Struggling with Disease Burdens

> The idea of full dress in preparation for battle
> comes not from a belief that it will add to the fighting ability.
> The preparation is for death in case that should be the result of the conflict.
> Every Indian wants to look his best when he goes to meet the great Spirit,
> so the dressing up is done whether imminent danger
> is an oncoming battle or a sickness or injury at times of peace.
> ~Wooden Leg, Cheyenne. (Curtis, 1994)

In Heidegger's fourfold, mortals or human beings are situated toward death (Kisner, 2008). Dwelling between earth and sky provides a sense of our own mortality as "we are a being in and of time" (Dittmar, 2000, p. 1). For participants in this study, mortality was always in the forefront, rather than in the background, of their daily lives as they dwelling in their fourfold world. Diabetes was the proverbial beast of death. Having seen many family and friends defeated by diabetes, the initial diagnosis struck a chord of fear. Lilly recounted that when she was diagnosed, all she heard was "die" not "diabetes." Diabetes was synonymous with a death sentence. Leo shared a story about his friend being diagnosed with diabetes: "When he found out he had diabetes, he said he wasn't doing dialysis–no way. He didn't and he was gone in a couple of weeks." Other participants recognized that it was the complications from diabetes that led to death. "Diabetes is a silent killer. The diabetes disease itself is not gonna do anything, the high sugars...can destroy my heart, my kidneys, and I have to keep my sugars under control so I can stay longer in this world" (Delores). There was a sense of pending doom and they felt weak and vulnerable in this state of always being-toward-death.

For the participants in this study, diabetes was a foe that must be defeated. As diabetes came into their lives, the participants felt very vulnerable: they were no longer the strong warrior that was expected of them. For the men especially, it was important to show strength. Within the Schitsu'umsh, there is little tolerance for others who show their weakness or vulnerability. Both Frank and Leo told of how they had no time for diabetes classes or support groups, because all they heard were pity stories. They had no patience for whiners. Leo shared his own struggles: "Get up and walk, quit lying down...soldier up and meet this new battle." The journey of life was difficult; rather than complain, the participants used fortitude and perseverance to keep going. As Casey explained: "the Native American people are not taught to express their emotions...you're not taught to show your weakness."

Another area of vulnerability was the risk of complications, which included blindness, kidney disease, and amputation. "Its chop, chop, chop." Daryl recounted, "First it's the toes, then the foot, then the leg, then its dialysis." For Casey, it was the risk of miscarriage: she was warned that if she didn't take care of her diabetes, she would lose her baby or end up having a cesarean section. For the men, there was also a fear of erectile dysfunction (ED). Leo explained, "When ED came, [I thought] I'm going to die. I am not a man anymore." They often felt vulnerable because of family histories. Frank shared, "Diabetes shows up a lot in Native Americans, so over the years I've kind of expected it. Sooner or later I'm gonna get this...the only thing that worries me is losing my eyesight." Leo had similar reactions because family members had bilateral leg amputations from their diabetes:

You know, for all of us Indian people who have diabetes, it's not easy for us. It scares us. The Indian people don't go to the clinic unless they are really sick. They don't do if for preventive maintenance...there's no pamphlet that you can read that will talk to you about what it's like when you are laying there in the middle of the night and you get shooting pains up your leg from you heel, and your toes, and your ankle, and that scares you. (Leo)

The burdens of diabetes have been linked to a decreased quality of life (Chyun et al., 2006; Evans & Morris, 2001; Goldney, Phillips, Fisher & Wilson, 2004; Rubin, 2000). In recent years there has been an increased focus on the psychological, emotional, and physical burdens of diabetes as they relate to quality of life (QOL). QOL has become an important outcome variable in many diabetes clinical trials (Tankova, Dakovaska & Koev, 2004). The burden of treatment through diabetes self-management has a negative impact on QOL. Lower QOL has also been associated with the presence of diabetes complications (Hart, Redekop, Bilo, Berg & Meyboom-de Jong, 2005), including peripheral neuropathy (Chyun et al., 2006; Davies, Brophy, Williams & Taylor, 2006), erectile dysfunction (De Berardis et al., 2005), peripheral vascular disease and foot ulcers (Evans & Pinzur, 2005), and retinopathy (Larsson, Lager & Nilsson, 1999)

Rubin (2001) created the term "diabetes overwhelmus" to describe the day-to-day troubles of living with diabetes. The overwhelming burden of diabetes was a common theme shared by the participants in this study. Carol lamented that diabetes was difficult to manage and made her life very stressful. She compared diabetes to a skunk: "It stinks, I hate that I have it and there isn't even anything to get rid of it." Virginia associated diabetes with "a big, old, ugly moose," because the moose "never get small." The moose is a huge beast, just as diabetes has been in her life.

Participants tried to change their lifestyle to manage their diabetes. They always had to be prepared for unpredictable nature of the beast and the loss of spontaneity was frustrating. Delores really missed the freedom of her old life. She said it made her feel like a prisoner.

> Diabetes can be a chain on your ankle. We used to just say, okay let's go somewhere. And we'd go for a drive and keep going and stay overnight. We can't do that anymore...you want to take off running and all of a sudden you just stop. Oh, that's right, I've got to plan; I've got to do this. It's a ball and chain. A lot of our culture is "let's go do this" and you just go do it. I can't, I can't do that anymore.

Even if they were prepared by carrying their glucometer, food, medications, and planning, participants found that diabetes itself was unpredictable. Carol told about going on a trip with a friend. "We went straight down 94, and I started shaking and I checked my sugar and it was 70...so we stopped and ate something." Anything could trigger a high or low blood sugar. Before they knew it, they had passed out in the shower or were on a gurney in the hospital emergency room. Virginia shared:

> It would go down to 92 and sometimes 80 and I'd be shaking. But the time it went down to 21, I didn't feel nothing. I went and took a shower and I passed out in the shower and I woke up in the hospital....Usually if it gets about 80 or lower I can feel it a little more. Why I never felt it that day, I don't know. But that's where it is; you have to watch it all the time.

Using a flood analogy, the need to always be prepared because of the unpredictability of diabetes is akin to the spring snow melt in the mountains of northern Idaho. Although it happens every spring, no one knows exactly when runoff will occur. If the weather warms up too quickly and the snowpack thaws too fast, there is a risk of flash flooding, so it is important to always be prepared for the rushing waters. For the participants, the burdens of diabetes were overwhelming: no spur-of-the-moment trips;

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never knowing when their blood sugar would drop unexpected; and always trying to balance the daily routine of diet, medications, monitoring, stress management, and exercise. To keep the enemy from winning, participants had accepted their disease and made sacrifices to keep their diabetes in control.

With diabetes, there is a constant worry about the present and future. Anxiety and fear can be fueled by concerns over resources, finances, job stability, and declining health (Penckofer et al., 2007). The insidious nature of diabetes and the constant vigilance required for self-management were overwhelming. In a tight-knit tribal community, where diabetes is so pervasive, the diagnosis is all the more distressing. "Some diseases are worse than diabetes, but none require such a complex balancing act, where the patient must do so much themselves...the disease infiltrates every moment and clouds the future" (Kaufman, 2005, p. 62).

Participants used seeking knowledge as a strategy to overcome their daily worries about diabetes. Acquiring knowledge gave them a sense of control over their lives, so knowledge became a powerful tool to counteract fears of the unknown enemy. Sandy mentions: "that's probably the most I've got going for me and diabetes, is having all of that knowledge." Seeking knowledge about diabetes was a sign of acceptance. Accessing the information needed to manage their diabetes on a daily basis, seeking balance in their life, and changing habits to stay healthy is what the participants did to prolong the inevitable. For participants, the goal was to keep death at bay for as long as possible.

Seeking knowledge also helped participants cope better with diabetes complications. As they canoed along the river of life, diabetes knocked them out of the boat. Complications were the riptides and currents that pulled them under and could

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ultimately lead toward their death. Unseen complications increased the participants' sense of vulnerability. Learning to understand situations from a different perspective helped the participants put their fourfold into balance. Leo described it as reaching into his medicine bag to find what he needed to keep going and to push through the difficulties. When this happened, life became a whole new adventure. It was like reaching into the huckleberry basket for a berry of knowledge or wisdom. As Leo suggests: "Deal with it. From the first day you are diagnosed and you can go to all of the trainings and everything, learn as much as you can about it. Become informed!"

Accepting diabetes into their lives was another strength used to counteract the burdens of living with diabetes. This occurred as a moment in the gathering of the fourfold when clarity and awareness revealed themselves. Heidegger referred to this as mindfulness (Maly, 2007). This awareness or knowing is through Dasein, where the authentic self is situated toward death. These "ah-ha" moments were pivotal points of strength for the participants as they recognized their own mortality and started to accept their diabetes. Although many of the participants reached a point of accepting their diabetes, there was a constant folding and unfolding of awareness, vacillating between acceptance and being pulled back into the whirlpool of inattentive caring. There was always a tenuous balancing act, which left them feeling vulnerable and fearful of what was to come next.

Participants' acceptance of diabetes in their lives meant making it a part of their routine and having to be aware of how the choices they made on a daily basis affected their diabetes. Casey shared: "I finally made my decision to take it seriously; that it does make a difference in what I eat, it does make a difference that I exercise...I found a

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pattern." It meant putting diabetes in the foreground instead of the background, and that

was not an easy task. A heightened awareness, however, made the participants reassess

their decisions. Mary acknowledged that when she didn't exercise in the morning then

she got up and walked more at work instead. She also told about how she changed her

family's diet to include more fish and fewer sweets. Even during the holidays, she does

not make a dessert for her family. Virginia mentioned that she watches her diet, except on

holidays. "The only time I don't care what I eat is Christmas, Easter, and Thanksgiving.

Three times a year, I'll eat whatever I want and that's it." The rest of the time she restricts

her diet to fruits, vegetables, whole grains, and yogurt. She has given up meats, breads,

potatoes, and her beloved margaritas. Even when participants attend social events they

made the choice to eat differently. Delores told about going to a graduation party where

cake was being served. She told others she couldn't have it and ate grapes instead. When

participants accepted their diabetes, their attitudes shifted as well. They felt successful for

taking charge of their lives, rather than diabetes taking control of them. As Casey

described it:

> There comes a time that – I don't know if other people do it, but I am
> actually proud that I am a diabetic and I am doing what I am
> doing....There is this accomplishment that goes along with keeping your
> sugars down and realize what you need to do. I need to exercise more and
> I think, okay, and I say, I am exercising more than I was. I'm kind of
> pushing myself along the way.

Immortals: Tensions in Patient-Provider Relations

> Men who are occupied in the restoration of health to other men,
> by the joint exertion of skill and humanity,
> are above all the great of the earth.
> They even partake of divinity,
> since to preserve and renew is almost as noble as to create.
> (Voltaire, n.d.)

Authority figures represent the immortals or divinities in Heidegger's fourfold

world and are a source of tension for the tribal members with diabetes. Healthcare

providers can be viewed as life guards or the coast guard, hovering high above the world

of the Schitsu'umsh. When they swoop in to rescue people, they drop down a life raft--

but the instructions to inflate the raft were written in a foreign language, so the raft is

useless. Lifeguards set the rules for engagement with the river and they must be followed.

Although the lifeguards have the safety and welfare of the people as their priority, their

concern comes from a hierarchical and paternalistic world-view rather than from

collaboration and cooperation. Patient provider tensions were the result of mistrust,

flawed communication, judgment, and lack of standards in care provided to the

participants in this study. These patient-provider tensions created a barrier and left

participants feeling unsatisfied with their client-clinician relations.

Mistrust of doctors was a reoccurring area of tension. Several participants

attributed this mistrust to historical roots of treatment by government and religious

leaders. As a child, Daryl's parents were heavy drinkers, so the priests and nuns decided

that his parents were unfit to care for him and they had the state (through BIA) remove

him and his siblings from their home and placed in orphanages. Now Daryl trusts only his

regular doctor. If he is not available, Daryl will not see anyone else. Casey also related

the issues of mistrust to experiences of historical trauma. A tribal history of abuse and

oppression created a cycle of fear and mistrust. Casey grew up with a "don't tell" attitude

in her family:

> It's what I was taught, that there's always someone out there trying to
> open you up, trying to find out who you are. Growing up, that wasn't
> right...you never told anyone anything...For our elders, it's almost

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impossible to treat them 100% because something as honest and upfront as [asking] Are you taking your pills everyday or what were your sugars?...can trigger this defense.

Historical consequences of colonization and oppression contributed to participants' reluctance to go to the doctor. They preferred to treat it themselves. Delores expressed concern about the elders waiting too long to go to the doctor with foot problems because they preferred to take care of it themselves: "I've had so many people just have something wrong with their feet until it got so infected that they would come in....But most of the time it's too late and with their diabetes it's harder to heal."

Paternalism was another aspect of mistrust in the client-clinician interactions. Ethnocentric approaches to healthcare diminish or marginalize patient-provider interactions. "Ethnocentrism refers to the assumption of a particular culture as the norm, other cultures being viewed through its lens and in relation to the taken-for-granted culture...the outside culture may be sentimentalized, marginalized, condescended to...diminished or ignored" (Thompson, 1997, p. 10). Paternalistically telling the patient what to do and expecting them to follow orders creates tension between the patient and the provider. Reflecting an ethnocentric worldview of the western medical model, the participants' doctors made many assumptions about adherence to diabetes treatment plans:

> A lot of doctors assume that it's being taken care of. They diagnose and if they see you once in a while and make sure you have your meds, that's about the farthest the doctor goes. He just assumes that the person knows how to handle it and they don't. They don't. They're just floating there by themselves and they're scared. So don't assume anything. (Delores)

Paternalism was also demonstrated in the providers approach to clinical practice. Some participants felt like they were being interrogated when they went to the clinic. The

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providers acted like drill sergeants and it was very intimidating. Experiencing the healthcare system in this manner brought up a lot of deep-seated emotions because of previous personal, family, and tribal experiences with authority figures. From a Native American perspective, "control is understood as creating a forced dependency that negatively affects maintaining balance" (Lowe, 2002, p. 7). Lowe continues to explain that, "Native Americans do not consider themselves the center of the universe or special creatures intended to dominate or control the world, rather they look at it from the group preference...group cohesiveness is the foundation for decision making" (p. 7).

Flawed communication also led to unsatisfactory client-clinician relations. Participants failed to connect with providers because of communication barriers. "Language itself is not a neutral vessel of communication, but a social power and an active site of contestation through which meanings are made and remade" (Kirkham et al., 2002, p. 229). For the tribal people to look down rather than make direct eye contact is a sign of respect. Providers, however, became frustrated because their patients don't look at them. Providers perceive this as not listening or as being non-compliant (Warne, 2008). Miscommunication was a frequent occurrence between the participants and clinicians. Heidegger would say that miscommunication is based in how individuals use language to understand and interpret their world. Language is grounded in an individual's history and context of how he or she is situated in the world (Allen, 1995; Parse, 2001). Participants perceived they were getting mixed messages about their diabetes care, especially about what kind of diet to follow. There also was considerable confusion about whether diet or regular soft drinks are a better choice. Some of the participants believe

that the chemicals added to diet pop are far worse for their body than the sugar in regular soda.

There also were difficulties in understanding the diabetes education classes. Regularly scheduled diabetes classes and support groups are rarely attended by the tribal people; usually only the non-Indians attend. The participants would meet with the dietician or diabetes educator individually, but not in group sessions. Native people don't learn in that type of environment and the word school or education has a negative connotation that is linked to tribal history in boarding schools. At least half of the participants attended tribal boarding school during their youth. Virginia noted that education is not effective if they are only told about diabetes or just given a brochure. "When you talk it doesn't make sense. Indian people are visual; you have to see it or it does not penetrate."

Miscommunication also happened when participants received mixed messages from different doctors; the participants became suspicious of the physician's motives. Are they covering up for each other? Are they just giving second-class care? Flawed communication between patients and providers perpetuated feelings of mistrust and resulted in a sense of receiving substandard care. Leo told of his experience with eye surgery. When he went to the doctor to get treated for his retinopathy (eye damage to the retina caused by diabetes) he still had good vision and wore glasses just for driving. He was uncomfortable with how many laser treatments the doctor was doing, but didn't say anything. The last treatment was in very center of his eye and was extremely painful. The doctor patched his eye and sent him home. When the patch was removed four days later, he was totally blind in his left eye. Several months later, he went to another eye specialist

for cataracts in his right eye. He asked her to take a look at his left eye. When he asked

her what she saw:

> She wouldn't say anything to me, she just wouldn't say anything....she just
> kept talking about pressure on the optic nerve and that would eventually
> take your sight away. And I am sitting there thinking, oh yeah, pressure on
> my optic nerve and a guy with a laser gun! I am most certainly no doctor,
> but I do know when I went in there I could see 20/30 out of my left eye
> and when I walked out I was blind.

Leo was skeptical and felt like the doctors were covering for each other. This is

just one example of the participants' experiences with the healthcare system that

fueled their distrust toward healthcare providers.

Flawed communication was also demonstrated in the western medical

ethnocentric approach to healthcare. Some participants felt almost neglected. They

perceived a total lack of interest in themselves as persons; the visit was only about the

numbers (e.g., labs and blood glucose readings) and not about how the patient was

feeling. The provider looked at the medical chart and labs, and made a diagnosis without

ever engaging with the patient. The patient felt like a disease rather than a person. The

ethnocentric biomedical approach to conquering disease through technology is a

significant barrier to satisfying patient-clinician relations (Luckmann, 2000). An

assumption that providers tend to make is that physiological parameters are important to

the patient and, "unfortunately these physiological measures dominate our interactions

with patients. We initiate, discontinue, and alter therapy based on these values. From the

patient's perspective, they are not rooted in any meaningful way in their everyday lives"

(Schultz, 2007, p. 159). From the client's viewpoint, there is no consideration for the

embodied experience of living with diabetes, just meaningless numbers. Diabetes as an

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embodied experience refers to corporeality, or how diabetes is manifested within the "unique, personal and subjective self, who is a social subject, molded and constrained by beliefs and practices that have been embedded by society [and culture]" (Estefan et al, 2004, p. 25).

Participants also felt that they were being judged by the health care professionals. Daryl recounted his experience of going to the hospital with a low blood sugar and stated that because he had drinking problems, the hospital treated him differently:

> How many of our families were overlooked because they just thought we were drunk Indians? Or my ancestors were drunk Indians and that's what was wrong. When they came to the emergency room, they thought – aw that's just a drunk Indian, just give him a shot and let him out the door.

These issues were prevalent at the clinic as well as at hospitals. People with diabetes have blue medical charts at the clinic so that everyone in the clinic knows that patient has diabetes. This makes people immediately pass judgments. It also sets the tone for the patient–provider interaction. Casey felt like she was being grilled every time she went to the clinic: "Have you checked you sugars, are you doing this, are you doing that." Even if it was for some minor ailment, her provider still went through the drill about her diabetes self-care. In this authoritarian model of care, the values of the caregiver dominate so that true self-care by the client does not emerge (Hagey & Buller, 1983).

Not following standards of practice, despite systems to facilitate care, was described by the participants as substandard care. Frank's story about his allergies and almost receiving the wrong medication was viewed as poor care. Carol's experience was comparable. She went to the clinic with flu-like symptoms and had been vomiting for several days. Health care providers told her it was just the flu and to drink lots of liquids.

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They never bothered to check her blood sugar even though she had diabetes. The next day she ended up being taken to the emergency room by her son and was in the hospital for over a week. Matlow et al. (2006) argue that standardized care practices such as blue charts for diabetic patients fail to improve quality of care because patients/provider relationships are complex and nonlinear. It is interesting to note that the efforts by the Benewah Medical Center to improve quality of care and address scheduling issues by implementing computerized medical records has only added to concerns about quality and access to care at the clinic. Perhaps it is time to demedicalize healthcare and give the power back to patients by encouraging self-determination, autonomy, and self-care (Dupuy, 2003).

Daryl equated his type of medications and supplies to substandard care. Although there are lots of commercials about new, high-tech glucometers (blood glucose testing machines) he complained that the tribal people just receive only old antiquated meters: "our machines are obsolete. I mean they're not up to code with a lot of the new ones." He also lamented that the tribal people always get generic medications, never the real ones. He said he gets "gallons and gallons" of generic pills and his blood sugars have not been as good since he was switched to generic medications:

> I can't understand why they give us so many generic drugs. I know somebody's making money off of them and I think we're supposed to be a real up-to-date clinic....There should be a better way to care for us, instead of cramming so much generic crap down us. Everything we take is now generic – everything! Especially all of my diabetes medications are generic.

All of the study participants were able to identify what they would consider "good" care. These included connecting and creating a collaborative partnership in

planning care. Have providers who are friendly, demonstrate concern, and listen

respectfully are the foundations for good care, and subsequently, good diabetes self-

management. What the participants are seeking is the concept of relationship-based care

(Koloroutis, 2004). Relationship-based care entails respectful listening and developing a

collaborative partnership between patient and provider. Establishing trust and displaying

presence or "being there" is essential in all aspects of care (Kavanaugh, 2002).

All of this study's participants commented about what they perceived as good

care or shared experiences of when they received good care in the health care system.

Frank mentioned that the clinic staff showed him (rather than told him) what he needed to

do to take care of his diabetes. Others noted that the services offered by the diabetes

educator and dietician were superb. Both were very committed. The yearly diabetes day

provided by the clinic also was viewed positively. Other support services including

transportation for medical appointments and the community health representatives were

described as positive resources offered through the clinic.

Sokoloski (1995) noted that good care was perceived by First Nations study

participants as providing explanations in a friendly, non-authoritarian manner. Other

recommendations to improve quality of care from racially disparate focus groups include

allowing patients to make informed choices in selecting their healthcare providers,

providing customer service training and cultural competency education to all employees

and providers, reducing the number of patients scheduled each day, and integrating

alternative care models such as relationship-based care or patient-advocacy models into

current healthcare delivery system (Gaston-Johansson et al., 2007).

Some participants reported that they received good care when a healthcare professional acted concerned and friendly toward them and when the provider took the time to really listen and did not rush them through the visit. Daryl described his physician visit as having a conversation: "He was very concerned and said, don't hold nothing out on me. I wanna know what's going on with you. I want to know if those meds are working properly." Carol mentioned that she liked it when the doctor pointed out improvements rather than always focused on the problems. The notion of being treated as a person rather than a disease was a common theme across interviews. Leo explained that each person has a life story and the provider needs to take time to listen to it. That's what good care is all about: "listening with the heart and not the head."

As discussed in the previous section, connectedness is one of the core values of the Native American tradition. It is the foundation for relationship-based care and is a crucial component to culturally competent care (Lowe, 2002). Native Americans place a high value on group consensus and cohesion as opposed to authoritarian leadership. Using a model such as relationship-based care, which promotes patient-provider connectedness, is better aligned with Native American traditional beliefs and values (Lowe). The relationship-based care model was developed by Koloroutis (2004) to create caring, healing environments for patients and their families. One of the tenets of the model is the concept of being emotionally present to a patient or client. Being present is predicated on listening, suspending judgment, promoting healthy and productive interactions, being aware of one's own reactions, and offering support. These are essentially the same components of good care that were identified by the participants of this study.

Open communication was also identified as important in creating positive patient-provider relations. The cornerstone of quality healthcare is communication involving the positive interchange of ideas and feelings between the patient and provider. If the healthcare practitioner understands cultures other than his/her own, the client-clinician interaction is more likely to result in achieving a mutually satisfactory resolution or treatment to the concern (Luckmann, 2000; Waxler-Morrison, 1990).

All agents within the healthcare system are interdependent and co-evolve together because they are social entities. The patients use social relationships to foster sense-making in their interactions. The key to good communication is creating a trusting relationship between the mortals and immortals. As a Navajo song describes it:

> Now I walk with Talking God;
> With goodness and beauty in all things around me I go;
> With goodness and beauty I follow mortality.
> Thus, being I, I go. (Gustafson, 1997, p. 132)

Bringing the Four into the Fourfold

Although each realm of the fourfold has been discussed separately, they are interconnected. Just as the elements of the fourfold are related, the major patterns were also entwined--one affects the other. It is not black and white, one or another, strengths or barriers; all exist within the fourfold. For example, the concepts of spirituality and connection to the creator can both be used to help find balance within the medicine wheel, but also may be viewed by others as a cause of disease through bad luck, a curse, or punishment. Like the medicine wheel, the path to health and wellness is through balance (Hodge, Limb & Cross, 2009). The mind, body, and spirit are intertwined with

culture, traditions, and history. Healing comes from finding a balance between strengths

and burdens and perseverance in this journey with diabetes.

How does the experiences of the Schitsu'umsh people with diabetes compare to

the experiences of other indigenous or ethnic groups? Several qualitative studies have

been conducted with First Nations people of Canada. Two studies in British Columbia

and one in Ontario have explored the experiences of aboriginal people living with

diabetes. The study with the Nuxalk people of British Columbia revealed the five themes

of using western and traditional healing practices, diet and exercise challenges,

communication issues, responsibility for choices, and living in the present (Barton,

Anderson & Thommasen, 2005). The themes around diet, communication and taking

accountability were also heard in the stories by the Schitsu'umsh people. The second

British Columbia study was with the Haidi Gwaii people living on Queen Charlotte

Island. Using grounded theory method with nine focus groups, the researchers found the

common themes of living with diabetes included fear; grief and loss; loss of control;

dietary issues; strengths (physical and personal); and traditional ways (Grams et al.,

1996). These categories are congruent with the findings in this present study.

The third Canadian study was conducted with a First Nations group in Ontario

and used the theory of integration as a theoretical framework for data interpretation. In

level one of integration, having diabetes was characterized by complacency: a lack of

interest or knowledge about diabetes, and desire to keep life as normal as possible. A

significant life event that became a turning point in the acceptance of diabetes comprised

stage two of the integration framework. The last step was integration of diabetes into

personhood, or "the science of one" (Hernandez, Antone & Cornelius, 1999). Although

the terminology is different, the descriptions are similar to those themes under "sky" in this study, including being inattentively caring, and risk-taking. Other common threads shared with the Schitsu'umsh experiences are self-blaming, diabetes attributed to the white man, turning points, and challenges with health care providers and educational methods.

Another study (Adams, 2003) focused on urban Latina women with type 2 diabetes and used descriptive phenomenology to explore their perceptions of living with diabetes. Six themes emerged in the analysis process: stress caused the diabetes; religion as a lifeline; sadness, anger and loss of control; living under a magnifying glass; obsession with dietary management; and too little, too late. The last category related to availability of resources and access to services. Although access to services was mentioned by several participants in this present study, it was not a major pattern throughout all interviews.

Gillibrand and Flynn (2001) used ethnographic methods to study the culture of diabetes from the patient's perspective among residents of an inner city area in Liverpool, England. The ethnicity of the participants was not addressed. The major themes consisted of information-knowledge about diabetes, psychological burdens, rationalizing, and reality avoidance. Although thematic titles differed, the descriptions of these themes are similar to those attentively caring in this present study. The participants in the British study also raised similar issues about patient-provider communication. The informants expressed greater concerned about coping with diabetes so they could live a balanced life style, whereas the providers were focused on blood sugar control.

The Analogy: The Perfect Storm

For the Schitsu'umsh people, dwelling within the fourfold of diabetes was akin to

surviving the flood waters after a torrential rain storm and diabetes was the destabilizing

force. Their canoe became unbalanced in these great burgeoning waters of diabetes. It

was a struggle to keep the canoe afloat or to climb back in every time they were knocked

out of the boat or pulled under by riptides and undercurrents. The Schitsu'umsh people

struggled to navigate the great merging rivers of the white world and Native world.

The major pattern of persevering through the dialectic tensions of diabetes self-

management represented the tenuous balance between strengths and weaknesses, between

tribal traditions, being inattentively caring, struggling with disease burdens, and

experiencing patient-provider tensions. Although the participants forged on through the

stormy waters of diabetes, they never walked alone, for they had their family and

community for support.

> *You'll Never Walk Alone*
> When you walk through a storm
> hold your head up high and don't be afraid of the dark.
> At the end of the storm is a golden sky,
> and the sweet silver song of a lark.
> Walk on through the wind; walk on through the rain,
> Tho' your dreams be tossed and blown.
> Walk on; walk on, with hope in your heart
> And you'll never walk alone, you'll never walk alone!
> (Rogers and Hammerstein, *Carousel*, 1945)

Sebastian Junger's book (1997), *The Perfect Storm* described the struggles of a

boat and fishermen against the sea as they attempted to survive the storm of the century.

This epic storm was created by the unusual convergence of three different weather

patterns which merged together into a larger storm of catastrophic proportions (American

Institute of Physics, 2000). Similarly, Native American's experience of living with

changing environmental conditions has created a perfect storm for developing diabetes.

During the process of colonization the Native people were confined to reservations,

which limited the availability of traditional foods. Loss of access to nutritionally rich

food was replaced with government subsidized commodity foods, further impairing their

nutritional status (Powers, 2008). Commodity foods provided a highly refined,

nutritionally poor, and energy dense food source to the Native people, whose lives were

characterized by little or no expenditure of energy. Restricting Natives' access to

seasonal rounds led to decreased physical activity. This sedentary lifestyle reduced the

calories required to maintain body weight. These occurrences created the perfect storm

for obesity and diabetes (Hill, Wyatt & Peters, 2005), which has permanently altered the

landscape of the Schitsu'umsh people.

    Although the changing topography of the Schitsu'umsh has been described as one

of two great rivers coming together (Frey, 2001), the diabetes epidemic has ravaged their

territory. As they have navigated the turbulent waters caused by this perfect storm, there

has been much struggle to stay afloat as unseen currents and riptides pull them under and

occasional snags knock them out of the boat. These are the burdens the Schitsu'umsh

experienced as they live with diabetes. Despite the challenges, life lines of support were

available to assist them to safety. There were people and resources that can provide an

anchor during the stormy times.

    The great flood of diabetes has assumed mythical proportions that are parallel to

many flood stories from the past. Examples of a deluge and archetypal flood myths are

threaded into stories throughout the world and tend to have similar themes of a great

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flood, a large boat or canoe, and one family or small group being saved. From Aboriginal, African, Celtic, and Native American traditions, these legends are surprisingly similar (Isaak, 2006). Gilliland reported recording at least 15 legends about floods from different parts of the world and different indigenous groups (as cited by Welker, 2004). One regional story from eastern Montana is *The Yellowstone Valley and the Great Flood*. The people in the story were told they needed to live as one with the animals, especially the buffalo. As other people came into the Montana area, they killed the buffalo and other animals for the sport of it and burned down the forests. The Great Spirit sent rains down to put out the fires. The water rose and the people moved out of the valleys to higher grounds. More rain came, so the people moved higher into the mountains. Several young men found a white buffalo struggling to survive and they helped it to safety. Realizing that the young people were no longer destroying the world, the Great Spirit gave the people a white buffalo hide under which to stay for shelter. The hide stretched and grew, protecting all of the people of the Yellowstone Valley from drowning. The people found a way to exist in harmony within the fourfold world of earth, sky, mortals, and immortals. The four directions were in alignment and they walked in balance again. The wind lifted the buffalo hide and it formed a sky dome over that valley so that all who resided there could live in peace (Welker, 2004).

Summary: Struggling to Stay Afloat

Living with diabetes is like trying to navigate the raging rivers of northern Idaho during early spring runoff. The melting of the mountain snowpack each spring is inevitable, but no one is ever quite certain when it will occur. With strong family histories of diabetes, the participants felt that getting diabetes was unavoidable. They

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foresee that complications eventually will kill them. The initial experience of being diagnosed with diabetes was like being thrown into a raging river. Without adequate support they likely would have drown. The assistance most needed was not diabetes classes and lectures or materials they receive from the health clinic and diabetes education class; what provided life support were their families and community and integrating traditional practices with western allopathic medicine. Although the participants felt vulnerable for getting diabetes, they persevered through the difficult journey. No matter what diabetes threw their way, they would get through it. The Schitsu'umsh people are survivors and their historical experiences of survival helped them preserve through the daily challenges of living with diabetes and diabetes complications.

What can we learn from these stories? The stories of the Yellowstone Valley flood, and dwelling in the fourfold world of diabetes are all about survival and finding the resources within to endure the world into which they have been dropped. Many hardships abound; the journey is difficult and sometimes treacherous, perseverance and lifelines are needed to just keep going. There also are life jackets that help keep us afloat. Will the raging river that has flooded the terrain of the Schitsu'umsh people subside? We will not see a return to the old topography, but the people will use available resources and knowledge to strengthen their canoes and build stronger lifelines between the members of their community. Like the people of Yellowstone Valley, the Schitsu'umsh experience tremendous change as they exist within their fourfold world of diabetes. There is always a dialectic tension and struggle to balance the canoe and stay afloat despite the multiple lifelines, lifejackets, and rescuers trying to help them. The Schitsu'umsh people have to

navigate the treacherous waters fraught with log-jams and undercurrents. It is time they

take back the power to guide their own destinies. Individual tribal members are still

accountable for their choices and actions, but the journey is always smoother when

family, community, and healthcare system unite to provide support along the way.

> *The Keep Going Prayer*
> Father Sky,
> it is I who raises my voice to you,
> have pity on me.
> Mother Earth,
> it is I who raises my voice to you,
> have pity on me.
> To all my relations who live to the West, North, East, and South,
> it is I who raises my voice to you,
> Have pity on me.
> Grandfather,
> it is I who raises my voice to you,
> have pity on me.
> Thank you for the blessings and the difficulties I have known,
> because everything is the source of strength and wisdom.
> You who knows the journey that waits for me,
> help me to face the path ahead,
> help me to find the strength to keep going.
> No matter the difficulty, no matter how weary I may be,
> help me to face each day,
> help me to face each test, each storm,
> one step at a time.
> Grandfather,
> I ask this in the name of all my relations. (Marshall, 2006, p. 127)

CHAPTER FIVE

Discussion and Implications

Introduction

This study illuminates the dialectic tensions of persevering in the Schitsu'umsh world with diabetes. It explores the experience of dwelling in the fourfold world of diabetes and offers notions of counterbalancing the burdens of diabetes with strengths from within the individual, families, and the tribal community. Walk on through the storm represents the Schitsu'umsh experiences of struggling for balance in the context of navigating life in the flooded confluence between the Native world and "Wal-Mart" world. As participants dwelled within the fourfold world, they tried to manage dialectic tensions between burdens and strengths of valuing tribal traditions, being inattentively caring, struggling with disease burdens, and experiencing patient-provider tensions. These findings open up the dialectic tensions between science and art, care and caring, nursing knowledge and indigenous ways of knowing. Now the challenge is to find a way to blend caring and culture in order to improve cross-cultural relations and improve health for all. To move beyond "us and them" to just being in our humanness. It is "not about fitting in or conforming to social standards...the challenge is to be yourself. Just BE. When you are BE-ing yourself, you will attract other like-minded BE-ings and co-create something new together" (Koerner, 2003, p. 184). From this stance, we can move forward together in action.

A Call to Action

This interpretive phenomenological study brings new cultural understandings to what it means to live with diabetes, in one Native American tribe. By increasing our

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understanding of Native American experiences of living with diabetes we can develop

collaborative partnerships with the tribes to address barriers to diabetes self-care. My

long term goal is to use information from this study to develop culturally relevant

diabetes education programs for Native American communities. There is also a great

need to address cultural competence of the health care community and to work at

eliminating biases and prejudice in our healthcare system.

This project grew out of my interest in social justice and patient advocacy.

Although my background is of a Caucasian nurse and diabetes educator of Euro-

American descent, I also have personal ties to the Native American culture. My mother-

in-law, husband, and children are all members of the Confederated tribes of Siletz Indians

on the Oregon coast. My mother-in-law told stories of not being allowed to speak about

her heritage or experiences of living on the reservation. She was forbidden to speak of it

because of the prejudice and discrimination toward the Native people as she was growing

up. Her stories and that of my clients have fueled my passion in addressing health

disparities among the Native Americans. Going forward from this project, I am

challenged to be a voice of advocacy to elimination health disparities by targeting health

care policy and public policy.

I titled this section "a call to action" because there is a need to move beyond

dialogue and discussion to action. The United Nations Millennium Goals (2010), the

World Health Organization (Commission on Social Determinants of Health, 2008), and

Healthy People 2020 (US Department of Health and Human Services, 2010) all identify

the critical need to eliminate health disparities by addressing social determinants of

health. Social determinants of health include a healthy living environment, access to

quality healthcare and education, fair and equal employment opportunities, social protection, and an equitable distribution of power, wealth, health, and resources (CDC, 2010; Washington State Department of Health, 2002). Because there are some many interrelated social determinants of health, actions are needed at many levels. This study has implications for tribal sovereignty and self determination, additional research, healthcare practice, and education. It calls for tribes to become change agents. Such leadership requires perseverance, empowerment, and hope for the future. As former Ambassador to Iraq Ryan Crocker explained, "It's perseverance in the face of adversity. Perseverance does not require hope, but hope does require perseverance" (Camden, 2009, p. A1).

Implications for Tribes

> Let us put our minds together and
> see what life we will make for our children.
> ~Sitting Bull, Hunkpapa Sioux. (Jacobs, 2008, p. 130)

Tribal sovereignty gives Native nations the inherent right to self-govern and to make decisions about their own future. With this power to self-rule, tribes are seeking greater autonomy and control over their destiny. "Opportunities for self-government may allow Native people to preserve and restore their communities in ways that represent their cultural views and traditions" (Champagne, 2007, p. 349). In the spirit of self-determination, it is essential that change happens from within the tribe, for the tribe, and by the tribe.

By drawing on tribal values and strengths, there are several strategies that tribes could use to target diabetes education and prevention. The first is to utilize the greatest tribal resource: the elders. Grandmothers and grandfathers are the taproot of the tribe and

traditionally have provided knowledge and wisdom about how to be-in-the-world. The elders could be pivotal in changing the current value-set among younger tribal members (Dickson, 2000). It is important to help support tribal traditions and values by connecting elders with the youth. There is a "unique place of grandparents in the lives of children. They...put their energy into helping the children find their place in the world. These are the carriers of tradition and stories that are meant to be given to the children" (Gustafson, 1997, p. 113). Several tribes developed education programs using grandmothers as leaders, educators, and trainers (Katz, Conant, Inui, Baron & Bor, 2000; Rodriquez, 2009; Strickland, Chrisman,Yallup, Powell & Squeoch, 1996). In several studies, the elders facilitated talking circles for tribal members to join together and have conversations about diabetes. Learning takes place as participants share and interact with each other (Murrock, Higgins & Killion, 2009; Struthers, Hodge, Geishirt-Cantrell & De Cora, 2003).

Storytelling is another strategy that can be used to influence change and is grounded in traditional tribal values. The stories need to be culturally-based and culturally relevant in order to be effective. There are several storybooks for children developed by IHS, CDC, and the Native Diabetes Wellness Center that are grounded in Native American traditions and values (Perez, 2002a, 2002b, 2002c). Using storytelling in diabetes education could help participants connect with one another through mutual support and respect. "Stories can allow the positive power of words to create a new empowering vision of the future and reshape the way one thinks about disease" (Carter, Perez & Gilliland, 1999, p. 187). Encouraging narrative stories of diabetes experiences

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can help participants transform one another in their healing process (Smith & Liehr, 1999).

Smith and Liehr (1999) described the use of storytelling in the mid-range theory "attentively-embracing story" as a means of assisting a client to transform a health challenge through intentional dialogue and active presence between the nurse and client. As the story unfolds, the client is able to find new meaning about the health issue and to move toward resolution. By listening to the story, the nurse and client are able to understand the experience from the storyteller's perspective and can create new meaning by connecting to the story in new ways. In addition to this mid-range theory, storytelling has been used via narrative inquiry in several research studies exploring indigenous diabetes experiences (Bailey & Tilley, 2002; Barton, 2004; Carter et al., 1999; Lindsay & Smith, 2003; Swatton & O'Callaghan, 1999).

Another interventional approach could use the tribal value of competition to develop a healthy lifestyle contest between friends, families, or school classes. Using the popular television show *The Biggest Loser*® as a model, a strategy to facilitate behavioral changes throughout the community could be to have a contest to see which family or group of friends or classmates have the greatest weight loss, consume the most servings of fruits and vegetables, or walk together over a specified time span. The winning team would receive a prize. In reality all competitors win because the community members are learning to support each other's lifestyle changes.

Cultural practices can be changed or transformed through social relationships because people tend to follow the prevailing standards of behavior (Estefan et al., 2004). If everyone in the group is changing habits, then each individual is more likely to have

long-term behavioral changes. This supports the tribal value of competition, but also is loosely based on complexity theory. Bahr, Browning, Wyatt, and Hill (2009) used complexity science to create a computer model of social networking and how those networks influence weight gain or weight loss. Using a few guiding principles and a large number of interconnecting agents, the researchers found that weight gain of individuals within social networks were positively correlated with weight gain in family and friends. The researchers concluded that long-term weight loss is difficult to achieve or maintain unless the extended social network of family and friends change behaviors as well. Complex adaptive systems are based on non-linear relationships and multiple interconnecting agents acting in unpredictable ways. Applying this to complex problems such as diabetes management and prevention means that an array of strategies that utilize minimal guidelines are required to drive interventions. These solutions can be modified as new information and feedback is provided within the complex interacting social system such as a tribal community (Brown, 2007; Murrock, et al., 2009).

At the community level, the tribe can play an instrumental role in health promotion and prevention programs. There are several community change models that could be used to develop culturally relevant diabetes prevention programs for Native American communities. The following section will describe community organizational development model (COD), PRECEDE-PROCEED model and Positive Deviance. All of these models would be appropriate for use with cross-cultural community development.

The Community Organization and Development (COD) model was developed to address health disparities in African American communities. The central premise of this model is community empowerment by building community coalition (Minkler &

Wallerstein, 2002). Community empowerment seeks to place greater control into the hands of the disadvantaged so that they can gain a sense of control over their lives (Neighbors, Braithwaite & Thompson, 1995). Empowerment and self-reliance are important for promoting large-scale elimination of health disparities within disenfranchised communities (Braithwaite & Lythcott, 1989). Mobilizing citizens helps develop community ownership and stimulates innovative change. When local citizens activate existing resources and develop a sense of control, this may help moderate the environmental, social, and political factors affecting their living conditions (Auslander, Haire-Joshu, Houston & Fisher, 1992). The basic concepts of the COD model are: 1) self-determination, 2) shared decision making, 3) bottom up planning, 4) community problem-solving, 5) cultural relevance, and 6) overcoming victimization. These concepts are operationalized through a seven step process (Braithwaite, Bianchi & Taylor, 1994).

The strength of the COD model for addressing diabetes in Native Americans is that the framework is grounded in cultural competency and community empowerment. At the community level, Native American tribes can play an instrumental role in promoting the health of their own people through health promotion and prevention programs and through collaborative partnerships with academic and government agencies (Andersen, Belcourt & Langwell, 2005). In the spirit of self-determination, many Native American tribes are seeking ways to disengage from government run Indian health programs in order to take a greater responsibility for the health of their own people (Strickland, 1999).

Weaknesses of this model are the challenges confronting communities as they try to overcome tremendous barriers to change. Empowerment is often a catch-all phrase for people to gain power over their lives; but, in reality, it is much more difficult to achieve.

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When members of a disenfranchised group are not a part of the governing body that develops policy and determines funding allocation, it is difficult to adequately effect change without adequate resources in place. It is unclear how creating the coalition board transfers power from those "in power" to those disenfranchised. Unless members of the community coalition board are part of the policy and resource allocation process at a governmental level, disenfranchised group members will continue to struggle with the complex ecological factors that impact their health.

The PRECEDE-PROCEED model takes into consideration the cultural and historical context of the group and setting toward which the health program is focused. This model is not a theoretical framework for health beliefs and behaviors, but instead serves as a sort of instruction manual for developing behavioral intervention programs (Green & Kreuter, 2005). The PRECEDE-PROCEED framework has two components. The first is a set of planned assessments and formative evaluations that guide policy and implementation processes. PRECEDE stands for predisposing, reinforcing, and enabling constructs in educational and ecological diagnosis. This component of the framework involves the diagnosis and assessment of data in order to establish target goals, priorities, and objectives. The second component of the framework is PROCEED which is an acronym for policy, regulatory and organizational constructs in educational and environmental development. The PROCEED component includes a summative evaluation process that is used as a baseline for outcome measures (Green & Kreuter, 2005).

Strengths of the PRECEDE-PROCEED model are its flexibility and adaptability to various group sizes. It has been used for health promotion, disease prevention, and

disease management efforts (Green & Kreuter, 2005). This model also has been used

successfully within Native American communities in several diabetes prevention studies

(Daniel et al., 1999; Hood, Kelly, Martinez, Shuman & Secker-Walker, 1997).

Unfortunately both the PRECEDE-PROCEED model and the COD model are lengthy,

time-consuming, and resource-laden. It would be most advantageous and more efficient if

either of these models were adapted into a rapid-cycle improvement method.

The COD and PRECEDE-PROCEED models both offer methods for developing

culturally competent diabetes prevention programs at a community level that could be

used within a Native American community. Both have been used in the past as

frameworks for Native American diabetes preventions programs. The drawback of both

models is the time and resources needed. The challenge of working with disenfranchised

populations is the time commitment needed to establish and build a relationship with the

key players of the community. These partnerships become instrumental in self-

determination and attaining improved health status.

Another model that uses a different approach is that of Positive Deviance.

Positive deviance has been used in many third world countries to address health issues

ranging from childhood malnutrition and infant mortality to safe sex practices. Rather

than using problem-oriented strategies, it uses a strength-based approach to solve health

disparities. Positive deviance focuses on community assets by discovering local solutions

using available resources (Walker, Sterling, Hoke & Dearden, 2007). The community is

actively involved in the change process, using an inside-out or bottom-up approach. The

positive deviance model looks for individuals within the community who differ from the

norm in a positive or healthy direction. Marsh et al., (2004) noted that, "the observation

that in most settings a few at-risk individuals follow uncommon, beneficial practices and consequently experience better outcomes than their neighbors who share similar risks" (p. 1177) is a good description of positive deviance. By recognizing those individuals who are able to survive and thrive with existing resources, communities can learn from these differing individuals how to help others in similar circumstances.

Strengths of the positive deviance model include the ability to enhance local capacity, use of existing resources makes further development of readily available solutions a viable option, and positive deviance helps mobilize and engage community members because they are already doing something right (Kim, Herrey & Kols, 2008; Marsh et al., 2004; Walker et al., 2007). Challenges to the positive deviance model are that it is sometimes difficult to find positive deviants within a community and that the model has not been rigorously researched using gold standard clinical trials (Marsh et al., 2004). Each of these community health models highlights the need for community partnerships as the foundation for social change. What is needed next is to move from understanding the phenomenon of diabetes and what it means to live with diabetes in the Schitsu'umsh world, to community participatory action research in an effort to move toward action and interventions.

Implications for Further Research

> In all your official acts, self-interest shall be cast aside.
> You shall look and listen to the welfare
> of the whole people and have always in view,
> not only the present but the coming generations-
> the unborn of the future nation.
> ~Dekawidah, Cherokee. (Jean, 2003, p. 111)

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Although there are research efforts to understand and address the health status and social conditions for health disparities, the results do not always mirror the voices of the minority group being studied (Perilla, Wilson, Wold & Spencer, 1998). Research needs to be based on the meaning of health and illness from participants' perspectives and the research should be developed in partnership with the communities being studied. Researchers need to approach Native American communities from the paradigm of community-as-partner. It is essential that the researcher and tribal community establish relationships to co-create a course of action. With supportive collaboration from the researcher, the tribe should set the research agenda and desired outcomes.

Using a model such as community-based participatory research, interventions that are created by the community help increase cultural relevance and community buy-in (Warne, 2006). There are two main components of community-based participatory research: community participation and community empowerment. This research approach can help the community create change from within by using group values and norms to influence behavioral patterns and gain a sense of ownership over any planned changes (Pender, Murdaugh & Parsons, 2006).

In community-based participatory research, the researcher is a resource, but community members are co-researchers rather than just participants. Any critical decisions are made by the community and tribal leaders (Kaye & Wolff, 2002). Community-based participatory research is often used for health promotion and behavioral modification interventional studies. The tribal community actively drives the research process to insure that interventions are based on the tribal worldviews and indigenous ways of knowing (Getty, 2010). Using this research method, the emphasis

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should be on community development and increasing community capacity via improved services, education, prevention, and information sharing.

This research approach also helps to focus on community assets and strengths, rather than deficits and problems. An empowered community is established by open dialogue, mutual trust, and engagement by community members working together to create social change (Olshansky, 2008). Social change is necessary to address health disparities within the context of the local community and tribe and this occurs by engaging community members in the change process. An empowered community sets the course of its own destiny by creating a space for community voices to be heard (Racher & Annis, 2007). Health professionals and researchers have an obligation to work with communities to address health disparities through engagement and strength-building for a healthier living environment.

Challenges of the community-partner research models include territorial battles, competition, poor communication, failure to implement the plan, insensitivity or dominance by the researcher (Kaye & Wolfe, 2002). Other barriers may include failure of the community to participate because of historical stigma associated with past research efforts, issues of ownership and publication of results, and concerns over data misinterpretation (Dickson & Green, 2001; Struthers, Lauderdale, Nichols, Tom-Orme & Strickland, 2005)

Implications for Healthcare Practice

> Give yourself completely to the act of listening.
> Beyond the sounds there is something greater:
> A sacredness that cannot be understood through thought.
> (Tolle, 2009, p. 26)

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Too often, as health care professionals, we engage with our patients on a cognitive level but never connect with them on a heart level, so our patients are left feeling unsatisfied with their care. We provide care rather than are caring. Communication is the foundation of a therapeutic relationship and yet we have far to go in providing culturally sensitive care. This study highlighted the need to improve cross-cultural communication between healthcare providers and Native American clients. The terminology of many medical school curricula in the 1990s was patient-centered care but, in reality, it was carried out through a western medical model and so little has improved in patient-provider relationships (Stein, Frankel & Krupat, 2005). A different approach is needed and should be tested for cross-cultural applicability. Two models that may have potential benefit for improving cross-cultural clinician-client relations are the Four Habits by Frankel and Stein (2001) and Relationship-based Care model by Koloroutis (2004). The Four Habits is simple, easy to remember, and based on appreciative inquiry. It uses a positive approach rather than problem-based orientation to address a client's health concerns. Relationship-based care also uses appreciative inquiry, but targets transforming health care organizations to create caring, healing environments with clients and their family at its core. Both are grounded in empirical research and evidence-based practice (Gulbrandsen et al., 2008; Stein et al., 2005; Watson, 2004). Both suggest that relationships are what matters most in the health care.

The foundation of relationship-based care is creating meaningful interconnections with patients, families, and colleagues. The relationship-based care model shifts from providing care to being a caring provider. Caring behaviors are identified as being gentle, treating one with respect, and listening. In addition, knowing that someone in the

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organization is coordinating care and communicating the plan with the patient or family also is viewed as caring by patients (Koloroutis, 2004). The goal of this model is to create a caring healing environment and transformative leaders to facilitate teamwork at all levels of the organization.

When practitioners are caring for patients, they need to commit to creating a caring, healing relationship with patients. This premise is grounded in Jean Watson's nursing theory of transpersonal caring and emphasizes the interconnectedness between caregiver and recipient of care. The only way to truly connect is through elevating levels of consciousness in our patient-provider interactions via self-reflection and self-awareness: "We must be responsible for knowing ourselves and own an intentional way of being with patients and their families" (Felgen, 2004, p. 31). The benefit of relationship-based care is that it promotes holistic healing and not just health care. As Koloroutis (2004) explained, "True healers provide the space by embodying caring as individual; we provide that space in behaviors that demonstrate caring; we provide that space by our deliberate creation of a physical environment that promotes healing...that supports and promotes relationships" (p. 249).

Providing a healing environment within a healthcare organization addresses the need to change the climate and culture of healthcare delivery and sets the tone for positive clinician-client interactions. There is still a need to address patient-provider relations and flawed communication. Efforts to improve communication are required on several levels to improve cultural sensitivity and to create meaningful, respectful, healthcare interactions between caregivers and recipients. Trust and communication provide the underpinnings for positive interactions and are needed to create a healing

presence and between the provider and patient. When this occurs, barriers break down and relationships start (Struthers & Lowe, 2003).

Frankel and Stein (2001) observed that, on average, patients are interrupted by their physician after 18 seconds into the appointment. Healthcare providers have a tendency to jump into the patient's story with a solution to the problem. This behavior misuses the provider's power by taking the patient's problem-solving abilities away and leaves the patient feeling disempowered (Koerner, 2003). The Four Habits (Stein et al., 2005) method could be used to improve patient-provider relations. The Four Habits are based on appreciative inquiry, adult learning pedagogy, and behavioral modification (motivational interviewing) theory. Appreciative inquiry focuses on strengths, virtues, and solutions, rather than deficits, failures and problems (Kowalski, 2008).

The Four Habits are specific communication skills for use in clinical interactions. The four steps are: 1) invest in the beginning, 2) draw out the patient's story, 3) show empathy, and 4) invest in the end. Habit one is used to quickly establish rapport, build trust and hear the patient's concerns. It is used to make a plan for the patient visit. Step 2 is used to bring forth more information from the patient. Do they have ideas or specific requests for treatment? How is the problem affecting their life? Questions are framed in a positive regard. Such as: "What needs to be done? How do you feel about this? What can I do to support you? What key results are you seeking? Can you remember what has worked well for this kind of situation in the past" (Stein et al., 2005)? The next phase is to respond with empathy using both verbal and non-verbal cues as appropriate. Habit four includes developing a plan for treatment in terms of the patient's original concern, summarizing, explaining, and educating. In this patient-centered approach to healthcare

interactions, the patient is empowered to be a partner in care planning and decision making.

The Four Habits were developed and tested in the Kaiser Permanente healthcare system throughout California in both inpatient and outpatient settings. Positive feedback was received from both providers and patients (Stein et al., 2005).The Four Habits has also been tested in several Western Europe countries with great success. Despite initial concerns by physicians that it would increase the length of the patient visits, the opposite occurred and interactions were more meaningful for both the clinician and patient. In addition, patients reported greater overall satisfaction with their visit (Gulbrandsen et al., 2008). It is interesting to note how the four habits follow the basic principles of complexity science: minimum specificity, feedback loops, and interconnectedness between the parts. The success of the Four Habits is attributed to the use of only a few basic rules (habits) and emphasizing building a relationship between the patient and provider. This approach helps establish safe relationships, but also supports the need to address cultural competence and improved cross-cultural care.

Implications for Nursing Education

> Much has been said of the want
> of what you term "civilization" among the Indians.
> Many proposals have been made to adopt your laws,
> your religion, your manners, and your customs.
> We would be better pleased with beholding
> the good effects of these doctrines
> in your own practices, than with hearing you talk about them.
> You say, "Why do not the Indians till the ground and live as we do?"
> May we not ask with equal propriety,
> "Why do not the white people hunt and live as we do?"
> ~Old Tassel, Cherokee. (Jean, 2003, p. 141)

As supporters for social justice in healthcare and advocates for patients, nurses have long been concerned about the healthcare needs of the underserved. Nurses have served as their voice when they went unheard. Health care professionals need to understand cultural perspectives about health and illness in order to provide the best care to members of different cultural groups (Leininger, 1991). Cultural competence, as mandated by the Joint Commission on Accreditation of Healthcare Organizations (Spector, 2004), requires personalized care based on an individual's cultural, ethnic, or religious background; therefore it is essential to understand the person's unique perspective of being-in-the-world (Finch, 2004). This is particularly true when helping patients manage the complexities of day to day living with a chronic illness like diabetes.

The challenge is that there is no uniform definition of cultural competence and some argue that being "culturally competent" leads to stereotyping. Cultural competence assumes that an individual has gained knowledge about another culture, but this cultural awareness does not always translate into culturally appropriate care from the recipient's perspective. Munoz, DoBroka, and Mohammed (2009) define cultural competence as "a developmental and dynamic process that involves integrating knowledge with awareness of diverse human experiences to increase the quality of cultural engagement among those preparing for leadership and service in a diverse society" (p. 496). However, does gaining knowledge about another culture through courses on multiculturalism, and diversity training just perpetuate the problem of stereotyping racial and ethnic groups? If we teach cultural competence in nursing curricula, should we then also teach antiracism? The paradox is that learning about marginalization from a cultural perspective challenges us to also recognize the opposing side–that of white privilege. As a healthcare profession,

we need to explore the sociopolitical inequities experienced by people outside the societal norms and the influence of the dominant culture on such inequities (Yonas et al., 2006).

There is much discourse in the nursing curricula literature about whether cultural competence or integration of antiracist pedagogy would go far enough to illuminate and eliminate racial biases and ethnocentrism (Drevdahl, 2001; Eliason, 1998; Niemonen, 2007). Tervalon and Murray-Garcia (1998) pointed out that "the concept of cultural competence gives the nurse a sense of expertise that actually stereotypes the patient's experience" (p.119). The issue is pervasive throughout nursing practice and research. In an analysis of the ten most commonly used instruments to measure cultural competence, Kumas-Tan et al., (2007) concluded that many instruments oversimplify race and ethnicity and fail to include other marginalized or subordinated groups. Several nurse scholars (Johnston & Herzig, 2006; Juarez et al., 2006; Racher & Annis, 2007; Tervalon & Murray-Garcia, 1998; Yonas et al., 2006) challenge the notion of cultural competence and suggest the concepts of cultural humility or cultural safety are more appropriate.

Cultural humility refers to a life-long process of self-reflection and critique (Yonas et al., 2006). Cultural humility is patient-centered and demonstrates to the patient that the practitioner does not just make assumptions, but values the patient's perspectives (Tervalon & Murray-Garcia, 1998). This helps create meaningful and respectful relationships between the patient and clinician.

Cultural competency originates from the provider's point of view, but cultural safety was developed from the context of the aboriginal populations in New Zealand and Australia (Nguyen, 2008). The model of cultural safety was developed by the New Zealand Nursing Commission (Spence, 2005). Cultural safety is defined by the recipients

of care, rather than by the healthcare providers (De & Richardson, 2007). Using an

approach similar to cultural humility, thoughtful learning and critical reflections at

individual, interpersonal, and institutional levels were necessary to create cultural safe

environments. In contrast, culturally unsafe care was considered any practice that reduced

or degraded the cultural heritage or welfare of an individual (Spence, 2005). As a

profession, we are challenged to create new educational approaches to safer, more

compassion cross-cultural nursing care. The following poem by Spence (2001) addresses

the need to shift our approach to cross-cultural nursing care:

> *Towards Right*
> I know 'it' and yet I don't, I am learning all the time.
> It is nursing that you need. But your view, is it the same as mine?
> I know some of what I think you need but does it fit with you?
> Is there more you wish to tell or have I made you blue?
> I want to help. I have these skills. I need your guidance please.
> I don't want to get it wrong. I want to meet your needs.
> Will 'they' help? Do 'they' care" Is there time to ask?
> Is there information on how best to do this task?
> If we work together,
> I think that we might come to know our differences
> and be on the way to 'right.' (p. 105)

Study Limitations

Past culturally biased research methods have hampered our ability to understand

racial health disparities and our ability to develop effective interventions to reduce these

disparities (Johnson & Smith, 2002). As a white woman researcher in the Schitsu'umsh

world, I cannot fully represent their experiences of living with diabetes because I am still

an outsider. I have family members who are members of the Siletz tribe, so I have some

personal experiences with the Native American culture. I have made concerted efforts to

understand the Schitsu'umsh experiences of diabetes within the context of their tribal

culture by participating in language classes, attending cultural events, and developing community-as-partner relationships between the Benewah Medical Center and nursing students in my community health clinical group.

The results of this study are not transferable due to the sampling methods used in this study. In addition, the participants in this study represent only one tribe's experiences of living with diabetes and should be not be generalized to all Native American tribes as the sample is drawn from one tribe and these members may not be representative of the experiences of living with diabetes in other tribes. In addition, the participants' stories occurred in the context of one researcher-participant relationship that cannot be replicated. A different researcher might elicit different stories. By using a phenomenological methodology, more than one interpretation is possible through constant immersion and revealing of new understandings. There is always bias with this research methodology because the researcher cannot bracket off assumptions. My assumptions are a part of how I am in the world and they influence my interpretations.

There was some perceived credibility of the findings, especially in regards to communication barriers, when I presented a research poster of my pilot study at the American Association of Diabetes Educators annual conference (August 2009). During the poster reception, both Native and non-native attendees acknowledged that my findings were congruent with their experiences in various Indian Health Service clinics, but all asked "what do we do about it."Although this was confirming, it was a call for action as well. There is a need to partner with tribes to develop diabetes prevention and intervention programs that are culturally grounded and validated by additional studies.

Educational approaches need to shift so they include tribal values and tribal members as trainers and facilitators.

There were repeated concerns by the participants in this study about the youth and the consistent lack of interest in their diabetes care. The theme of being inattentively caring was particularly strong as parents and grandparents told of their children and grandchildren's struggles with diabetes. Future research studies need to focus on the tribal youth. Additional effort is needed to address diabetes prevention during the formative years. In addition, as programs are developed, studies need to be conducted on the effectiveness of these culturally-based diabetes interventions.

Summary

This study provides a new understanding of the day-to-day challenges Native Americans face when living with diabetes. Findings can help tribes plan and evaluate their current programs and develop new strategies for providing culturally relevant diabetes education and self-management programs. As the Coeur d'Alene tribe plans ahead for their future possibilities, they will be challenged to overcome adversities from the past and present. Moving forward will help instill hope and a renewed sense of perseverance to overcome the barriers they may face as they work toward improving the health of their people for today and future generations. All the Schitsu'umsh people play important roles in restoring balance and wellness to their nation and ours.

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Young, T. K. (1996). Recent changes in Native American population. In G. D. Sandifur, R. R. Rindfuss & B. Cohen (Eds.), *Changing numbers, changing needs: American Indian demography and public health* (pp. 53-75). Washington DC: National Academy Press.

Young, V. (2002). Pieces of time. *Nursing Philosophy, 3*, 90-103.

Zuckerman, S., Haley, J., Roubideaux, Y., & Lillie-Blanton, M. (2004). Health service access, use, and insurance coverage among American Indians/Alaska Natives and whites: What role does Indian Health Services play? *American Journal of Public Health, 94*(1), 53-59.

CURRICULUM VITAE

Jane A. Tiedt

EDUCATION:

Undergraduate:	Nursing: University of Iowa	B.S.N.	1983
Graduate:	Nursing: Gonzaga University	M.S.N.	1994
	Nursing: Indiana University	Ph.D.	2010

ACADEMIC APPOINTMENTS:

Lecturer	Gonzaga University, Spokane WA Department of Nursing	2004-present
Adjunct Faculty	Gonzaga University, Spokane, WA Department of Nursing	1999-2004
Community Liaison	Gonzaga University, Spokane, WA Department of Nursing Part-time	1996-2004

PROFESSIONAL EXPERIENCE:

Diabetes Educator Supplemental	Community Health Education and Resources, Spokane, WA	2006-2008
Continuous Care RN Supplemental	Hospice of Spokane Spokane, WA	2004-2006
Diabetes Educator/ Case Manager	Sacred Heart Medical Center Spokane, WA	1999-2004
Staff Nurse Cardiac ICU	Sacred Heart Medical Center Spokane, WA	1989-1999
Staff Nurse Neonatal ICU	Sacred Heart Medical Center Spokane, WA	1986-1989
Staff Nurse Intermediate Nursery/NICU	University of Iowa Hospitals and Clinics Iowa City, IA	1983-1986

CERTIFICATION AND LICENSURE:

- Certified Diabetes Educator
- American Heart Association: BLS Health Care Provider
- Licensure, Registered Nurse, Washington
- Licensure, Registered Nurse, Idaho

PROFESSIONAL ORGANIZATIONS:
- American Public Health Association
- Sigma Theta Tau International Honor Society of Nursing, Delta Chi Chapter
- Midwest Nursing Research Society
- Transcultural Nursing Society
- American Association of Diabetes Educators
- Washington Associate of Diabetes Educators

PROFESSIONAL SERVICE:

NIP-IT National Advisory Board	
(Nursing Initiative Promoting Immunization Training)	2009- present
Board of Directors	
Washington Association of Diabetes Educators	2008-2009
Annual Meeting Chair	
Washington Association of Diabetes Educators	2009
Eastern Washington Diabetes Collaborative	2008-present
O.C. Olson Diabetes Center, Advisory Board	1999-present
Planning Committee	
Annual City-wide "Pride in Nursing Conference"	2004-2006
Planning Committee – "Diabetes the All American epidemic"	
Regional diabetes conference for health professionals	2005
End of Life taskforce, Sacred Heart Medical Center	2003-2004
Program coordinator	
City-wide diabetes conference- professional update	2003
Program coordinator	
City-wide diabetes conference – professional update	2002
Program coordinator	
4-day regional workshop on Dying with Dignity	2001
Planning Committee	
Northwest regional parish nurse conference	2000
Member – City-wide diabetes taskforce	1999-2004
Chairperson	
Hospital-wide diabetes improvement committee	1999-2004
CEARP Reviewer and Committee member	
Washington State Nurses Association	1998-2000
CICU Research committee	
Sacred Heart Medical Center	1993-1995
Education planning committee	
Inland Empire Nurses Association	1992-1994
Legislative committee	
Inland Empire Nurses Association	1991-1992
Recruitment and retention committee	
Sacred Heart Medical Center	1991-1992
Critical care family needs taskforce	
Sacred Heart Medical Center	1991-1992

CICU Unit Organizational Committee
  Sacred Heart Medical Center   1990-1994
Hospital-wide charting taskforce
  Sacred Heart Medical Center   1987-1988
NICU Primary care taskforce
  University of Iowa Hospitals   1985-1986
Staff Nurse Council
  University of Iowa Hospitals   1985-1986

UNIVERSITY SERVICE:
  Gonzaga University
    Service Learning Advisory Board   2007-present
    University Committee on Academic Standing   2006-present
  Department of Nursing, Gonzaga University
    Faculty Affairs Council   2009-present
    Leadership Council   2009-2010
    Community Building Council, Chair   2006-2010
    BSN Strategic Planning Team   2005
    BSN Implementation Team   2005

COMMUNITY SERVICE:
  Volunteer, Cheney Middle School 7th grade field trip chaperone   May 2009
  Volunteer, KHQ/Coeur d'Alene tribe booth, at Diabetes Day   March 2009
  Salnave Elementary School, 5th grade camp out, camp nurse   May 2008
  Salnave Elementary School, 5th grade camp out, counselor   May 2007
  Liberia diabetes Assessment project, United Methodist church   2007-2009
  Cub Scouts, Chinook District day camp, camp nurse volunteer   July 2006
  Cub Scouts, Assistant den leader, Pack 356, Cheney, WA   2005-2006
  Cub Scouts, Pack Awards Chairperson, Pack 356, Cheney, WA   2004-2005
  Parish Nurse, St. Rose of Lima Catholic Church, Cheney, WA   1999-2001

PAPERS/SPEECHES/PRESENTATIONS:
  Presentation: 4th Annual on the Edge: Nursing in the age of   July 2010
                 Complexity Conference, Spokane, WA.
                 Oral presentation with Dale Abendroth, Lindsey
                 Perez, and Heidi Sedra.
                 "Integrating Complexity Science into Nursing
                 Curricula." (Peer-reviewed)

  Presentation: Sigma Theta Tau International 40th Biennial   Nov. 2009
                 Convention, Indianapolis, IN.
                 "A cross-cultural perspective of living with
                  diabetes Implications for culturally sensitive
                 healthcare." (Peer –reviewed)

Presentation:	36th Annual Professional Nursing Education And Development Conference, Rochester, MN. "Reframing Nursing Education and Practice Using Complexity Science." (Peer-reviewed)	October 2009
Presentation:	International Conference on Communication in In Healthcare, Miami, FL. Oral presentation with Mary Isaacson, RN, PhD "Research in Native American Communities: Promoting cross-cultural communication and Community partnerships." (Peer-reviewed)	October 2009
Poster:	American Association of Diabetes Educators Annual Meeting, Atlanta, GA. "Flawed cross-cultural communication: Native American perspectives on diabetes self-management." (Peer-reviewed)	August 2009
Presentation:	City-wide diabetes education program. Spokane, WA and via telehealth to six Rural hospital sites. (Invited)	May 2006
Panel Member:	Regional Diabetes Professional Update Spokane, WA. "Diabetes – The All American Epidemic – Ask the experts." (Invited)	Nov. 2005
Presentation:	American Association of Diabetes Educators Annual Meeting, Washington DC. "Improving hospital-wide diabetes care using The CQI process." (Peer-reviewed)	August 2005
Poster:	American Association of Diabetes Educators Annual Meeting, Salt Lake City, UT. "The effectiveness of a pediatric inpatient education program." (Peer-reviewed)	August 2003
Article:	Sacred Heart Medical Center, Spokane, WA Women's Wellness Newsletter (Invited) "Are you at risk for developing Diabetes?"	Nov. 2002
Presentation	Sacred Heart Medical Center, Spokane, WA Food and Nutrition Clinical Staff (Invited) "Update on Oral Medications in Diabetes"	May 2002

Presentation	Sacred Heart Medical Center, Spokane, WA Washington Assoc. of Diabetes Educators Diabetes Update Conference. "Diabetes is a Juggling Act – Tips on Patient Education." (Invited)	March 2002
Presentation:	Sacred Heart Medical Center, Spokane, WA Pediatric Core Curriculum Training "Diabetes in Children." (Invited)	Feb. 2002
Presentation:	Deaconess Medical Center, Spokane, WA "Diabetes management in the pediatric patient." (Invited)	May 2001
Presentation:	Sacred Heart Medical Center, Spokane, WA 5N Skills Fair: "Update on Diabetes and Oral Medications." (Invited)	July 2000
Presentation:	Sacred Heart Medical Center, Spokane, WA "Care of the long-term critical care patient." (Invited)	Oct. 1994
Panel Member:	Inland Empire Critical Care Nurses Assoc. Fall Symposium, Spokane, WA. (Invited) "Care of the long-term critically ill patient."	Oct. 1992
Presentation:	Sacred Heart Medical Center, Spokane, WA NICU Staff: "Charting with a jury in mind."	July 1992
Presentation:	Sacred Heart Medical Center, Spokane, WA NICU Staff: "Legalities of Documentation"	July 1988
Presentation:	Sacred Heart Medical Center, Spokane, WA NICU Staff: "The CAIER Charting System"	Sept. 1988
Presentation:	University of Iowa Hospitals and Clinics Iowa City, IA. Pediatric Grand Rounds "Coping with the imperfect child"	Aug. 1985

RESEARCH EXPERIENCE:

- Diabetes Grant: "Improving Access to Diabetes Care in Liberia using Community-based primary health care and Train-the-Trainer Model" (Trainer/Consultant) – In collaboration with United Methodist Church Volunteers in Mission and Ganta United Methodist Hospital in Liberia – funded for $45,000, World Diabetes Foundation, 2009-2011.
- Service Learning Mini Grant: "Creating Community-Campus Partnerships for Community Health Promotion" – $700, Gonzaga University, 2009-2010.
- Pilot study for dissertation: "The Experience of Living with Type 2 diabetes from a Native American perspective" Indiana University, School of Nursing, December 2008.
- Research Grant Proposal: "The Native American Perspective of Living with Type 2 Diabetes" Joint application to the American Association of Diabetes Educators and Sigma Theta Tau International - $6000, submitted but not funded – October 2008.
- Educational Enhancement Grant: Indiana University, Graduate Student Organization – funded for $500, Summer 2008.
- Research Grant: "The experience of living with type 2 diabetes from a Native American perspective." Washington Association of Diabetes Educators, submitted and funded for $2000, May 2008.
- Research Grant: "The experience of living with type 2 diabetes from a Native American perspective." Delta Chi Chapter-at-large of Sigma Theta Tau, submitted and funded for $500, May 2008.
- Research Grant Proposal: "The impact of a parish nurse lead diabetes support group." Washington Association of Diabetes Educators. Submitted but not funded. April 2004.
- Research Grant Proposal: "Managing diabetes with multi-family group intervention." (Team member). National Institutes of Health, Submitted but not funded. February 2004.
- "Go the Distance" Developmental Grant to develop an on-line diabetes management course for the Department of Nursing. Gonzaga University, Funded for $1000, Fall 2001.
- Graduate Thesis: "Coping Styles and personality hardiness of critical care nurses working in reverse isolation." Gonzaga University, MSN program. August 1994.
- Data collector. SUMMIT CABG Study. Sacred Heart Medical Center. 1994-1996.

HONORS AND AWARDS:

- **William and Doris Rodie Dissertation Scholarship**   2009-2010
  Indiana University, School of Nursing
- **Graduate Student Nursing Research Proposal Fund**   2009-2010
  Indiana University, School of Nursing
- **Travel Fellowship**   2009-2010
  Indiana University, School of Nursing
- **Ruth Orem-Orgain Scholarship**   2009-2010
  Indiana University, School of Nursing
- **Michelle White Scholarship**   2009-2010
  Indiana University School of Nursing
- **Research Incentive Fellowship**   2008-2009
  Indiana University, School of Nursing
- **Promise of Nursing Regional Faculty Fellowship**   2008-2009
  (Washington Region)
  Foundation of the National Student Nurses Association
- **Florence Nightingale Scholarship**   2008-2009
  Indiana University, School of Nursing
- **Martha Akers Scholarship**   2008-2009
  Indiana University, School of Nursing
- **Michelle White Scholarship**   2007-2008
  Indiana University, School of Nursing
- **Florence Nightingale Scholarship**   2007-2008
  Indiana University, School of Nursing
- **Promise of Nursing Regional Faculty Fellowship**   2007-2008
  (Washington Region)
  Foundation of the National Student Nurses Association
- **Washington State Health Professions Scholarship**   2006-2009
- **AACN Membership Award**   1999
  Inland Empire Chapter:
  American Association of Critical Care Nurses
- **Graduate Assistantship**   Fall 1992
  Gonzaga University, Department of Nursing
- **Graduate Assistantship**   Spring 1993
  Gonzaga University, Department of Nursing
- **Inducted into Sigma Theta Tau**   Spring 1993
- International Honor Society for Nurses
- **Dean of Iowa Scholar**   1979

TEACHING ASSIGNMENTS:
Gonzaga University

Spring 2010	Course Title	Credits	Students
NURS 210	Growth and Development	3	25
NURS 466	Community and Populations as Clients	4	29
NURS 467	Practicum IV: Provider of Care	3	15

Fall 2009	Course Title	Credits	Students
NURS 210	Growth and Development	3	31
NURS 466	Community and Populations as Clients	4	17
NURS 467	Practicum IV: Providers of Care	3	9
NURS 632A	HSL Practicum II	2-3	4
NURS 354	Creating Healthy Work Environment	3	7

Summer 2009	Course Title	Credits	Students
NURS 631A	HSL Practicum I	1-2	4
NURS 632A	HSL Practicum II	2	1
NURS 633A	HSL Practicum III	2-3	3
NURS 552	Theoretical Foundations for Advanced Practice	3	12

Spring 2009	Course Title	Credits	Students
NURS 200	Practice of Complex Adaptive Systems (CAS)	3	20
NURS 210	Growth and Development	3	31
NURS 465	Professional Nursing Practice in CAS	3	30
NURS 467	Practicum IV: Provider of Care	3	6

Fall 2008	Course Title	Credits	Students
NURS 100	Nursing Perspectives	1	53
NURS 210	Growth and Development	3	36
NURS 350	Complexity within Healthcare Organizations	3	15
NURS 465	Professional Nursing Practice in CAS	3	13

Summer 2008	Course Title	Credits	Students
NURS 552	Theoretical Foundations for Advanced Practice	3	17
NURS 496	Client-based Health-care Delivery	2	1

Spring 2008	Course Title	Credits	Students
NURS 210	Growth and Development	3	19
NURS 350	Complexity of Healthcare Organizations	3	29
NURS 465	Professional Nursing Practice in CAS	3	37
NURS 468	Practicum V: Senior Capstone	3	20

Fall 2007	Course Title	Credits	Students
NURS 210	Growth and Development	3	31
NURS 310	Complexity of the Healthcare system	3	30
NURS 350	Complexity within healthcare organizations	3	13
NURS 495	Senior Capstone	3	2

Summer 2007	Course Title	Credits	Students
NURS 200	Practice in Complex Adaptive Systems	3	19
NURS 465	Professional Nursing Practice in CAS	3	17

Spring 2007	Course Title	Credits	Students
NURS 200	Practice in Complex Adaptive Systems	3	28
NURS 210	Growth and Development	3	24
NURS 310	Complexity of the Healthcare system	3	13
NURS 350	Complexity within healthcare organizations	3	36

Fall 2006	Course Title	Credits	Students
NURS 100	Nursing Perspectives	1	24
NURS 210	Growth and Development	3	27
NURS 310	Complexity of the Healthcare system	3	36

Spring 2006	Course Title	Credits	Students
NURS 210	Growth and Development	3	35
NURS 485/685	Diabetes Management	2-3	12

Fall 2005	Course Title	Credits	Students
NURS 100	Nursing Perspectives	1	11

Summer 2005	Course Title	Credits	Students
NURS 530	Dying with Dignity	2-3	10

Spring 2005	Course Title	Credits	Students
NURS 485/685	Diabetes Management	2-3	17

Fall 2004	Course Title	Credits	Students
NURS 100	Nursing Perspectives	1	27

Summer 2004	Course Title	Credits	Students
NURS 485/685	Diabetes Management	2-3	21

Spring 2004	Course Title	Credits	Students
NURS 499/690	Spirituality and Health	3	23

Fall 2003	Course Title	Credits	Students
NURS 100	Nursing Perspectives	1	44

Fall 2002	Course Title	Credits	Students
NURS 100	Nursing Perspectives	1	34

Summer 2002	Course Title	Credits	Students
NURS 485/685	Diabetes Management	2-3	14

Fall 2001	Course Title	Credits	Students
NURS 100	Nursing Perspectives	1	25