

THE LIVED EXPERIENCE OF TYPE 2 DIABETES IN URBAN-BASED  
AMERICAN INDIAN ADOLESCENTS

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Lisa Martin  
Strong Hearted Women,  
Eagle Women

**Dedication**

To Emma,  
Lady of the Birds

## Abstract

This qualitative nursing research study used a hermeneutic phenomenological perspective to discover meaning in urban-based American Indian adolescents' experiences living with Type 2 diabetes. The aim of this study was to understand what it meant for urban-based American Indian adolescents to live with and experience Type 2 diabetes. The study used phenomenologic unstructured interviews to describe and represent the adolescent's voice and experiences of living with the disease in an urban community.

The study was guided by Max Van Manen's methodology for phenomenological research. This method entailed turning to the phenomenon of interest, then, inquiring and investigating the experience as it was lived rather than as it was conceptualized. The study reflected and analyzed essential themes that characterized the phenomenon of living with Type 2 diabetes and presented the phenomenon through the art of writing and re-writing.

Data collection involved in-depth, in-person interviews with analysis of the resulting transcripts. Adolescents in this study described connections with the American Indian culture, past and present family members, and the pragmatic details of living each day with the disease. Essential themes of the adolescents' experiences were found in the lifeworld areas of relationality and temporality, followed by incidental themes in the areas of corporeality and spatiality.

The study findings illuminated the participants' personal meanings and validated the phenomenological research process. A preliminary conceptual model based on the lifeworld categories for understanding adolescents' experiences was proposed and had implications for education, research, and practice, supporting continued inquiry.

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## **CHAPTER I**

### **Aim of the Study**

The goal of this study was to understand what it meant for urban-based American Indian adolescents to live with and experience Type 2 diabetes. Descriptions of adolescents' experiences were explored through individual, face-to-face interviews eliciting in-depth recollections and descriptions on the impact of the disease in their lives. Max van Manen's (van Manen, 1997) approach for hermeneutic phenomenological inquiry was used to explore the adolescent's experiences and used towards text analyses and to guide interpretation.

The participants highlighted contributions from surrounding social groups, family, and the urban community, to their lived experiences. Hermeneutic phenomenology brought forth the adolescents' stories in their own words on events in their lives, contributions from social supports, and how they were living with the disease. The study discovered adolescents' personal meanings in living with Type 2 diabetes and the results were presented through statements on the essence of the adolescents' experiences in living with the disease in an urban community.

Chapter one provides a review of the study topic, the justification for the study, and why further understanding in this area is greatly needed. The hermeneutic phenomenological method and the reason for its use in this study are described. The assumptions, personal experiences, and reflections of the researcher are presented.

### **Specific Aims**

The purpose of this research study was to understand the lived-experience of five urban-based American Indian adolescents living with Type 2 diabetes. The specific aims of the study were: 1) to describe the lived experience of American Indian adolescents with Type 2 diabetes living in Minneapolis/St. Paul, Minnesota, and, 2) to understand the role of family and community for urban-based American Indian adolescents living with Type 2 diabetes.

### **The Phenomenon of Interest**

The phenomenon of interest for this study was the lived experience of urban-based American Indian adolescents with Type 2 diabetes in Minneapolis/St. Paul, Minnesota. The researcher sought to foster greater understanding through discovery of essential themes evolved from the adolescents' personal experiences in living with the disease.

### **Type 2 diabetes in US Adolescents**

In order to understand the need for research on the phenomenon it is helpful here to summarize what is currently known on the status of Type 2 diabetes in adolescents and American Indians in the United States (US). Type 2 diabetes (previously known as type II diabetes mellitus, non-insulin-dependent diabetes mellitus, or adult-onset diabetes mellitus) develops most frequently in older adults and accounts for 90 – 95% of all diagnosed cases of diabetes worldwide (American Diabetes Association [ADA], 2008). Type 2 diabetes has been known to develop within the period of middle and late adulthood, however, several sources now report the downward trend in the age of

diagnosis and in the onset of diabetic symptoms (American Diabetes Association, 2005; National Diabetes Education Program, 2008; Indian Health Service [IHS], 2007; Acton, 2002; Centers for Disease Control and Prevention [CDC] National Center for Chronic Disease Prevention and Health Promotion, 2005). While true population-based prevalence data are not yet available, statistics do show an increasing prevalence of diagnosed diabetes especially among young people less than 20 years of age in the US. This is seen in up to 45% of recently diagnosed cases of Type 2 diabetes were among young people less than 20 years of age (Acton, 2002, CDC National Center for Chronic Disease Prevention and Health Promotion, 2005).

In addition, sources report the downward trend in age of diagnosis and early onset particularly among American Indian youth (American Academy of Pediatrics and the American Diabetes Association, 2004; Fagot-Campagna, 2001). The Federal Indian Health Service reports an increase in the prevalence of Type 2 diabetes in American Indian young people between 1990 and 2002 in the following age groups: (a) 132% prevalence rise for 25-34 year-olds, (b) 69% rise for 20-24 years-olds, and (c) 106% rise for those aged 15-19 years (IHS, 2007). The IHS indicates that the diagnosis of Type 2 diabetes in American Indian youth corresponds with (a) onset of puberty, (b) a family history of Type 2 diabetes, (c) exposure to diabetes in utero, (d) female gender, and (e) symptoms of insulin resistance, obesity, physical inactivity, and diet change (Fagot-Campagna, 2001). Considering the health status for American Indian adolescents has been lower than that of the majority adolescent population in the US for decades and lower than all racial and ethnic populations combined in this country, these developing

trends are greatly disturbing (Blum, 1992; Davis, 2003; Division of Adolescent Health and Medicine in the Department of Pediatrics, 1992; Inouye, 1993).

New cases of Type 2 diabetes are being reported in all adolescents and this is becoming an area in health care that is rapidly changing. US adolescents who are African American, American Indian, Asian and Pacific Islander American, and Hispanic/Latino American are at the highest risk for developing Type 2 diabetes. The American Diabetes Association (2005) has developed standards of health care to serve young people with this disease and the National Diabetes Education Program (2008) maintains an overview on the most current literature on the topic.

Type 2 diabetes is a disease characterized by abnormally high levels of glucose in the blood resulting from the inability of the body's supply of insulin to be effective in regulation. Type 2 diabetes is a chronic disease associated with serious complications and premature death, yet those living with diabetes can make changes to control the disease and lower the chance of developing complications. The increased prevalence of Type 2 diabetes in greater numbers of adolescents in the US often co-occurs with overweight, obesity, and inactivity.

Type 2 diabetes is typically preceded by a condition of insulin resistance, where the body requires increased production of insulin by the pancreas in order to control high blood glucose levels. The pancreas responds by producing increasing amounts of insulin, but, over time the organ fatigues and insulin production decreases causing ineffective regulation of blood glucose at normal levels. It is at this point that symptoms of pre-diabetes and insulin resistance appear. Signs of insulin resistance include hypertension,



acanthosis nigricans (a condition where skin around the neck or in the axilla appears dark and thick, and feels velvety to touch) and dyslipidemia, an elevation of lipids in the blood, often due to diet and lifestyle. Those who develop Type 2 diabetes can experience fatigue, nausea, intense thirst, and the need to frequently urinate. Other symptoms may be weight loss, blurred vision, frequent infections, and slow healing of wounds or sores. Symptoms specific to adolescent girls include vaginal yeast infections or burning on urination due to yeast infection, polycystic ovary syndrome with infrequent or absent menstrual periods, excess hair, and acne. Some adolescents may present with extremely high levels of blood glucose (i.e. some may exceed 800 mg/dl, where 70-110 mg/dl is considered normal), dehydration, and possible diabetic coma. In contrast, some adolescents may be asymptomatic at the onset of the disease.

Risk factors for the disease are overweight, a family member who has Type 2 diabetes, being a member of a high risk racial or ethnic group for the disease, having symptoms of insulin resistance, older than 10 years of age, and experiencing puberty. Adolescents with Type 2 diabetes are at risk for long-term complications of the disease (Appendix B) and other disorders associated with insulin resistance, such as lipid abnormalities and hypertension (Bennett, 1999).

Type 2 diabetes develops slowly in adolescents and it is important for health care providers to screen, identify, and test those who are at risk for the disease. Timely diagnosis and treatment can prevent or delay the onset of the disease and diabetes complications. The foundation of disease management for adolescents is healthy eating, and increased physical activity. Adolescents with Type 2 diabetes may also need to take

oral glucose-lowering medications or insulin injections to control their diabetes, however, few of the available diabetes medications have been approved for use with adolescents.

To address prevention and treatment of Type 2 diabetes in adolescents, collaboration of health care providers, school personnel, community members, community organizations, and government agencies is vital (United States Department of Health and Human Services - Indian Health Service, 2005).

### **Urban Influence on American Indian Adolescents with Type 2 Diabetes**

Consideration of relevant history towards urban living and mobilization is important in order to understand the American Indian adolescent's experience living with Type 2 diabetes. Patterns of residency for American Indians have favored large urban areas and such patterns may be traced to the history between American Indian people and the US government. The relationship began in the early 1900's, characterized by cultural oppression with consistent attempts at annihilation to the American Indian way of life. Historical perspectives documenting this period in US history reveal a direct link with US policy to the devastating social, economic, and health conditions American Indians face today. The policy agenda with American Indians has continued, profoundly impacting subsequent generations living on reservations and in urban American Indian communities. The most recent US census data shows 61% of the approximately 4.1 million American Indians/Alaska Natives are now residents of urban areas (Castor, 2006; The Commonwealth Report, 2004; United States Census Bureau, 2002; United States Department of the Interior, 2006). The census data also reflects the need for economic

opportunity and stability for American Indians on reservations and in rural communities, to address high levels of poverty occurring there.

A common condition in the lives of American Indian adolescents is frequent mobility and re-location. Many American Indian adolescents, as a lifestyle, move between the reservation and an urban community. Frequent geographic transitions play a prominent role in the life of American Indian adolescents living in urban areas and contribute to the social, economic, and environmental stressors that challenge normal adolescent development. Life stressors increase the likelihood of poorer health outcomes (Schulz, 2006) and the ability to successfully manage health needs. Understanding urban-based American Indian adolescents' daily experiences is important towards informing researchers and health providers on, (a) how adolescents live with Type 2 diabetes, (b) how their experiences may contribute to a higher prevalence of the disease, and (c) solutions towards prevention of the disease in current and future generations. Included in the present study were adolescents between the ages of 12-19 years, living with Type 2 diabetes for at least six months, who resided in an urban community.

### **Healthcare Available to American Indian Adolescents**

The Indian Health Service is a federally-funded branch of the Department of Health and Human Services. It came into existence through treaty negotiations in the 1800's between leaders of Indian Nations and the US government in order to provide health care and services in exchange for land. The IHS currently has the responsibility for the delivery of health services to federally-recognized American Indian and Alaska Natives (AI/AN) through a system of IHS, tribal, and urban (IHS/T/U or I/T/U) located

facilities and programs. The existence of the I/T/U has been outlined in past treaties, judicial determinations, and Acts of Congress (Senate Committee on Indian Affairs, 2000).

American Indian health facilities that comprise the I/T/U provide general health care services for eligible American Indians in the US. Each type of facility may not offer identical services; and some services may be available only at certain facilities. Usually available services may include, but are not limited to: emergency health care, dental, immunizations, primary care, behavioral health care, and, children's health care (About American Indian Health Providers, n.d.). The I/T/U facilities and programs are considered "pre-paid" with the land ceded by American Indian tribes in greater than 800 treaties and presidential executive orders. Therefore, tribal members using I/T/U health programs are not charged for services (The Urban Institute, 2005). In terms of providing adolescent-specific health care, the IHS is not fully funded by the federal government to fulfill its mission. Therefore, age-specific diabetic health care and coordination that are needed to support an adolescent with Type 2 diabetes may not exist in all areas. In addition, diabetes-specific health care becomes even more challenging to obtain and maintain when the adolescent is frequently mobile or re-locating.

Over successive generations, the I/T/U organizations continue to develop the capacity to serve traditionally medically-underserved communities of AI/AN in the US and are considered essential health care providers by the communities they serve (National Native American AIDS Prevention Center, 2011). Many facilities provide health care in the most remote locations in the US, where without such programs,

services would not be available. Furthermore, the unique cultural background of American Indian people require providers in the I/T/U network to understand the language, community norms, unique health needs, and how to incorporate traditional American Indian healing, ceremonies, and practices in all areas of health care.

### **The Specific Context of the Study Phenomenon**

The specific challenges of urban-based American Indian adolescents living with Type 2 diabetes supported a research approach that allowed exploration and description of the adolescents' experiences and inclusive of their perspectives. The analysis, patterns, and themes of the experiences portrayed in the study interviews, revealed supporting social and family structures. Through this research approach understanding could be gained to direction future research and programmatic efforts.

A convenience sample of five urban adolescent participants was identified through the researcher's contacts with American Indian families, community stakeholders, and through affiliations with urban American Indian organizations. The referral source assessed the interest and willingness of the adolescent and their parent/guardian to participate. The contact information for each adolescent willing to participant was provided to the researcher or the participant contacted the researcher directly.

A phenomenological interview was scheduled to occur at the location of the adolescent's choosing. The interview occurred in the same meeting where consent was provided to the participant and their parent/guardian. The interviews occurred in a time frame that allowed the researcher the opportunity to review a prior study interview, thus

obtaining familiarity with emerging themes of the phenomenon. The researcher's field notes on conversations with community contacts to learn more of the adolescent's availability comprised secondary data sources. Establishing a trusting relationship with the participant was of paramount importance for a successful one-time interview. American Indian families and stakeholders were in the position of gate-keeping for the adolescent, allowing the interview to take place after study information had been portrayed to the adolescent through contacts they knew and trusted.

At the completion of the interview, the audio-tape was transcribed verbatim and a second meeting was scheduled with the participant to review the resulting written transcript for accuracy and to allow for questions. After this meeting, the participant was given a \$25.00 gift card in recognition for their contributions and time volunteered towards the study. Some participants expressed appreciation for being interviewed.

### **Researcher Assumptions and Perceptions**

Explication of the researcher's assumptions and perceptions are an important step in qualitative research in order to distinguish the worldview of the researcher from the worldview of the study participant. Explication of the researcher's perspectives were held and regarded separately, in order for the researcher to be more fully conscious and present with the participant as they recalled their experiences. In so doing, the researcher was better prepared to listen for and identify the phenomenon, the lived experience, from the participant's perspectives and point of view. At the same time the researcher carefully considered the study aims and progress towards the aims, in order to achieve clarity from the findings.

**Assumptions of the Researcher**

1. Urban-based American Indian adolescents have similar experiences related to living with Type 2 diabetes.
2. Living with Type 2 diabetes in an urban area is distinct from the experience of living with the disease in a reservation or tribal community.
3. Social and economic realities affect the urban-based adolescent's experiences in living with Type 2 diabetes.
4. The unstructured phenomenological interview can provide valid, vivid, and useful recollections of everyday life with Type 2 diabetes.
5. The opportunity to interview provides the adolescent the opportunity to reflect on their experiences and can contribute to development and growth.

**Perceptions of the Researcher**

The researcher's background as an American Indian from a Northern Plains Ojibwe tribe brought supporting knowledge to the study in American Indian history, culture, and traditions. This background also brought a cultural understanding to the recruitment process and to the experiences presented by each participant. The researcher's life experience contributed to making important connections with referral sources, community forums, and in reaching participants and their parents/guardians. The researcher's background contributed to the likelihood for a successful one-time interview for the group of adolescents who participated.

As a member of a federally-recognized tribal community, the researcher has a lifetime of personal history with American Indian culture. One aspect of this history is

the researcher's experience with life on a reservation. Another aspect of the researcher's history is knowledge of the spiritual traditions and beliefs of American Indian culture, the center of the American Indian lifeworld that continues to define Indian people through centuries of poverty and oppression in the US. Knowledge on American Indian spirituality and its effect on health is an infrequent topic in the scientific literature, yet, it is the center of American Indian culture and survival over time. Typically, this knowledge has been passed through generations via storytelling, or an oral history shared between generations. The researcher's knowledge and personal experience of American Indian spirituality contributed to belief of hope for the future of American Indian adolescents, and visualization of cultural strength in the midst of poverty, oppression, and declining health statistics. The researcher was influenced by knowledge on low health status and dire outcomes that portray the health of the American Indian adolescent today, and by an affirmative life belief system and world view that adolescents can embrace a better future.

The researcher's professional experience as a public health nurse and in management and administration of public health programs also contributed towards a belief in adolescent resilience, adolescent potential, and the value of including the youth voice in the creation of programs for youth. This experience included working with adolescents interested in developing their future and participating in their health care despite challenging circumstances.



## **Phenomenology as a Research Method and Justification for its Potential**

Hermeneutic phenomenology is a qualitative research method originating with the existential philosophies of Husserl, Heidegger, and Merleau-Ponty. As a research method, phenomenology strives to assist the participant in discovering the meaning and essence of their experience through unstructured recollection and discussion of their life experiences. The researcher assisted the participant in the study interviews with question prompts as needed, to recall specifics of their experiences. The participant began and ended the interview as desired and the length of the interview was as short or as long as desired. The phenomenological interview is different than social conversation or a therapeutic intervention in that the participant is reminded that they are in control of what they said and what they do not say. The researcher listened to the experiences and prompted greater detail as the participant could remember.

The phenomenological interview provided the researcher with examples of how adolescents experienced life with this disease within an urban community. The interview data brought forward stories from the adolescents and created a rare glimpse to the experiences that are part of the phenomenon of urban-based American Indian adolescents living with Type 2 diabetes.

### **Summary**

The aim of this study was to understand what it meant for urban-based American Indian adolescents to live with and experience Type 2 diabetes. The rationale for the study was supported by the fact that Type 2 diabetes, an adult form of the diabetes, is now increasingly found in American Indian youth. Generally, what is currently available

in the scientific literature on Type 2 diabetes in American Indian adolescents does not include the youth voice or expression of their experiences in living with the disease.

The selection of hermeneutic phenomenology as the qualitative method and justification for its potential was included. The researcher disclosed assumptions, personal, and professional experience, and perspectives, as a key step in preparing study results for the phenomenological analyses. This chapter also included a discussion on connecting the world of the researcher to the world of the participants in the study.

### **Overview of Chapters**

To assist the reader with further understanding of the research study and phases of implementation, a chapter summary is provided.

Chapter 2 discusses in detail the rationale for the study and the development of the study from historical, conceptual, and philosophical contexts. A focused literature review surveying the last 20 years of knowledge development as well as analysis, identification of strengths and limitations of the literature, and recommendations for further research is provided.

Chapter 3 includes an introduction to hermeneutic phenomenology as a research method, its general background, rationale for use, and anticipated outcome. Max van Manen's phenomenological method is presented. The chapter introduces an application of van Manen's method to the study. Specific details include a description on the purpose of the method, the sample, data collection, reliability and validity, human subjects, along with strengths and limitations.

Chapter 4 presents the findings of the study and how the essential themes encompassed the essence of the meaning representing the adolescents' experiences. Findings from the data were integrated into thematic statements representing the adolescents' experiences. The statements were applied to van Manen's four lifeworld categories to spotlight the essence of the youth voice and to validate the method.

Chapter 5 contains a discussion of the findings, the significance and limitations, along with implications and relevance for nursing education, research, and practice.

## CHAPTER II

### Evolution of the Study

#### Introduction

This chapter presents the rationale and the development of the study from historical, conceptual, and philosophical contexts. A focused literature review surveyed the last 20 years of knowledge on the topic area as well as an analysis, identification of strengths, limitations, and recommendations for further research.

#### Historical Context

Whereas there is a growing understanding of the complexities of factors contributing to early onset of Type 2 diabetes and the disease course, research has had little to offer in terms of insights into the daily experiences of American Indian young people who must live with the disease (Joe, 1994). It is this researcher's viewpoint that future research efforts related to Type 2 diabetes in American Indian adolescents must consider the complex origins and development of the disease in order to understand its growing prevalence in American Indian youth today. Therefore, to understand the study phenomenon, it is important to include a review on American Indian history in the US, to appreciate the historical contributions to the present time. A historical perspective can illuminate specific factors impacting American Indian youth today and can be used for consideration in future research and prevention efforts in this area.

Prior to World War II, diabetes was not a topic of concern for American Indians and chronic disease like Type 2 diabetes was rare or non-existent (Dixon & Roubideaux, 2001). It is this researcher's belief that events contributing to the recent development of

Type 2 diabetes in American Indian youth date back to the early 1880s, the beginning of the US assimilation policy era with colonization of the US by early European settlers.

The goal of the European colonization period was to acquire greater and greater amounts of North American territory - territory previously home to American Indians. In order to accomplish acquisition of the desired land, American Indians and their way of life were viewed as an obstacle.

From the first encounter of Columbus and the early colonists with American Indians in North America profound differences in worldview were clear. The term *worldview* originates from the German word *weltanschauung*. In German, *wel* is world and *anschauung* is view or outlook. Worldview is a concept fundamental to German philosophy and epistemology, and refers to a wide-world perception (Husserl, 1970). The term is selected in reference to this study for its broad appeal and its inclusiveness of individual, community, and global perspectives. An individual's worldview is comprised of a framework of ideas and beliefs through which they interpret the world and interact with it. Individuals construct a worldview; where others can see a worldview operating at a community or systems level, or from the subconscious realm (van Manen, 1997).

The relationship between the predominant worldview of American society and the worldview of American Indians has been referred to in numerous ways. In health care and nursing literature, worldview of the predominant American society is often referred to a "western" or "linear" view, where that of the American Indian has been called "relational" or "holistic" (Plumbo, 1995). Table 1 reviews and compares key characteristics of each perspective.

*Table 1: A Comparison of Western and Relational Worldviews*

<b>Characteristics of the Western or Linear Worldview</b>	<b>Characteristics of the Relational or Holistic Worldview</b>
Based in Western European and American thought.	Based in tribal cultures.
Based on logic.	Includes sometimes illogical relationships.
Cause must occur before effect.	Obtaining balance between many factors in one's life.
Interventions are logically targeted to a symptom or cause.	Interventions utilize cyclical nature, spiritual forces, balance, and achieving harmony.

Shared aims between the western and relational worldviews are difficult to ascertain. Inherent in each view are opposing beliefs and priorities which have evolved to the present time with little to offer in terms of common ground. Each worldview is comprised of its own priorities and the differences lend insight to the struggling relationship between the US federal government and American Indian tribes that has existed from the first encounter with the early colonists through the present time.

For the past century, a predominant characteristic associated with American Indian life in this country is that of oppression. The experience of oppression is common to American Indians related to differences in worldview. In order to integrate differing worldviews, sharing and incorporating unique elements offered by the different disciplines and various systems of knowledge is necessary (Aerts, 1994). It is through worldview collaboration and integration that progress can be made.

Beginning in the early 1990's, assimilation became a focus of US policy in order to bring American Indians into a Western or linear worldview, Leclerc (2008) observed the following with assimilation policies that begin with the removal of cultural language:

A policy of assimilation is one that uses strong measures to accelerate the downsizing of one or more linguistic minority group(s). The ultimate goal of such policies is to foster national unity based on the idea that a single language in the country will favor that end. The measures taken to enforce such policies may include banning the social use of a given language, the exclusion and social de-valorization of a language group, and in extreme cases repression by force and even genocide (p.256).

In the earlier days of the colonists, in order to prevail over the vast American Indian population at that time, the US government pursued an approach of assimilation for expansion and territory acquisition. The goal was to re-mold the Indian's system of values into the mainstream society and ways of thinking (Scasz, 1999). In American history it was the early assimilation and displacement period that brought destruction to the American Indian population no less than genocidal in proportion. American Indians were forcibly removed from their lands and communities destroyed. Indians who lived through the removal were eventually displaced to distinct areas called reservations, a small fraction in size compared to the North American territory they had previously inhabited. With the influx of European life came disease, removal of Indian livelihood, language, and way of life. Reservations served as holding areas for tribal communities and often were places of intense suffering from poverty, starvation, and disease.

During this time, education for American Indians was considered essential to achieve assimilation policy objectives and off-reservation schooling, through use of the boarding school, was initiated. Off-reservation schooling resulted in removal of a

generation of American Indian children from their families without cultural support and often forbidding children from practicing the culture, language, and Indian way of life.

Key to the present study, in this period began the shift from the traditional American Indian diet to the modern diet, a diet of primarily processed, high fat, high carbohydrate foods (King, 1963). Today, the modern diet is considered a major contributor to the increasing levels of Type 2 diabetes among American Indian youth (King, G., 1963).

The oppression experienced by American Indians during this time continues into the present day. The devastating impact of the assimilation is revealed today in the lower health status and challenging life circumstances realized by American Indian youth. The health of the current generation of American Indian youth is in crises with poor health indicators, family break-up, and continued discrimination against the Indian way of life. All of these aspects continue to disproportionately affected American Indian youth. Conditions of poverty persist on reservations and many live without intact families or the opportunity to learn traditional beliefs that were historically the basis of healthy, functioning communities. Racism, discrimination, alienation, poverty, loss of natural resources, and the characterization of American Indians as victims comprise the environment of most American Indian adolescents today (Armstrong, 2002; Duran & Duran, 1995; Zitzow, 1990). These conditions must be recognized in current day approaches to diabetes health care if positive change is to be realized.

The history of oppression continues in US policy affiliated with the American Indian population today. For example, the IHS, the federal health care program with the sole mission to serve American Indians, has a long history of receiving inadequate



funding by the US government to meet the health needs of Indian people in the US (IHS Budget, 2009).

### **Philosophical Context of Oppression**

Because of the history of American Indians in the US, knowledge on the concept of oppression is applicable to the present study, American Indian adolescents, and the promotion of quality health care to this population. Oppression is a concept that has been described in multiple ways, but rarely studied conceptually as a sphere of influence through health care.

Oppression is a concept not unique to nursing and with broad applicability within nursing. Many areas of nursing research focus on the experiences of persons living with an alteration in health status, secondary to physical, psychological, or socially oppressive circumstances. Numerous acute and chronic health conditions can be associated with oppressive circumstances, such as mental illness, neglect, sexual abuse, physical abuse, delinquency, chemical dependency, parenting difficulties, cancer, and chronic illness. Interestingly, while nursing is the largest professional provider of health care in this country, it has also been portrayed as a profession that itself is oppressed, presenting characteristics associated with oppression such as horizontal violence and leadership elitism (Roberts, 1997; Roberts, 2000). Nurse leaders, nurse administrators and nurse executives in all health care settings respond regularly to issues affecting nursing practice that could be understood within an interpretation of oppression within the organizational setting. Within the nursing paradigms of health and caring, nurses promote well-being everyday to populations experiencing oppression. Understanding more on the concept of

oppression can have profound influence on the development of the nursing profession, including nursing theory, administration, research, education, and practice. It is this researcher's view that it is possible to develop specific nursing responses to individuals, communities, and populations who have experienced or are experiencing oppression.

### **Definition of Oppression**

Understanding humanization and dehumanization is fundamental to understanding oppression. Friere (1970) defined oppression as, "Any situation in which 'A' objectively exploits 'B' or hinders [their] pursuit of self-affirmation as a responsible person, is one of oppression.

To be familiar with humanization, one must first understand that while humans reflect their respective settings, they are beings in the world and with the world, and will make choices on what they are to be, to self-affirm their "being" (Friere, 1970).

"Humanization is an attempt to affirm human beings in this context as the subjects of all decision" (Friere, 1970, p. 43). "Once humanization is perceived, almost automatically, dehumanization is perceived" (p.43).

Oppression is initiated by those who choose to deny humanness by disengaging from moral or ethical ramifications of their actions. Friere viewed the initiation of oppressive circumstances when individuals, (a) fail to recognize their own humanness, (b) fail to recognize the need for humanization, and (c) fail to see others as human beings with human ambitions. In other words, oppression involves disengagement from being human as it is defined here, in order to pursue individualism. Individualism is a moral position, a political philosophy, or social outlook that stresses independence and self-

reliance. Individualism promotes attainment of one's goals and desires, while opposing most external interference upon one's choices, whether it is by society, or other group or institution. The term individualism is opposite to the term collectivism which stresses communal, community, group, societal, or national goals taking priority over the individual. Individualism is also opposed to tradition or other form of external moral standard used to influence an individual's choice of actions.

With the commencement of oppression, economic survival and social transformation are key to creating a world without oppression. Frere's (1970) definition referred to oppression as it is often presented to the oppressed as a false generosity to participate in their own dehumanization. "...such a situation in itself constitutes violence, even when sweetened with false generosity, because it interferes with the individual's ontological and historical vocation to become more fully human" (p.55). Oppression is paradoxical in nature in that it is the rebellion of the oppressed, or those who have not disengaged from humanness, that restores humanization and alleviates oppression.

One well-known example on a method of eliminating oppression can be seen in the political philosophy of Marxism. Theoretically, Marxism saw humanization through labor, and as a means to respond to dehumanization where humans struggle to affirm life and themselves as meaningful (Marxists Internet Archive Student's Section, [n.d.]). Marxism viewed workers in a capitalistic society alienated from their true selves as members of society and from nature. A Marxist solution for workers was to unite in labor unions and political parties, to take political and economic power back from the bourgeoisie. Marxism held the directive that collective self-liberation was the only true

liberation from oppression of the working class and called for a greater focus on social justice. Criticism of Marxist theory, which envisions a world order beyond race and class, is that it lacks an ethical or moral absolute, thus, justifying the treatment of individuals in by any means to achieve the theoretical end. (King, Martin Luther, Jr., 1963).

### **Literature Review on the Concept of Oppression**

In order to develop further understanding of oppression, exploration on the concept's philosophical origins, allied concepts, and a literature review were conducted. The goals of the literature review were, (a) to identify disciplines that have used the concept of oppression, and, (b) to create an organization schema for the purpose of concept evaluation and application to the present study.

#### **Initial Search Strategy**

The initial search strategy aimed at locating publications that included oppression as a key word from widely used database indexes. The results showed extensive availability of literature that included the concept of oppression. The initial search strategy produced a cumulative data set of 271,198 sources mapped to the keyword of oppression. This total occurred between the nineteenth century and 2004. While there was some overlap in database time periods the conclusion from the initial search was that literature from the disciplines of health, psychology, and social science incorporated the greatest number of references matching to the concept.

The initial literature search utilized several data base indices. *Academic Primer* was used as a general data index, one of the largest academic, multi-disciplinary databases providing full-text sources for near to 4,600 scholarly publications. The

database coverage spanned almost every area of academic study and offered information dating back to 1975 up until the present. The database is updated on a daily basis and was searched with the key word of oppression. Through the Academic Primer search there was identification of 2534 articles representing a variety of disciplines and perspectives.

The literature search continued in the *Cumulative Index to Nursing and Allied Health* (CINAHL) database which has a multidisciplinary scope covering nursing, 17 allied health disciplines, biomedicine, consumer health, health sciences librarianship and selected standards of professional practice. CINAHL provides a database covering 1982 through the present. In the keyword search, 104,570 articles were found, the most common sub-headings were students, post RN, violence, teaching methods, nursing homes, attitude to disability, nurses, disabled, nurse practitioners, oppressed group behavior, and education-post-RN.

Two additional databases were searched: *Civil War: A Newspaper Perspective* and *The Nineteenth Century Masterfile*. *Civil War: A Newspaper Perspective* provided coverage from November 1860 - April 1865 of major articles from the Charleston Mercury, The New York Herald, The Richmond Enquirer, and seven other newspapers of this time. *Civil War* identified 3126 sources. *Masterfile* was a digitized, enhancement and integration of every relevant index to the printed output of the nineteenth century. *Masterfile* identified 136 references. The database time coverage varied but results were primarily nineteenth century sources.

The *Ingenta* index identified 517 articles from table of contents pages of over 26,000 journals covering October 1988 through the present. The *Humanities & Social*

*Sciences Retrospective* searched nearly 1200 of the more recognized journals and found 116 articles. Searching in *Psychological Abstracts* produced subject headings such as: Blacks; Violence; Counseling; Lesbianism; Racism; Psychoanalysis; Racial and ethnic groups; Human sex differences; Sexual orientation; Employee interaction; Spirituality; Social identity; Minority groups; Bisexuality; Power.

Further searching of these subheadings revealed 161,710 articles tied to the keyword of oppression covering the time period of 1994 through the present. *The Social Sciences Citation Index* subheadings included: Social sciences; Anthropology; History; Industrial relations; Information science; Library science; Law; Linguistics; Philosophy; Psychology; Psychiatry; Political science; Public health; Social issues; Social work; Sociology; Substance abuse; Urban studies; Women's studies.

This search revealed 1159 articles, covering a time period from 1994 through the present.

### **Organization of the Data Set**

The literature search provided abundant numbers of sources on the definition of oppression, theoretical and philosophical backgrounds of the concept, characteristics of the concept, and allied concepts. With the wide array of subheadings and titles addressing the concept with the keyword search approach, a revised search strategy was used to conduct a refined search on more recent publications listing the concept in the publication title. While there was some overlap of coverage periods within the database search, overall, publications were most numerous between 1980 through the present time.

The next step was to review data sources in order to create an organization outline for the purpose of concept evaluation and application to the present study. A convenience sample of  $n=50$  was selected from abstracts and full-text articles published within a purposive time frame of 1960-2004. Table 2 provides a description of the topic categories observed in the sample publications and the number of references reviewed in each category.

*Table 2: Convenience Sample Topic Categories and Number of References for Each*

<b>Category</b>	<b># of Ref</b>	<b>Category</b>	<b># of Ref</b>
addiction	1	African, Sudan	4
anthropology	1	art	1
biblical, religion	1	Chile	1
disabilities	2	foreign affairs	1
Gay, Lesbians	1	Guatemalan	1
Hmong	1	Italy	3
medicine	1	Mexico	1
Middle East Affairs	5	Nazi Germany	1
nursing	5	preventive health services	1
politics	4	political science	1
psychology	2	research	1
social work, social work education	3	women/Feminist study/Feminist	7

\*( $N=271,198$ ;  $n= 50$ ; 1.84%; 1960-2004).

From the convenience sample, Paulo Freire's (1970) book on oppression emerged as a primary source on the concept. The book is internationally known and addresses a unique pedagogy and paradigmatic perspective on oppression. In this work, Freire addressed the concept's definition, theoretical and philosophical perspectives, and examples of educational approaches with groups living in oppression. Considering the

importance of Friere's work, a refined search was conducted in the CINAHL database, focusing on publications retrospectively between 2004 – 1970, the latter being the publication date of Friere's text. The purpose of the refined search was to identify sources inclusive of Friere's understanding of oppression, in nursing and related health science areas. The final data set was selected from publications sources in the search including oppression, or an allied concept, in the title signifying the importance of the concept to the article's content. This de-limiting factor was important to navigate the sizable return of 104,570 publications in the refined search.

An organizational outline emerged from reviewing publications in the convenience sample and the final data set. The organizational outline defined categories of literature as, (a) literature on the origination of oppression, (b) literature on the outcome of oppression, and (c) literature on the legacy of oppression. Table 3 presents the categories along with theoretical and philosophical perspectives found in the literature reviewed. Table 4 identifies citations of sources in the final data set (n=14).

*Table 3: Oppression Literature Categories and Philosophical Perspectives*

Origination of oppression	Critical social theory, Marxism.
Outcomes of oppression	Post-modernism, Neo-Marxism, Feminism Post- colonialism.
Legacy of oppression	Liberation philosophy, Emancipation theory, Cognitive dissonance theory.

*Table 4: Final Data Set from Literature on Oppression (n=14)*

Abrums, M. (2004). Faith and feminism: How African American women from a store-front church resist oppression in healthcare. <i>Advances in Nursing Science</i> , 27(3), 187-200.
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Cox, H. (1991). Verbal abuse nationwide, part 1: Oppressed group behavior. <i>Nursing Management</i> , 22(2), 32-35.
Dunn, H. (2003). Horizontal violence among nurses in the operating room. <i>The Association of Perioperative Registered Nurses</i> , 78(6), 977-980, 982, 984-988.
Hall, J. M. (1999). Marginalization revisited: Critical, postmodern, and liberation perspectives [global health and nursing practice]. <i>Advances in Nursing Science</i> , 22(2), 88-102.
Johnson P. S., & Johnson, J. A. (2001). The oppression of women in India. <i>Violence Against Women</i> , 7(9), 1051-1068.
Kirkham, S. R., & Anderson, J. M. (2002). Postcolonial nursing scholarship: From epistemology to method [critique and replication]. <i>Advances in Nursing Science</i> , 25(1), 1-17.
Leyva, Y. C. (2003). "There is great good in returning". <i>Frontiers: A Journal of Womens Studies</i> , 24 (2/3), 1-9.
Poupart, L. M. (2003). The familiar face of genocide: Internalized oppression among American Indians. <i>Hypatia</i> , 18(2), 86-100.
Roberts, S. J. (1996). Point of view. Breaking the cycle of oppression: Lessons for nurse practitioners? <i>Journal of the American Academy of Nurse Practitioners</i> , 8(5), 209-214.
Roberts, S. (1997). Nurse executives in the 1990s: Empowered or oppressed? <i>Nursing Administration Quarterly</i> , 22(1), 64-71.
Roberts, S. (2000). Development of a positive professional identity: Liberating oneself from the oppressor within [vulnerability and empowerment: part 1]. <i>Advances in Nursing Science</i> , 22(4), 71-82.
Stamm, B. H., Stamm, H. E., Hudnall, A. C., & Higson-Smith, C. (2004). Considering a theory of cultural trauma and loss. <i>Journal of Loss and Trauma</i> , 9(1), 89-111.
Struthers, R. (2003). Nursing in the Native American culture and historical trauma. <i>Issues in Mental Health Nursing</i> , 24(3), 257-272.
Wittmann-Price, R. A. (2004). Emancipation in decision making in women's health care. <i>Journal of Advanced Nursing</i> , 47(4), 437-445.

## **Findings of the Literature Review**

The concept of oppression was seen repetitively in religious, social, philosophical, feministic, and historical contexts. The basis for its use conceptually was not uniform. When examined further, most uses of the term itself and allied concepts incorporated references to history, loss, and grief. Legacy of oppression literature was qualitative in nature and focused on a variety of aspects of experience, described in combination with allied concepts.

### **Pre-Conditions of Oppression**

Individualism and objectivity are pre-conditions or antecedents to oppression and are represented and described in the literature. While pre-conditions of oppression were not consistently named nor associated with the concept, descriptions, stories, and metaphors describing pre-conditions of oppression were repeatedly seen in the available sources.

### **Concept Characteristics**

The concept of oppression was multidimensional and possessed characteristics in three categories: the origination of oppression, the outcome of oppression, and the legacy of oppression (Table 3). The actions and origination of conditions that commence oppression existed in the first category. Concept characterizations in other categories were non-linear and included unique representations on the lived-experience of oppression. In the second and third categories, the term was sometimes referred to in combination with allied concepts, which had similar meaning but are qualitatively

different. Literature addressing outcomes of oppression was abundant and included lengthy descriptions on lived-experience with the concept.

The concept of oppression was used and understood in everyday life, but distinguishing characteristics associated with the initiation of oppressive actions were rarely found in the literature. These characteristics were abstract enough to define the concept in more than one context, but not unique enough to differentiate the concept from allied concepts.

### **Origination of Oppression**

The primary focus of this category was in the creation of the circumstances that originate oppression. Literature reviewed showed allied concepts of *marginalization*, *peripheralization* or *periphery* were used in this category. The definition of marginalization referred to a process that relegates to a marginal position within a society or group, excluded from or existing outside the mainstream of society, a group, or a school of thought (Mirriam-Webster Online Dictionary, 2004). In exploring the definition of the root word *periphery*, peripheralization can be understood as the process of creating the outward bounds of something as distinguished from its internal regions or center, an area lying beyond defined limits (Mirriam-Webster Online Dictionary, 2004).

The primary focus of this category is in the creation of the circumstances that originate oppression. Allied concepts of marginalization and periphery were selected as they included this focus. The ideas inherent in critical social theory, Marxism, and the work of Jurgen Habermas could be viewed as the philosophical underpinnings and the lens of the literature in this stage. Adaptations of critical social theory and Marxism

(Fontana, 2004) are applicable to the initiation of oppression, where attention is on the pre-condition of individualism. In Marxism, the focus on elimination of dehumanization or disregard for workers and their contributions to society ultimately relates to exploitation of workers for individual economic gain (Marxists Internet Archive Student's Section, [n.d.]).

Fontana (2004) stated, "Western critical social theory has been most heavily influenced by the work of the critical theorists of the Frankfurt school, along with Jurgen Habermas and Paulo Freire" (p. 2). Jurgen Habermas, an advocate of networking and dialogue, developed an eclectic form of Marxism drawing on insights coming from a variety of directions. (Glossary of People, Habermas, [n.d.]). "For Habermas, research with a critical theory focus is needed to expose concealed domination and oppression. Such research would uncover and analyze hidden power structures and be committed to liberating change" (Fontana, 2004, p. 3).

### **Outcome of Oppression**

Literature in this category focused on the outcome or experiences of living in oppression. Several philosophical perspectives were represented, namely, post-modernism, post-structuralism, neo-Marxism, feminism, and post-colonialism. An assumption behind these perspectives was to reject governing or control viewpoints on the interpretation of the narrative experience. Importance was given to the intricacies of the individual's experience and power which is dynamic in nature.

Michael Foucault's post-structuralism philosophy applied widely to literature in this stage. Foucault examined the concepts and codes by which societies operate,

especially the principles of exclusion by which a society defines itself (Glossary of People, Foucault, [n.d.]). The focal points of Foucault's philosophy were discourse and power (Fontana, 2004). Foucault believed that societies control themselves by positing external rules (e.g., forbidden speech, regimes of truth, privileged access to education). The external rules restrict a system of discourse and aim at classifying, ordering, and distributing discursive materials so that no one will access the discursive space unless certain pre-requisites are met (Curry, 1997).

In this category, characteristics of the outcome and experience of oppression were observed. The outcome and experiences of living in oppression illuminated complexities in power, language, desire, and subjective experience. Several allied concepts were observed for this stage and each represented a unique perspective to the experience living with oppression. Allied concepts were *xenophobia*, *exteriority*, *patriarchal oppression*, *colonialism*, *exploitation*, *subjugation*, *colonial oppression*, and *deconstruction*. Table 5 provides definitions of the allied concepts. The outcome of oppression literature focused on the negativity of the experience, of being considered different from mainstream society, controlled in a variety of ways for interests not collectively valued. Literature addressing the outcomes of oppression was the largest representation in the search.

*Table 5: Allied Concepts Addressing the Outcomes of Oppression*

Xenophobia	Fear and hatred of strangers or foreigners or of anything that is strange or foreign. (Merriam-Webster Online Dictionary, 2004)
Exteriority	The quality or state of being on an outside surface, situated on the outside. (Merriam-Webster Online Dictionary, 2004)
Patriarchal Oppression	Social organization marked by the supremacy of the father in the clan or family, the legal dependence of wives and children,

	<p>and the reckoning of descent and inheritance in the male line. More broadly, it is the oppression that commences with the control by men with a disproportionately large share of power. (Merriam-Webster Online Dictionary, 2004)</p>
Colonialism	<p>Control by one power over a dependent area or people or a policy advocating or based on such control. Relating to a characteristic of a group of individuals or things with common characteristics or interests situated in close association; the section occupied by such a group. (Merriam-Webster Online Dictionary, 2004)</p>
Exploitation	<p>An act or instance to make productive use of, or to make use of, meanly or unjustly for one's own advantage. (Merriam-Webster Online Dictionary, 2004)</p>
Subjugation	<p>To bring under control and governance as a subject, or one that is placed under authority or control, and lives in the territory of, is protected and owes allegiance to a sovereign power or state; to make submissive. (Merriam-Webster Online Dictionary, 2004)</p>
Colonial Oppression	<p>The oppression that commences by the control of one power over a dependent area or people, relating to, the characteristics of the group of individuals or things with common characteristics or interests, situated in close association, the oppression created by occupation by such a group. (Merriam-Webster Online Dictionary, 2004)</p>
Deconstruction	<p>A method of literary criticism that assumes language refers only to itself rather than to an extra-textual reality, that asserts multiple conflicting interpretations of a text, and that bases such interpretations on the philosophical, political, or social implications of the use of language in the text rather than on the author's intention. (Merriam-Webster Online Dictionary, 2004)</p>

## Legacy of Oppression

The focus in this category was how the oppressive experience persisted over time. The literature included historical views of oppressive experiences that created a legacy of oppression through multiple generations. While similar to the stage on the outcomes of oppression, it was the transmission of oppression between human beings across generations that differentiated this category.

The focus in the literature was on overcoming, re-creation, renewal, survival, and creating a non-oppressed social order. Themes of hope, unification, and social activism were observed. There was a dichotomy of philosophical perspectives in this stage. Some literature supported perspectives of liberation and emancipation theories - forms of critical social theory. Few authors explained a theory of emancipation, although use of the phrase *theory of emancipation* was commonly used in this category. Freire (1970) supported emancipation theory as a resource to his pedagogy. One author, Milton Curry (1997) discussed the application of emancipation theory to social spaces and architecture and how workers construct spaces of resistance and liberation. Curry gave perspective to the theory of emancipation through description of a metaphor, "...a garret (i.e., a room in an unfinished part of the house), where emancipation is as a spatial void, detached, and isolated, surrounded by the solidity of the structures (i.e. oppression), where liberation is planned and enacted" (p.1).

Also present in this category was literature representing a social psychological perspective, cognitive dissonance. Harmon-Jones and Mills (n.d.) reviewed Festinger's theory of cognitive dissonance developed in 1957. Festinger's theory was one of the more

influential theories in social psychology and utilized several paradigms in dissonance research. Harmon-Jones and Mills explained:

Basically, the theory postulates that pairs of cognitions can be relevant or irrelevant to one another. If the cognitions are relevant, they are either consonant or dissonant. Two cognitions are consonant if one follows from the other, and they are dissonant if the obverse of one cognition follows from the other. The experience of dissonance, being psychologically uncomfortable, motivates the person to reduce dissonance and leads to avoidance of information likely to increase the dissonance. (p.1)

The dissonance research paradigm applied to this category of oppression literature was described as the *induced-compliance paradigm*. In the induced-compliance paradigm, the individual was induced or given incentive to decrease dissonant cognitions. Harmon-Jones & Mills (n.d.) described the dissonance experience commencing when an individual does or says something that is contrary to a prior belief or attitude. Based on the cognition of the prior belief or attitude, the individual usually does not engage in the behavior. However, "...with inducements to engage in the behavior, such as promises of reward or threats of punishment, cognitions become consonant with the behavior." (p.5)

The cognitive dissonance theory represented literature in this stage, and focused more on evolution of oppressive phenomenon between subsequent generations. In replication of oppression between generations, there was eventual adaptation to the oppressive reality and this redefined identity. In oppression, conformity is taught and repeated in subsequent generations. This occurs when a previous generation's beliefs evolve to include the oppressive phenomenon and oppression becomes a part of identity over time. Because of the ingrained nature of the oppression in this stage, liberation can be mistaken as the opportunity to become part of the system that oppresses. Allied



concepts were: *emancipation*, *empowerment*, *learned helplessness*, *historical trauma*, *cultural trauma*, and *hopelessness*. Each allied concept represented a unique perspective to the legacy of oppression. Table 6 represents definitions and comparisons of the allied concepts in this category.

*Table 6: Allied Concepts Found in the Legacy of Oppression*

Emancipation	To free from any controlling influence, such as traditional mores or beliefs. (Merriam-Webster Online Dictionary, 2004)
Liberation	The act of the state of being free, the power to do as one pleases, freedom from physical restraint, freedom from arbitrary or despotic control, the positive enjoyment of various social, political, or economic rights and privileges, the power of choice. (Merriam-Webster Online Dictionary, 2004)
Empowerment	The state of giving official authority or legal power to promote self-actualization. (Merriam-Webster Online Dictionary, 2004)
Learned Helplessness	This term is not in the dictionary. However, referring to dictionary definitions to “helplessness” and “learned” portions of the phrase, the combined terms refer to a gained knowledge or understanding of, or skill in, by study, instruction, or experience of an inability to act or react. (Merriam-Webster Online Dictionary, 2004)
Historical Trauma	This term is not in the dictionary. “Also referred to as post-colonial psychology, used specifically in the context of indigenous people of North American recognizing the psychological, physical, social and cultural aftermath of systematic subjugation. (Stamm et. al., 2003, p. 89)
Cultural Trauma	This term is not in the dictionary. “The past inhabits the present as a transmission of cultural memory; ... appears as a term in the work of different cultural groups and has unique meanings to each group.” (Stamm et al, 2003)

Hopelessness	Giving no ground for hope, desperate, incapable of solution, management, or accomplishment. (Merriam-Webster Online Dictionary, 2004)
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### **Relevance of the Findings to the Present Study**

Oppression is a concept present in many forms of literature since the nineteenth century and has relevance as a concept to nursing, health care, and to the present study. The concept of oppression in this review was found to be rooted in individualistic strategies to achieve economic gain. The experiences of oppression can be long-term, violent, and inhumane. How can oppressive circumstances be focused towards social justice? Future research towards the development of economic theory that retains the goals of humanization and social justice at the center may hold promise in answering this question.

### **Perceived Justification for Studying the Phenomenon**

There are few US health programs specific for American Indian adolescents living with Type 2 diabetes. In general, most health professionals do not understand the meaning diabetes has for American Indian people, are not aware that Type 2 diabetes is increasingly diagnosed in American Indian adolescents, and that there is great need for primary and preventive health care in this area. While research emerges, three important gaps in the literature related to urban American Indian youth living with Type 2 diabetes provided justification for the study:

- Despite advancing empirical and descriptive studies in the field of diabetes research, diagnosis rates in American Indians continue to be the highest of any population group in the world and this remains unexplained.
- Type 2 diabetes is the adult form of this disease now increasingly found within American Indian adolescents and this also remains unexplained.
- In addition, there is a gap in the extant literature on Type 2 diabetes in American Indian adolescents and what is known about adolescents' experiences in living with this disease.

The gaps in the literature support the need for the present research study and future research efforts to create understanding on the meaning of experiences of young people living with this disease within the American Indian community.

When Type 2 diabetes occurs earlier in life, the serious health complications associated with the disease may also be realized. (Appendix B). For example, in a southwestern US tribal community Pavkov (2006) found adolescents diagnosed with

Type 2 diabetes before the age of 20 had a substantially increased risk during middle-age adulthood for kidney failure requiring dialysis and a significantly higher rate of early death. Pavkov found there was a crucial need to learn more about the prevention of Type 2 diabetes in current and future generations of American Indian youth, as early diagnosis threatened to impact their productive years and longevity (IHS, 2007). More than ever before American Indian adolescents are being diagnosed with the adult form of this disease and without further research towards culturally appropriate prevention and intervention strategies, an increasing number of adolescents will likely deal with life-changing health complications as a result of early diagnosis. Today's lifestyle presents a stark contrast to the early 1900's, and diabetes prevalence rates have now soared in some geographic locations to over 50% in American Indian adults over the age of 35 years (Joe, 1994).

In response, research initiatives with American Indian communities are beginning to reveal new complexities and a broader scope of factors associated with this disease. Some of the factors include gender, age, diet, activity level, as well as genetic susceptibility related to American Indian ancestry, migratory patterns, the effects of modernization, as well as social and economic conditions. In the future, understanding what degree these factors contribute to the occurrence and management of the disease in young people will be necessary to create solutions toward disease prevention earlier in life. With continued research it is possible to discover new methods of prevention and disease management as the diagnosis occurs at earlier ages.

There are important areas for consideration to actualize the goals of Type 2 diabetes prevention in American Indian adolescents. One is prevention and treatment during adolescence is challenging due to the developmental milestones that are managed during this period of life. Grey (2005) found there is a common reluctance in adolescents to adhere to recommended diabetes treatment and management and adolescents are particularly vulnerable to poorer outcomes in diabetic metabolic control, because of the necessity for family involvement in daily disease management, or the potential for family conflict in this area (Grey, 2005; Rosenbloom, 1999). Two, is that many American Indian adolescents, their families, and cultural communities are geographically fragmented, absent, or not available for needed support. To address these challenges, research methodologies focused on the period of adolescence are needed to understand adolescent needs, how to incorporate the family environment (Grey, 2005), as well as American Indian adolescents' perspectives and experiences in living with Type 2 diabetes. Three, it is difficult to reverse obesity which often occurs concurrently with the diagnosis of Type 2 diabetes. Lastly, four, improving health care for American Indian adolescents requires health professionals to obtain specialized knowledge on American Indian culture, history, and the similarities and differences between tribes and their beliefs, values, and practices.

The most recent US census cannot provide a total number of American Indian adolescents between the ages of 12-19 years and therefore epidemiologic evidence of Type 2 diabetes using census data is an approximation of the true population occurrence. US census and IHS data include American Indian people from federally-recognized tribal

communities, but participation and representation from federally un-recognized tribal communities is unknown. Recognition of all tribal communities in the US, including those not registered with the Federal government, and a revision in the Federal definition of who is American with Indian heritage are policy changes needing consideration in order to include all tribes, and to bring health improvement to all American Indian adolescents (Bierman, 2002).

American Indian adolescents are mobile in society and therefore, use of health services is variable depending on the type of health insurance used, the status of the adolescent's residency, mobility between rural, reservation, and urban areas, the ability to afford co-payments, and family circumstances. In order to improve health care for American Indian adolescents living with this disease, effective clinical practice guidelines are needed that incorporate the unique circumstances of adolescents in urban areas who are mobile between different communities. This will also include recognition of the history between American Indian tribes and the US federal government and how this may influence lack of trust and American Indian participation seen in census counts, surveys, and healthcare.

As our society begins to encounter the full challenge of Type 2 diabetes appearing earlier in life, research is needed to understand adult versus adolescent disease experiences (American Diabetes Association, 2000; Bennett, 1999; Hannon, 2005; Pavkov, 2006). To improve health outcomes for American Indian young people, researchers and health professionals must develop effective ways to prevent and treat Type 2 diabetes in this population. In order to develop further knowledge about living

with Type 2 diabetes in urban communities, it is important to talk directly with American Indian adolescents to learn of their experiences and perspectives. Adolescents' experiences and stories of life with Type 2 diabetes in their own words can begin to assist in creating effective policy and funding mechanisms for culturally appropriate health care programs. These programs can then aim to lessen the impact of serious complications for adolescents diagnosed early in life.

### **Literature Review on Type 2 Diabetes in American Indian Adolescents**

The scope of the literature review included the last two decades of theoretical and data-based research addressing Type 2 diabetes in American Indian adolescents from the disciplines of medicine, nursing, and public health. A review of quantitative and qualitative scientific publications between 1986 and 2010 provided further justification for studying the phenomenon and for discovery on the essence of adolescents' experiences. Literature published outside of this time frame and from other disciplines was excluded, unless directly relevant to the phenomenon of interest, the lived experience of Type 2 diabetes in urban-based American Indian adolescents. There were two rationale for the literature review inclusion and exclusion criteria: (a) to obtain a sample of published primary literature that provided a comprehensive, multi-disciplinary presentation on the phenomenon, and (b) to be able to conduct a critical review on literature that described, explained, and directed future research in this area.

The initial search began with a keyword survey to identify the words to direct the literature search. From the keyword survey, three search categories were created to address the phenomenon of interest: (a) Type 2 diabetes, diabetes mellitus, non-insulin

dependent, (b) Native American or American Indian, urban, and (c) adolescence. These keywords were used in three strategies to initially identify primary sources, those that directly relate to the research question, and secondary sources, those with supporting information towards the research question.

The first strategy involved electronically identifying available literature addressing Type 2 diabetes in urban-based American Indian adolescents through four internet search engines: CINAHL, PubMed, Medscape, and The Native Health Database. The first strategy produced 24 sources. A second broader search strategy was used to electronically assess the identical search engines, with the addition of the MEDLINE database and the new keyword health disparities. The second strategy produced 10 sources. A third strategy was used to manually review reference sections of primary publications for other relevant sources.

The first search strategy yielded few published primary sources related to the phenomenon of interest. The returns from the second and third searches were also limited and yielded more secondary literature than primary sources, mainly in the areas of: (a) Type 2 diabetes in children, (b) Type 2 diabetes in all adolescents, and (c) health disparities with Type 2 diabetes. Secondary literature sources included descriptive and demographic reports that addressed a variety of socio-economic indicators in the American Indian population, such as insurance status, level of education, family, and economic status.

Eleven publications matched the inclusion criteria and represented the disciplines of medicine, public health, and epidemiology (Table 7). The publications were



categorized based on the primary focus: (a) Type 2 diabetes prevalence, (b) programmatic interventions, (c) epidemiological literature review and clinical guidance, and (d) perceptions of Type 2 diabetes.

*Table 7: Eleven Publications Matching the Search Inclusion Criteria*

1. Acton, K. J., Burrows, N. R., Moore, K., Querec, L., Geiss, L.S., & Engelgau, M. (2002). Trends in diabetes prevalence among American Indian and Alaska Native children, adolescents and young adults. <i>American Journal of Public Health</i> , 92(9), 1485-1490.
2. Dabelea, D., Hanson, R. L., Bennett, P. H., Roumain, J., Knowler, W. C., & Pettitt, D. J. (1998). Increasing prevalence of type 2 diabetes in American Indian children. <i>Diabetologia</i> , 41, 904-910.
3. Fagot-Campagna, A., Burrows, N. R., & Williamson, D. F. (1999). The public health epidemiology of Type 2 diabetes in children and adolescents: A case study of American Indian adolescents in the Southwestern United States. <i>Clinica Chimica Acta</i> , 286, 81-95.
4. Fagot-Campagna, A., Pettit, D. J., Engelgau, M. M., Burrows, N. R., Geiss, L. S., et. al. (2000). Type 2 diabetes among North American children and adolescents and epidemiologic review and a public health perspective. <i>Journal of Pediatrics</i> , 136(5), 664-672.
5. Fagot-Campagna, A., & Narayan, K. M. V. (2001). Type 2 diabetes in children; Exemplifies the growing problem of chronic disease. <i>British Medical Journal</i> , 322, 377- 378.
6. Harwell, T. S., McDowell, J. M., Moore, K., Fagot-Campagna, A., Helgerson, S., & Gohdes, D. (2001). Establishing surveillance for diabetes in American Indian youth. <i>Diabetes Care</i> , 24(6), 1029-1032.
7. Joe, J. R. (1994). The perceptions of American Indian adolescents with diabetes. In J.R. Joe & R.S. Young (Eds.), <i>Diabetes as a disease of civilization: The impact of culture change on indigenous peoples</i> (p. 329-356). Berlin: Mouton de Gruyer.
8. Lee, E. T., Begum, M., Wang, W., Blackett, P. R., Blevins, K. S., et. al. (2004). Type 2 diabetes and impaired fasting glucose in American Indians aged 5-40 years: The Cherokee study. <i>Annals of Epidemiology</i> , 14(9), 696-704.
9. Moore, K. R., Harwell, T. S, McDowall, J. M., Helgerson, S. D., Gohdes, D. (2003). Three-year prevalence and incidence of diabetes among American Indian youth in Montana and Wyoming, 1999-2001. <i>Journal of Pediatrics</i> , 143(3), 368-371.

10. National Indian & Inuit Community Health Representatives Organization (2000). *Type 2 diabetes mellitus in First Nation youth*. Retrieved September 19, 2002 from <http://www.nichro.com/CHild/child3.html>

11. Rosenbloom, A. L., Joe, J. R., Young, R. S., & Winter, W. E. (1999). Emerging epidemic of Type 2 diabetes in youth. *Diabetes Care*, 22(2), 345-354.

### **Type 2 Diabetes Prevalence**

Six (n= 6, 54.5%) of the primary publications examined trends in Type 2 diabetes prevalence among young American Indians and Alaska Natives. Three of the six publications utilized IHS outpatient and inpatient data. The IHS compiled data from its 12 area offices and facilities located in or near federally-recognized American Indian tribes throughout the US. Each area office and its facilities serve a number of different tribal communities. In three of the publications, patient data was accessed from IHS medical records that were associated with any of ten International Classification of Diseases, 9<sup>th</sup> revision, Clinical Modification (ICD-9) codes for diabetes (i.e., 250-250.9).

Of the three remaining prevalence publications region-specific methodology was used to estimate prevalence of Type 2 diabetes. Lee (2004) estimated prevalence in Cherokee tribal members between the ages of 5 and 40 years and Dabelea (1998) utilized a region-specific methodology to estimate the prevalence of Type 2 diabetes in youth from the Pima tribe in Gila River, Arizona. Lastly, Fagot-Campagna (1999) conducted a comparative prevalence analysis on Type 2 diabetes data between the Pima tribe and the Southwestern IHS service region of the US.

### **Programmatic Intervention**

One publication (n=1, 9%) focused on an evaluation of a program intervention used with American Indian adolescents attending a Zuni Pueblo tribal high school in New Mexico and living with Type 2 diabetes (Johnson, 2003). This school-based intervention used a multiple cross-sectional design to evaluate outcome measures at 0, 1.5, and 3 years compared to an Anglo-American comparison group. The Zuni high school diabetes prevention program included an educational component targeting decreased consumption of sugared beverages, knowledge of diabetes risk factors, and a youth-oriented fitness center. The conclusion was among at-risk youth, an environmentally-based lifestyle intervention may significantly suppress markers of Type 2 diabetes risk.

### **Epidemiologic Literature and Clinical Guidance**

In addition to literature addressing disease prevalence and programmatic approaches, Fagot-Campagna (2000) conducted an epidemiologic literature review from 1997 to 1999 via the internet search engine MEDLINE and Gahagan (2003) provided clinical guidance for pediatric health practitioners providing care to children with Type 2 diabetes, with a special emphasis on American Indian and Alaskan Natives. Both sources verified that Type 2 diabetes in children has been recognized as a potential public health problem in North America as obesity is currently on the rise in several industrialized countries. A similar increase in Type 2 diabetes in children may soon emerge worldwide, requiring preventative measures (Fagot-Campagna, 2000).

It was estimated that Type 2 diabetes represents up to 45% of patients diagnosed in large US pediatric centers; however, this is likely to be an underestimation and

incidence is probably rising. The young patients diagnosed with Type 2 diabetes in the US were generally overweight, had a strong family history of Type 2 diabetes and often had signs of insulin resistance. The majority belonged to ethnic groups at high risk for Type 2 diabetes. More girls than boys were diagnosed. Follow-up data available suggest a high prevalence of microvascular and macrovascular complications among young adults who developed Type 2 diabetes during childhood. Several interventions have proved effective in preventing diabetes complications among adults, and evaluation of these interventions in children with Type 2 diabetes is urgently needed. It is expected that clinical trials using behavioral and treatment interventions for children with diabetes will soon be developed (Fagot-Campagna (2000), Gahagan (2003)).

Finally, results of research efforts in primary prevention of Type 2 diabetes for adults and youth soon will be available. The increasing amount of evidence will challenge current treatment guidelines and ultimately improve the health of children living with Type 2 diabetes over the lifespan (Gahagan 2003).

### **Perceptions of Type 2 Diabetes**

Two publications (n=2, 18.2%) addressed perceptions of Type 2 diabetes from the viewpoint of American Indian adolescents. In the first publication, Joe (1994) conducted research with adolescent residents of four Southwestern reservations (i.e., the Apache, the Yaquie, the Navajo, and the Pima) who were participating in a summer youth program on their reservation. Joe (1994) found, "... despite their cultural perceptions, experiential background and emotional status, American Indian youth

remained, in general, confused and uninformed about the actual causes, treatment and complications of Type 2 diabetes” (Joe, 1994, p.352).

In the second publication, The National Indian & Inuit Community Health Representatives Organization [NIICHO] website Introduction (2000) created web-based descriptive summaries on the status of Type 2 diabetes in First Nations aboriginal youth from Manitoba, Saskatchewan, and Northwestern Ontario, Canada. NIICHO studies have shown that Aboriginal youth identify the importance of knowing their traditions and history and want to learn how to sustain their culture and language as a means of strengthening well-being. According to the Aboriginal youth perspective in the 1996 Royal Commission on Aboriginal Peoples Report (RCAP) several key points were developed for programs that work for Aboriginal youth with Type 2 diabetes (NIICHO Introduction, 2000).

### **Theoretical Framework**

A majority of the publications (i.e. n=10, 91% ) did not describe theoretical frameworks, theoretical perspectives, conceptual frameworks or the application of theory in knowledge development addressing Type 2 diabetes in urban-based American Indian adolescents. One publication discussed the future development of conceptual understanding in this area. Joe (1994) included a discussion of concepts relevant to measuring the perceptions of Type 2 diabetes by American Indian adolescents. Joe reviewed research from several investigators, including, Piaget’s (1930) theory of cognitive development, Radius’s (1980) findings on the establishment of adolescent health perceptions and beliefs by age 12, and, the health belief model (Janz, 1984). Janz

supported use of explanatory models in future diabetes research stating, “When all of the respondents emerge from a similar socio-cultural situation, a tri-level explanatory system could be used to synthesize culture, social-cognitive and emotional factors” (Janz, 1984, p.351).

**An American Indian cultural framework.** At this time, limited models and theory exist that can guide cross-cultural healthcare with American Indian adolescents. A cultural framework would be meaningful to the profession of nursing as cultural competency and proficiency are necessary in a world of multiple worldviews (Leininger, 1995). In order to appreciate what was different in the relational/holistic worldview for the American Indian adolescent participant in the present study, it was recognized that within every culture, a unique approach exists that is used to define health, wellness, illness, and death. It was also recognized that with over 500 American Indian tribes in the US, each has its’ own culture, life beliefs, and tribal characteristics that vary greatly and with the degree of assimilation to the Western worldview. Therefore, each tribe is unique, but similar, and there is a strong cultural connection that exists between all American Indians and tribes.

American Indian culture utilizes a relational/holistic worldview that is experienced in a circular manner, and based on the five characteristics of spirituality - relationship, unity, honor, balance, and healing (Struthers, 1999). Struthers interviewed American Indian nurses to describe what they found in their own nursing practice with American Indian clients. Nurses identified components of the five characteristics of spirituality; relationship, unity, honor, balance, and destiny.

On the characteristic of relationship, nurses named components including touching, learning, and utilizing traditions. For example, the art of touching someone has spiritual power. Relationship would include learning from community and traditions across generations, such as with ancestors from a past time, elders in the present time, or being a mother to the next generation for a future time. Relationship is also valued with other living entities, such as animals and birds. Nurses found in the characteristic of relationship there was recognition of unity and oneness (Struthers, 1999).

Transcending boundaries and pursuing oneness were components named representing the characteristic of unity (Struthers, 1999). The characteristic of honor included the components of appreciation and respect: For example, it is considered an honor to be present at birth and at death. Components of the characteristic of balance involved sensing destiny, centering with Mother Earth, and the care for self. The characteristic of healing include gifting, praying, and resonating with the Great Spirit or the Great Mystery. Lastly, American Indian nurses were overall comfortable with paradox, the role of destiny in their lives, and their relationship with the Great Mystery, (Struthers, 1999). From these descriptions, Struthers created a cultural framework that represented the relational/holistic worldview and could be used to guide culturally competent nursing practice with American Indian populations.

## **Methods Used in the Publications**

Descriptive and exploratory research designs were used in all of the 11 publications reviewed. Various sampling and analysis approaches were used, for example, most of the publications (n=6, 54%) aimed to establish and measure disease prevalence. Two studies (Joe, 1994; Justice, 1994) and a web-based summary (NIICHR0, Youth and Diabetes, 2000) discussed traditional American Indian cultural components, community involvement, and family presence to influence the experiences of American Indian youth living with Type 2 diabetes. In the non-prevalence based publication, Joe utilized a qualitative constant comparative analysis method to analyze narrative data obtained from a true-false questionnaire administered to a convenience sample of American Indian adolescents. The analysis was descriptive in nature and resulted in, "...useful information and insights about knowledge, beliefs, and understanding of diabetes in a sample of American Indian youth from a Southwest that could be used as a guide for diabetes education programs" (Joe, 1994, p. 332).

The website of The First Nations Canadian tribal community recommended standards for programmatic approaches for adolescents living with Type 2 diabetes (NIICHR0, Type 2 diabetes mellitus in First Nation youth, 2000) and emphasized youth and community involvement and the inclusion of tribal traditions. As a result, The First Nations tribal communities have supported successful programs throughout Canada that have addressed the growing number of First Nations adolescents with Type 2 diabetes. Similar recommendations in planning, programmatic approaches, and



interventions specifically for American Indian adolescents were not found in other areas of this review of two decades of theoretical and data-based literature published in the US.

**Prevalence publications: methods and results.** Cross-sectional designs (n=6, 54%) were used to estimate the prevalence of American Indian youth with Type 2 diabetes in specific US geographic and tribal populations (Table 8). The publications utilized descriptive and inferential statistical analyses to interpret findings as seen in mean, median, percentage, and chi square tests. Two studies analyzed data for the risk status of American Indian youth developing Type 2 diabetes in the future. Overall, the prevalence of Type 2 diabetes varied in the publications from 4.1 per 1000 in 12 to 19 year old to 50.9 per 1000 in 15 to 19 year olds in youth specifically from the Pima tribe in Arizona (Fagot-Campagna, 2001).

The variance in prevalence rates represented different sample inclusion criteria between publications, namely, different geographic locations, time frames, and age-ranges. Prevalence was examined in 7 general regions of the IHS, including Alaska, the Great Lakes, the Northern Plains, the Pacific, the Southeast, the Southern Plains, and the Southwest. With the exception of the Pima study, these regions did not explore prevalence in individual tribal communities. Computational formulas for determining prevalence rates varied based on these differences in geographic location, time frame, and age-range.

All the publications reviewed referred to the challenge of differential diagnoses between Type 2 diabetes and Type 1 diabetes in children and adolescents. This challenge was a primary consideration in determining eligibility criteria for sample inclusion.

Harwell (2001) and Moore (2003) used similar sample inclusion criteria including the IHS geographic region sampled, time frame, and age-range. Despite use of common criteria, these authors found prevalence rates of 2.4/1000 and 1.1/1000 respectively. Acton (2002) and Lee (2004) were similar in the inclusion of adults in their samples (i.e., 0-35 and 5-40 years of age) and these authors found adolescent-specific prevalence rates of 5.4/1000 and 1.3/1000 respectively. Dabelea (1998) and Fagot-Campagna (2000) sampled adolescents in a similar age range of 15 – 19 years, over a broad time frame (i.e., 30 and 10 years respectively), specific only in a Southwestern US region with resulting rates of 5.31/1000 and 4.5/1000 respectively.

Overall, sample inclusion criteria, population versus regional sampling techniques, and sampling time frames varied between the publications with a wide range of prevalence rates reported from 0.46/1000 to 5.31/1000. The highest rates for Type 2 diabetes in American Indian adolescents were found in a prevalence analysis conducted across seven IHS regions (Acton, 2002) with a prevalence rate for adolescents 15-19 years of age at 5.4/1000 as well as the analysis for American Indian adolescents with the Pima tribe of the Gila River Indian Community in Arizona (Dabelea, 1998) with a prevalence rate for adolescent girls at 5.31/1000. Two publications (Harwell, 2001; Moore, 2003) utilized the same area-specific IHS data in similar timeframes, 1997-1999 and 1997-2001. Harwell (2001) and Moore (2003) focused their analyses in the Billings, Montana IHS service region outpatient and inpatient data, representing federally recognized tribal communities in the states of Montana and Wyoming. Acton (2002)

used IHS outpatient data in seven geographic areas including the Billings Area within the time frame of 1990 -1998.

Despite the variation between publications (n=6, 54%) Type 2 diabetes in American Indian adolescents was noted to have increased significantly in recent years, especially for adolescent girls, adolescents with a higher percentage of American Indian heritage, and adolescents with a family history of the disease. The regional or tribe-specific publications relied on American Indian community involvement for success in data collection; whereas with IHS data, community involvement did not play a direct role in data collection.

Finally, the epidemiological prevalence analysis by Fagot-Campagna (2000) revealed similar prevalence rates to Dabelea (1998), but focused on Type 2 diabetes in North American children and adolescents, sampling across a variety of racial and ethnic groups. In comparison, similar to the prevalence articles reviewed, Fagot-Campagna's literature review used similar sample inclusion criteria, referenced the same diagnostic challenges, and called again for broad public understanding in this area (2000).

Table 8: Characteristics of the Prevalence Studies (n=6)

Author	Requirements for sample inclusion	Time frame of study data	Prevalence rate	Incidence rate	Specific population or tribal groups served
Moore (2003)	<ul style="list-style-type: none"> <li>-did not meet criteria for Type 1 diabetes</li> <li>-Weight per age at diagnosis was greater or equal to the 95<sup>th</sup> percentile</li> <li>-C-peptide or insulin was elevated within 1 year of diagnosis</li> <li>-family history</li> <li>-Oral hypo-glycemics or insulin used</li> </ul>	Study: occurred 1999-2001 3 years of data from 1995-1997	<p>2.4/1000 CI 1.8-3.2                      Highest among youth 10-14 years of age, mean age 13.2                      Girls under 20 years of age 2 x higher</p> <p>(Formula used:  <math display="block">\frac{\text{Sum of prevalence cases for each year} / 3}{\text{Sum of youth population estimates} / 3}</math>)</p>	<p>23 cases (70%) probable Type 2 diabetes</p> <p>33.6/100,000 CI 23.9-48.1</p> <p>(Formula used:  <math display="block">\frac{\text{Sum of cases in each of the 3 years} / 3}{1997 \text{ population estimate} - 2001 \text{ prevalence cases}}</math>)</p>	<p>6 IHS facilities Included: Northern Plains Indian reservations, (Blackfeet, Crow, Fort Belknap, Fort Peck, Northern Cheyenne and Wind River.)</p> <p>Tribal groups living on these reservations included Arapha, Assiniboine, Blackfoot, Crow, Gros Ventre, Northern Cheyenne, Shoshone, Yanktonai and Sisseton Wahpeton Sioux.</p>

Harwell (2001)	<p>-did not meet criteria for Type 1 diabetes.</p> <p>-Weight per age at diagnosis was greater or equal to the 85<sup>th</sup> percentile</p> <p>-Acanthosis nigrogans present</p> <p>-C-peptide or insulin was elevated within 1 year of diagnosis</p> <p>-family history</p> <p>-oral hypoglycemics or insulin used</p>	3 years of data used 1997-1999	<p>1.1/1000</p> <p>Median age at diagnosis = 11 range 1-19</p> <p>Median current age = 15 range 2-19.</p> <p>51% male</p> <p>Higher rates in girls and in adolescents</p>	Not included in results	<p>Same as 1. Moore</p> <p>Also included PIH (percentage of American Indian heritage)</p> <p>8% full, 42% ¼-3/4, 10% less than ¼. 39% unknown</p>
Acton (2002)	<p>American Indian/Alaskan Native younger than 35 with at least 1 of the 10 ICD-9 diagnostic codes in 7 IHS regions:</p> <p>Contributes to the age-specific prevalence in youth younger than 15, 15-19 20-24 and 25-34</p>	8 years of data 1990-1998	<p>Less than 35 years of age 9.3/1000</p> <p>Children under 15 1.2/1000</p> <p>Adolescents 15-19 5.4/1000</p> <p>Young adults 20-24 11.5/1000</p> <p>Adults 25-34 26.9/1000</p> <p>Used US census, population data and the number of persons younger than 35 in the IHS database to estimate</p>	Not included in results	<p>Examined trends in prevalence in 7 IHS regions:</p> <p>Alaska</p> <p>The Great Lakes</p> <p>Northern Plains</p> <p>The Pacific</p> <p>The Southeast</p> <p>The southern plains</p> <p>The southwest</p> <p>Specific tribal communities were not named.</p>

Dabelea (1998)	<p>Pima tribe. Subjects aged 5-19 years whose heritage was at least ½ Pima or Tohono O'odham, and who resided in the community at any time during the study time frame.</p> <p>In addition, results from:  75 g oral glucose tolerance test results using WHO diagnostic criteria:  BP;  Weight; Obesity screening questions;  Question on exposure to diabetes in utero: was mother diabetic prior to delivery?</p>	<p>1967-1996  n=5274  in three, ten year periods</p>	<p>1.4% for boys 10-14  2.88% for girls 10-14  3.78% for boys 15-19  5.31% for girls 15-19</p>	<p>Not included in results</p>	<p>Pima tribe, Gila River, Arizona</p>
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<p>Fagot-Campagna(1999)</p>	<p>Compared between two sources</p> <p>The Gila River Community reported by the NIH and reported cases from the national IHS database of outpatient visits.</p>	<p>1986 and 1996-7</p>	<p>For Southwestern American Indian adolescents 15-19</p> <p>1996: NIH estimate of prevalence 5.1%</p> <p>IHS estimate of prevalence 0.46%</p> <p>Prevalence was 1.7 greater in females than in their male counterparts</p> <p>Different denominators used in IHS and census; NIH clinic examinations</p>	<p>Not included in results</p>	<p>Data from 27 IHS service units in Arizona, Colorado, Nevada, New Mexico, and Utah</p>
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### **Implications for Ethical Practice**

In 1978, the Belmont report presented three principles for the ethical conduct of research in the US: respect for persons, beneficence, and justice (The National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, 1978). In research with adolescents, special consideration of these principles is necessary.

For adolescents, the respect for person principle balances adolescent participants' independent decision making and continued special protections. Continuation of special protections is important in research with adolescents in order to address their emerging cognitive capacity to consent to research participation (Society of Adolescent Medicine [SAM], 2003). The beneficence principle is applied through extending and maximizing benefits of research to adolescents by inclusion in studies either as individuals or in groups. The justice principle focuses on inclusion and promoting the participation of groups, like American Indian adolescents, who have been historically excluded from participation in research. Another important consideration in the implementation of the justice principle is the researcher's preparedness to work with the American Indian adolescent's culture, environment, and community to access all of the direct or indirect benefits the research may provide.

Within this review of two decades of theoretical and data-based literature, it is concerning that details on the consideration of these ethical principles, inclusion of adolescents, and researcher preparedness to work with American Indian adolescents and



their communities were not addressed. While existing federal policies have occurred as a result of the Belmont report to include women, minorities, children, and adolescents in research (SAM, 2003), knowledge development on methods of inclusion for American Indian adolescents continued to develop. In future research focused on American Indian adolescents, the Belmont's ethical principles of respect for persons, beneficence, and justice, could be used as a framework for discussing knowledge development and best practices in working with American Indian adolescents and their communities.

Nursing research utilizing the justice principle has taken place in Africa, Canada, and New Zealand, where studies have considered the concept of cultural safety to nursing practice with diverse cultural populations (Anderson, 2003; Polascheck, 1998; Smye, 2002; Spence, 2001). Cultural safety is based in post-colonial discourse aimed at understanding power relationships in nursing service delivery (Smye, 2002). Within this discourse, nursing sets up systems which enable the less powerful to genuinely monitor the attitude and service of the powerful to create useful and positive change (Polascheck, 1998). Cultural safety is designed to focus attention on the idea of "life chances" which Smye referred to as health services, education, and decent housing within an environment where it is safe to be born of a different racial or ethnic group. Cultural safety is not about cultural practices, but rather about recognition of the social, economic and political position of certain groups within society, such as the indigenous people of New Zealand, and the aboriginal people of Canada (Smye, 2002). Cultural safety focuses on nursing with less powerful populations in a society and prompts nurses to, "think critically about ourselves, our patients and to be mindful of our own social, cultural, economic, and

historical location” (Anderson, 2003, p. 196). The ideas represented in the concept of cultural safety are of ethical significance, relate to the concept of social justice, and have implications for future nurses and other health practitioners represented in this literature review.

In the US, research involving cultural safety could impact nursing practice positively by preparing nurses to consider the relational worldview and to develop new methods of providing quality and comprehensive health care to American Indian communities. Now and in the future, the profession of nursing will increasingly be called upon to provide culture-specific health care in a society of growing numbers of languages, family structures, and values. To address this challenge, future research can move forward by including ideas represented in cultural safety and in the Belmont principles. In addition, Christopher (2005) discussed seven more areas for effective, culturally appropriate, ethical research with American Indian communities:

- a. Researchers must work to know and understand the impact of historical relations between the US government and Native Americans on the present day attitude of Native people and research;
- b. Researchers must show knowledge of the issues specific to tribes being studied and avoid the common mistake of grouping all tribes together;
- c. Native American individuals and communities must be invited to be involved with research;
- d. Native communities must receive information back from researchers and have access to data collected from them;

- e. Native communities must receive benefits from research;
  - f. Researchers must address assets and broader social issues; and,
  - g. Researchers must place the need of the community ahead of their own interests.
- (p. 45).

These areas can be instrumental towards creating specific research approaches with American Indian populations within academia oriented in a Western or linear worldview. Future research including these areas could also contribute to extending research and its benefits to more American Indian adolescents and their communities.

### **Future Research**

The literature review in this chapter revealed sources that strongly support further research on health care for American Indian adolescents with Type 2 diabetes. In the future, coordinated research will be needed to test interventions that reduce multiple risk factors present for American Indian adolescents living with Type 2 diabetes and explore the benefits of interventions for practical health outcomes. Research studies on the quality of health care, potential interventions successful among adolescents, and the importance of behavioral and environmental factors are especially needed.

Another area in need of continued research is the diagnostic classification of Type 2 diabetes in adolescents. Case definitions need further development in order to differentiate between types of diabetes in adolescents (i.e. Type 1, Type 2, and others) and to alleviate the diagnostic challenge in this age cohort. Further developed case definitions can assist health systems to coordinate medical record data used for research on disease trends and prevalence, to estimate the magnitude of the disease in this

population, and be used for future clinical diagnosis approaches (Fagot-Campagna, 2001).

Research is needed on philosophical, theoretical, and conceptual approaches appropriate to guide future research on Type 2 diabetes in American Indian adolescents. A successful approach to guide further research would allow inclusion of a holistic and spiritual context of the American Indian adolescent including cultural components, and social/economic circumstances. The Four Winds Model for Native Nutrition (Conti, 2005) based on the beliefs of the Oglala Sioux tribe in South Dakota, is an example of model development in this area. Conti demonstrated dramatic change in the availability of food, diet composition, the amount of physical activity, and lifestyle in American Indian communities that most likely contributed to the health disparities that currently exist. This culturally-specific nutrition model provided a prescriptive approach for returning to a traditional diet, with use of traditional and contemporary foods. Lowe & Struther's (2003) conceptual model of nursing with Native Americans was another example of a successful approach to guide nursing practice in American Indian communities within a holistic or relational worldview.

There was evidence in the literature review of increasing numbers of American Indian adolescents with Type 2 diabetes with a shortage of health care available through the IHS to serve them. There was also a gap in the literature on health care for un-insured American Indian adolescents, namely for those adolescents in rural, urban, or federally non-recognized tribes not served by the IHS. The mission of the IHS was specific to meeting the health care needs of all American Indian people and federal funding of the

IHS played a major role in the quality and quantity of services available to American Indian communities and to American Indian adolescents living with Type 2 diabetes. Urban, tribal, or regional-specific disease incidence was not well-represented in the primary publications and further development in this area would contribute to understanding the scope, nature, and presence of this disease.

With exception of two regional-specific studies (Dabelea, 1998; Lee, 2004), an identified gap in the literature was data representing specific tribal communities. With the US health care system ill-prepared to serve individuals with chronic long-term illnesses like Type 2 diabetes, future tribe-specific research may reveal innovative primary, secondary or tertiary care approaches to this problem. Tribe-specific data could lead to tribe-specific interventions. Such interventions could direct the development of research methods that empower adolescents with Type 2 diabetes to self-engage in prevention and disease management strategies within their own tribal community.

A national perspective on all American Indian adolescents living with Type 2 diabetes is also needed. Secondary sources reported on a broader range of knowledge including socio-economic indicators, insurance use, level of education and family status. A secondary source literature review could contribute to a national perspective on American Indian adolescents with Type 2 diabetes and would be instrumental to evaluate descriptive and demographic sources and trends. This perspective would be useful to compare with the status of American Indian adolescents and does not currently exist.

Finally, future research is needed on methods of developing collaborative relationships with American Indian adolescents and their communities. The Canadian

First Nation's recommendations support research and program approaches to embrace the adolescent, family, and community in future research on Type 2 diabetes in adolescents.

The Canadian First Nations community recommend that efforts should include: (a) involvement of American Indian youth in the development of research, programs, and services accessed by youth, (b) family and community perspectives in the design of future research and programs addressing Type 2 diabetes with American Indian adolescents, and (c) American Indian history and traditions (NIICHR0, Youth and Diabetes, 2000).

### **Synthesis**

Overall, a key finding from the literature review was that the state of the science in this area is in its formative stages and represented two domains of knowledge development. The first domain was the positivist paradigmatic perspective. These sources employed quantitative research methods primarily from medical research. The second domain was literature from a constructivist paradigmatic perspective, utilizing qualitative methodologies. Future scientific development could include research utilizing mixed methods, based on the constructivist paradigmatic perspective which was limited in the sources reviewed.

Convenience, purposive and cross-sectional sampling including several tribal communities was a common and appropriate research approach for the state of knowledge development in this area. Greater than 50% of the primary sources were designed to conduct secondary analyses on the longitudinal study with the Pima Indian tribe in central Arizona. These analyses were important to the future development of

clinical case definitions and diagnostic criteria to further medical research with Type 2 diabetes in American Indian adolescents. Specific recommendations on creating collaborative, tribal-supported research endeavors, however, were absent in both knowledge domains and important to address for future culturally appropriate research in this area.

There were a variety of terms used in referring to adolescents, supporting the state of knowledge is in its formative stages. For example, some authors used the term *youth* to refer to the age range of 10-14 years, *child* for the age range of 5-10 years, or *adolescents* for the age range of 15-19 years of age (Acton, 2002). Other authors used no specific age range in reference to the terms *child*, *children*, or *youth*, which could encompass a number of ages within childhood and adolescence. Use of a variety of terms to define adolescence prevents direct comparisons between studies. Therefore, development of a standardized terminology would advance knowledge development specific to these disciplines.

Limitations in findings of the prevalence publications were found in IHS data representing a portion of all American Indian adolescents in the US. This limitation was influenced by a complex array of economic and political influences, one being that the current IHS mission is to serve a portion of the total American Indian population in the US from federally-recognized tribes. Another limitation was a regarding cost-shifting in American Indian health care, involving the shift of health programs, services, and their budgets from the IHS to individual federally-recognized tribes (IHS, 2008, IHS, 2009; List of federally non-recognized tribes, 2004; Native American Indian Resources, 1997).

Cost-shifting empowers tribes to create a regional or tribally-based and more self-determined or empowered health care infrastructure. What is not acknowledged, however, is the funding required for implementation within tribal organizations. Lastly, health data cannot be collected, managed, and maintained over time without funding and the capacity of tribes to take responsibility for these areas. This was a limitation to use of tribal data for future research where tribes will not conduct regional or tribe-specific data approaches (e.g. measuring separate health status in the Lakota, the Navajo and other tribes).

### **Healthy People 2010**

*Healthy People 2010* (United States Department of Health and Human Services, 2010) is a comprehensive national initiative that provides a framework for disease prevention and health promotion efforts in the US. It includes national health objectives designed to identify the most significant preventable threats to health and establishes national goals to reduce those threats. *Healthy People 2010* is designed to achieve two overarching goals: (1) to increase quality and years of healthy life; to help individuals of all ages increase life expectancy and improve their quality of life, and, (2) to eliminate health disparities among different segments of the population. The Health People 2010 goals are addressed by several objectives, one of which is assigned to diabetes.

The goals of the *Healthy People 2010* diabetes focal area were to address westernization, which included a diet high in fat and processed foods as well as total calories, and has been associated with a greater number of overweight persons in the US when compared to a decade ago, especially within high risk racial and ethnic groups.



*Healthy People 2010* also documented diverse and complex factors to the increasing presence of diabetes in adolescents:

1. Obesity, improper nutrition (including increased ingestion of fats and processed foods), and lack of physical activity are occurring in persons under age 15 years and may explain the increasing diagnosis of Type 2 diabetes in adolescents.
2. Increased television watching associated with diminished physical activity also may contribute to the emergence of Type 2 diabetes in youth.
3. Personal behaviors are influenced by beliefs and attitudes, and these are greatly affected by community and cultural traditions.
4. In many racial and ethnic communities, fatalism, use of alternative medicine, desirability of rural living conditions, lack of economic resources, and other factors will influence significantly both availability of health care and the capabilities of persons with diabetes in handling their own care.
5. Thirteen percent of the total US population speaks a language at home other than English.
6. Cultural and linguistic factors affect interactions with health care providers and the larger health system (United States Department of Health and Human Services, n.d.)

The degree to which diabetes prevention strategies recognize and incorporate these traditions will determine a program's effectiveness. The current study within the

Health People 2010 priorities for diabetes is timely and will lend insight and contribution to achieve these overall goals.

In summary, the state of science on Type 2 diabetes in American Indian adolescents is evolving. The literature in this review described the health status of American Indian adolescents and presented the concern of a growing incidence and prevalence of Type 2 diabetes in this population. Several publications reviewed trends and while prevalence rates did not represent a national perspective and varied significantly, the findings consistently showed an increasing morbidity of the disease that was not solely related to increased surveillance.

Important to framing the next generation of research on Type 2 diabetes in urban-based American Indian adolescents is exploration and testing of theoretical perspectives based on the constructivist or critical theory paradigmatic perspective, which was under-represented in the literature. There is need for innovative research methods specific to adolescents, to include behavioral considerations, family, and the tribal community. Research based in this perspective would be most beneficial for knowledge development, would allow for inclusion of culturally-specific factors for the American Indian adolescent, family, tribal community, and include the adolescents' perspectives on living with this disease. To advance scientific understanding on preventing and treating Type 2 diabetes in American Indian adolescents, it is important to find ways to include all American Indian adolescents in this country and the factors of their lives that influence their experience.

## **Summary**

This chapter has presented the rationale for the present study and has described the evolution of the study from historical and philosophical perspectives. Oppression is an important concept to give relevant perspective to the analysis of narrative data and in the hermeneutic interpretation of the resulting themes. A philosophical and conceptual perspective was presented on oppression and discussed through a review of three main categories of literature.

A focused literature review surveyed the last 20 years of knowledge on the research area, including knowledge development, data analysis, identification of strengths and limitations of the literature, and recommendations for further research. A review of the quantitative and qualitative scientific research literature provided justification for studying the phenomenon and for future research efforts to focus on discovering the essence of American Indian adolescents' experiences in living with Type 2 diabetes.

## CHAPTER III

### Methods

#### Introduction

A qualitative research design is appropriate when little is known about a research area and when the aim is to understand or describe a particular phenomenon (Miles & Humberman, 1994; Morse, 1995). A naturalistic qualitative design was used in this inquiry to achieve the study's aims and to investigate the phenomenon of interest in a natural and unique setting. Phenomenology was selected for the study as it allowed the researcher to examine the participants' experiences in their own culturally and socially-defined circumstances.

In American Indian research, a qualitative research method like phenomenology is appropriate because it is compatible with traditional or indigenous ways of knowing involving holism and interdependent relationships between all things (Crazy Bull, 1997). Phenomenology in research is a unique scientific endeavor because it strives to unveil insightful descriptions of how a person experiences the world. Phenomenology does not bring the researcher to theoretical explanation, but provides insight towards theoretical consideration on the *essence* of an experience. Use of this analytical method was well-suited to the current study where little was previously known on the topic area.

In all disciplines of the humanities and social sciences, hermeneutics and phenomenology have been involved in interpreting meaningful expressions of the inner, cognitive, or spiritual life of human beings in social, historical, or political contexts.

Hermeneutic and phenomenological philosophies are essential elements of how knowledge is acquired and have provided a foundation for human science research (Dahlberg, 2002). This study used narrative data to discover patterns, themes, and other unique qualities found in the individual life stories of American Indian adolescents with Type 2 diabetes living in an urban area. The phenomenological research question for the study was: What is the lived experience of urban-based American Indian adolescents living with Type 2 diabetes?

A phenomenon is an occurrence perceived through an individual's senses and their response observable to the outside world. Phenomenology is the intense study of a particular occurrence or experience in order to reveal its true essence. Hermeneutics is the phenomenological tool used to understand the essence by revealing an in-depth, first time understanding of experience. Hermeneutics aims to reveal what is hidden (Dahlberg, 2002) within a person's life experience. The aim of hermeneutic phenomenology is to understand the essence of an experience and to provide insights to the meaning of the experience to the individual.

### **Background of the Method**

Phenomenology began in the early 20th century with the philosophy writings of Husserl, Heidegger, Sartre, and Merleau-Ponty. Husserl especially was credited with the inception of phenomenology, and his philosophies developed from the increasing criticism at that time of the scientific method, seen as reductionist and mechanistic. Husserl wrote prolifically during his lifetime and through his work in phenomenology presented a new way of understanding the world (Dahlberg, 2002). Husserl warned that

cultivation of the scientific ideal of positivism would sever science from the everyday world, ultimately resulting in the de-humanization of society rather than producing the anticipated benefits scientific knowledge was expected to bring about (Dahlberg, 2002).

### **Max van Manen's Approach to Phenomenology**

Max van Manen's (1997) approach to hermeneutic phenomenology was used in this study. van Manen stated that phenomenology is the study of the *lifeworld*, where life experience is viewed as it is lived before structuring through language, concepts, categories, or theory. The lifeworld is explained as a person's daily life experiences, as they actually occur without reflection, categorizing, or conceptualizing. The lifeworld is also known as the lived experience.

van Manen (1997) believed phenomenological research was unique in its aim to poeticize human activity, and his approach to phenomenology in research involved the interplay of four courses of action:

- Turning to a phenomenon that seriously interests us and commits us to the world;
- Investigating the experience of the phenomenon as it is lived, rather than as it is conceptualized;
- Reflecting on the essential themes of the experience;
- Describing the phenomenon through writing and re-writing (p. 2-3.)

van Manen's methodological approach for conducting hermeneutic phenomenology utilizes the four courses of action as desired by the researcher, including

use of the actions simultaneously. Table 9 reviews and further explicates van Manen's approach.

*Table 9: Max van Manen's Four Courses of Action*

<ul style="list-style-type: none"> <li>• Turning to a phenomenon that seriously interests us and commits us to the world <ul style="list-style-type: none"> <li>• Orientating to the phenomenon</li> <li>• Formulating the question</li> <li>• Explicating assumptions and pre-understandings</li> </ul> </li> <li>• Investigating the experience of the phenomenon as it is lived, rather than as it is conceptualized <ul style="list-style-type: none"> <li>• Exploring the data</li> <li>• Using personal experience as a starting point</li> <li>• Tracing etymological sources</li> <li>• Obtaining experiential descriptions from participants</li> <li>• Interviewing</li> <li>• Obtaining experiential descriptions from other sources</li> <li>• Consulting phenomenological literature</li> </ul> </li> <li>• Reflection on the essential themes of the experience <ul style="list-style-type: none"> <li>• Conducting thematic analysis</li> <li>• Uncovering and isolating thematic statements</li> <li>• Composing linguistic transformation</li> <li>• Using the lifeworld existential as guides to reflection</li> <li>• Identification of incidental and essential themes</li> </ul> </li> <li>• Description of the phenomenon through writing and re-writing <ul style="list-style-type: none"> <li>• Attending to the speaking of language</li> <li>• Varying the examples</li> <li>• Writing and re-writing</li> </ul> </li> </ul>
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The lived experience is the focal point of phenomenological research. According to van Manen (1997), the nature of conducting research on lived experience involves, “transforming lived experience into a textual expression of its essence – in such a way that the effect of the text is at once a reflective re-living and a reflective appropriation of something meaningful: a notion by which a reader is powerfully animated in their own lived experience” (p. 36).

The aim of phenomenological research is to study the essence of the lived experience and to create a linguistic description that represents the phenomenon studied. The linguistic description, a phenomenological writing and re-writing of the text on the essence of the lived experience, is the final product of the research process. In the final written description, “a structure of a lived experience is revealed to us”, and the reader can better understand. “Now we are able to grasp the nature and significance of this experience” (van Manen, 1997, p. 39).

In this study the phenomenological method offered the researcher the opportunity to describe the experiences of American Indian adolescents with Type 2 diabetes living in an urban area and provided guidance to articulate the meaning of the phenomenon as it existed and was portrayed through the adolescents’ experiences.

### **Cognitive Processes of Qualitative Analysis**

Qualitative analysis requires the researcher to engage in several cognitive processes. These processes can occur sequentially and involve identification of main themes, organizing supporting text into theme sections, writing extensive descriptions on how the lived experience can be described, and re-creating a statement of broader

interpretation. In this study, Morse's (1994) cognitive processes of qualitative research were selected to guide data analysis and to create an audit trail (Lincoln & Guba, 1985), a technique of research validation and confirmability.

Morse (1994) found there were four cognitive processes integral to all qualitative research: (a) comprehending, (b) synthesizing, (c) recontextualizing, and (d) theorizing. In this study, these cognitive processes guided identification of themes within and across the transcript data. Application of Morse's (1994) four cognitive processes to the present study is explained further.

### **Comprehending**

In the first process, the researcher reviewed each interview transcript to highlight main themes in the participant's experience. The full interview transcript was reviewed repeatedly, at least five times, in order to locate sentences and phrases that represented prominent or re-occurring ideas on the adolescent's experience of living with Type 2 diabetes. The review also included sensitivity to subtleties in the adolescent's use of language and to their unique voice of experience to guide identification of prominent ideas.

### **Synthesizing**

In this process, the researcher developed categories to organize prominent and recurring ideas and with the use of supporting text, created phenomenological theme sections. A phenomenological theme statement was created for each section by synthesizing sentences and phrases that represented unique highlights and occurred at a higher frequency in the transcript data. The phenomenological theme statements

composed the first data transformation that later gave way to a hermeneutic phenomenological description of the lived experience.

### **Recontextualizing**

Recontextualization was the final theme transformation the researcher used to transcend the world of the participant's text to broader, reflective statements. This transformation yielded broader theme statements on what it was like for the adolescent to live with the disease.

### **Theorizing**

The final cognitive process utilized van Manen's (1997) four existentials or fundamental life world themes--spatiality, corporeality, temporality, and relationality--to consider the broader recontextualized statements. The lifeworld themes will be explained in depth later in this chapter.

Each lifeworld theme was used to compare and contrast the recontextualized reflective statements to determine if they were essential or incidental to the adolescent's lived experience. The results of this cognitive process identified the essential themes of the adolescents' experiences of living with Type 2 diabetes.

### **Rationale for Choosing Hermeneutic Phenomenology**

This study intended to give rise to knowledge by way of exploring urban-based American Indian adolescents' lived experiences with Type 2 diabetes. The goal was to describe the actual life experiences of American Indian adolescents aged 12-19 years with Type 2 diabetes from one urban community. In urban areas American Indian communities are often geographically dispersed and little is known about the role of

family, community, tradition, and culture in the adolescents' experiences in living with the disease. The study results provided insight to the presence of essential components in the lives of the adolescents who participated. The study results also provided insight to the phenomenon through the language and voice of the adolescents who participated.

The participant's experiences in living with Type 2 diabetes were elicited through a face-to-face unstructured interview at a location of their choosing. The adolescents' experiences were audio-taped and prepared as a written transcript for application of the processes of data analysis to comprehend, synthesize, re-contextualize, and consider theoretical implications. The four existential or fundamental lifeworld themes (van Manen, 1997) were used to compare and contrast each participant's statements to determine if they were essential or incidental to their actual experiences in living with the disease.

In the study, hermeneutic interpretation involved application of van Manen's (1997) four existential or fundamental lifeworld themes--spatiality, corporeality, temporality, and relationality-- to consider further understanding of the recontextualized statements, which are discussed further in Chapter 4. Each lifeworld theme was used to compare and contrast the recontextualized reflective statements to determine if the statements were essential or incidental to the adolescent's lived experience, and to understand the essence of the live experienced for the participant. Considerations of essential versus incidental qualities of the data transformation statements led the researcher towards selection of predominant themes most representative of the participants' experiences. van Manen (1997) explained how the phenomenological

researcher uses *free imaginative variation* in order to determine whether a theme area is essential or incidental to the lived experience. Free imaginative variation involves a review of all steps of the hermeneutic interpretation towards selection on the emerging essential theme or themes, “In determining the universal or essential quality of a theme our concern is to discover aspects or qualities that make a phenomenon what it is, without which, the phenomenon could not be what it is” (p. 107).

### **Applying Max van Manen’s Four Courses of Action**

Use of phenomenology illuminated the personal meaning of the individual’s experiences so that a greater understanding was possible, while hermeneutics guided interpretation of the adolescents’ experiences. Finally, application of van Manen’s (1997) four courses of action was used to address the research question.

### **Turning to a Phenomenon: The Experiential Context**

Turning to the nature of lived experience is the first step of van Manen’s approach (1997) and involved the researcher discovering an interest in a phenomenon and asking questions to discover the nature of the phenomenon. The following is an example of discovery and application of this step to the present study:

I, the researcher, am American Indian. I am knowledgeable about American Indian history, culture, spirituality, living on a reservation, living in an urban community, and on healthcare and health issues for American Indians. In general, my research interests are focused on understanding health disparities for American Indians. A contribution to this area of interest would be to understand more on the occurrence of Type 2 diabetes, a form of diabetes that usually occurs in the later adult years and now occurring in Indian young people. In order to look closer and become more familiar with this problem, I need to learn about the actual experiences of American Indian adolescents living with this disease. I recognize that American Indian adolescents are increasingly mobile in our society between reservation, rural, and urban areas, and that very little is known about serving American Indian youth with this disease, especially in the urban areas.

Therefore, my attention is focused on what American Indian youth experience as they live with the disease in the context of the urban setting. What do they see, what do they feel, and what do they think about as they live with the disease day-by-day? How do they manage diabetic symptoms and how do they experience and perceive their health care? How do they experience health professionals, such as nurses? Whom do they seek for support in their family and community? Who makes up their support network?

I, the researcher, am American Indian, and know much of the culture. I am an individual with American Indian background and a career in nursing. My interests in the phenomenon comes from a lifetime of living in an American Indian family, experiencing life on a reservation, and in observing family and community members live with and die from complications of Type 2 diabetes. I have found standard health care in this country to often overlook American Indian cultural views when treating Type 2 diabetes. While symptoms may be controlled, the functional and spiritual decline from the disease is detrimental and of great concern. The disease has evolved into my personal history and family story and now is an expected part of life. In other words, diagnosis of the disease has almost become expected, a way of connecting with past and future generations through negative health experiences and negative health outcomes. In general, many forms of research create research questions in an attempt to decrease ambiguity and achieve greater clarity. In addition to this intent, phenomenological research questions are also lived or experienced in some way by the researcher. The focus of this research study was to respond to the research question by constructing a possible interpretation of the meaning of urban-based American Indian adolescent's experiences in living with Type 2 diabetes. Through education in mainstream environments, the researcher had the ability to look at the phenomenon from different worldviews, both from the American Indian perspective and as a health professional. The researcher's interest in the study came from a lifetime of experiences representing differences in the worldviews and the desire to learn more about the development of Type 2 diabetes occurring in American Indian young people. A linear-oriented worldview was learned through institutions and educational experiences where Western viewpoints were predominant. Upon reflection, the researcher's personal experiences with Type 2 diabetes represented two worlds, one linear and the other relational, each with its own language, each attempting to inform the other.

### **Investigating the Experience of the Phenomenon as it is Lived**

**Participant sample.** Phenomenological samples are at all times purposeful, selective, and very often small in size (Corben, 1999). Boyd (2001) regarded two to 10 participants as sufficient to reach data saturation in phenomenological research, yet

recognizing the intent of qualitative inquiry is to not solely reveal data similarities.

Sandelowski (1993) explained this intent further by commenting on the use of the small sample size in qualitative research, “Repeatability (data saturation) is not an essential (or necessary or sufficient) property of the qualitative things themselves (being the qualitative research or the qualitative interview). In the naturalistic interpretive phenomenon, “reality is assumed to be multiple rather than singular and tangible” (p.3). Purposive sampling as a study method can bring to light a wider range of participant experiences and realities that are of interest in a naturalistic inquiry (Isaac & Michael, 1997).

The study’s inclusion criteria for sample selection were, (1) adolescents who were residing in an urban area and self-reporting American Indian heritage; (2) adolescents 12 through 19 years of age; (3) adolescents with the ability to speak and understand English; (4) adolescents who could verbalize their thoughts and feelings; and, (5) adolescents living with Type 2 diabetes for no less than 6 months. Exclusion criteria were: (1) adolescents identifying with an ethnic group other than American Indian, (2) adolescents who do not reside in an urban area, (3) adolescents living with Type 2 diabetes less than 6 months, (4) adolescents 11 years of age and younger or 20 years of age and older, (5) pregnant adolescents; and (6) adolescents with a diagnosed mental health, emotional, or developmental disability.

Tribal communities are not uniform in verifying an individual’s American Indian heritage for tribal enrollment. Tribal communities typically use the blood quantum or Percent of American Indian Heritage (PIH) as verification of American Indian ancestry

and as a requirement for tribal membership. Due to the variability in tribal enrollment verification practices, the participant's self-report of American Indian heritage was accepted for the study. American Indian heritage was confirmed secondarily for each participant in the face-to-face interviews through their shared experiences.

Purposive sampling techniques aided significantly to locating participants who were not easily accessed in the large urban area for the study. The sample selection process required the urban community's participation to establish, (a) sample representativeness, (b) credibility, and (c) culturally appropriate methods of sample recruitment. Adolescent participants were recruited by the researcher through a wide variety of methods (Table 10).

*Table 10: Methods of Sample Recruitment*

Posting of fliers in high traffic and public areas
Word of mouth recruitment by community members
Home visits
Direct recruitment at middle and senior high schools
Attendance at American Indian urban organization community meetings
American Indian community youth program offices
Homeless shelters
Food shelves
American Indian and other health clinics
Study information letters sent to American Indian community leaders,
Direct contact from interested parent or guardian
Advertisement in American Indian community newspaper
Announcements sent to the American Indian community internet email list serve.
Attendance at urban pow-wows as a vendor information booth



While participants were initially solicited directly by a wide variety of means, few calls were received from interested adolescents for participation in the study. After the first outreach attempts yielded no study participants, the researcher revised the sampling approach by obtaining permission from the IRB to obtain adolescent names and contact information from urban American Indian health care providers serving adolescents in the urban area. The providers screened active adolescents in their health clinic or practice population through use of the study inclusion criteria, gave information on the opportunity to participate in the study, along with information on the incentive payment of a 25-US dollar gift card if the adolescent participated. The revised sampling approach produced results of interested guardians and adolescents contacting the researcher and requesting to discuss or participate in the study.

As sampling evolved, the data collection process was influenced by the outcome of the emerging analysis. Participants were interviewed based on need rather than a prior decision in the research design. A purposive sample of five adolescents was reached based on the study's inclusion and exclusion criteria, in collaborative agreement between the researcher and urban community stakeholders, and insights learned from previous adolescent participants in the phenomenological interview process.

**Setting.** The study setting included a seven county metropolitan area surrounding and including Minneapolis/St. Paul, Minnesota. One third of Minnesota American Indians live in the central city areas of Minneapolis and St. Paul, with an additional 15 percent living in the suburbs. The Twin City's minority population increased rapidly between 1980 to 1990, growing by 81 percent (Minnesota Senate, 2011). The American

Indian population was part of this increase. One percent of metro area residents are American Indians, the third highest percentage of the 25 largest US cities. Forty-three percent of the American Indian population is comprised of children under the age of 18 (Minnesota Senate, 2011).

Most American Indians living in the Minneapolis/St, Paul area live in census tracts where they account for less than 2.5 percent of the population. However, there is one census tract in South Minneapolis where American Indians account for almost 50 percent of the population. This is the area located in the Phillips neighborhood that contains Little Earth, an American Indian controlled housing program. There are also a number of American Indians residing in North Minneapolis. Areas in St. Paul with the highest concentration are the Payne-Phalen, Thomas-Dale, and North End planning districts. American Indians in the Minneapolis/St, Paul area have ties with Minnesota reservations as well as those in North and South Dakota and Wisconsin. There are many organizations in the metro area which focus on meeting the needs specifically for the American Indian community (Minnesota Senate, 2011).

**Interviews.** The nature and meaning of living with Type 2 diabetes was explored through face-to-face interviews with participating adolescents to produce real life accounts of their experiences. Initially, the researcher made contact with three adolescents, including at least one from each gender. Participants beyond an initial sample of three were interviewed to the point where narrative content from the interviews began to repeat. The point of saturation was determined by multiple reviews of the

transcript data with a final number of five interviews selected to address the aims of the study and to provide the desired insight to the research question.

At the time of the consent to participate in the study over the phone, the researcher encouraged each adolescent to reflect on their experiences in living with Type 2 diabetes in preparation for the first interview. Prior to each interview, the researcher addressed bracketing by creating written journal entries on personal pre-conceptions and goals of the interview, a part of the process to establish trust and confidence in the interview results.

The adolescents were asked to participate in one unstructured audio-taped interview with the researcher to learn of their experiences in living with Type 2 diabetes. The interview was to last no longer than one and one-half hours to minimize the participant's fatigue. The interview began with a grand tour question: "What is your experience in living with Type 2 diabetes? Please tell me your story from the beginning and what has happened in your life as you can remember". From this point throughout the adolescent's statements or stories of experience, if necessary, question probes were asked by the researcher to clarify information or to ask for details on the story shared by the participant. (Appendix C). If there was a gap in the adolescent's story or if it appeared that the adolescent was having difficulty responding, the researcher prompted the participant for more information through pre-determined question probes to fill in detail or missing parts of their story.

Written transcripts were created removing identifying information in order to maintain confidentiality for the participant. One additional follow-up meeting took place

with the adolescent in order to review and discuss the resulting interview transcript for accuracy and to provide a 25-US dollar gift card to a local grocery or convenience store. As outlined in the informed consent process, the resulting data in the transcript was shared with the researcher's advisor and doctoral dissertation committee members for review of completion and consistency with the project's aims and intent.

**Confidentiality and data protection.** The researcher provided interested parties who requested more information on the study, an overview and explanation of interview confidentiality. The interviews were scheduled at a location selected by the participant, and if desired, a community location was made available to conduct the interview. The interview audio tapes were transcribed into an electronic narrative format (i.e., a Microsoft Word document), printed as a paper copy, and the paper copy provided to the participant in the follow-up meeting. The interview was transcribed, stored on the researcher's password protected personal computer, and accessed only by the researcher. Signed assent forms, signed consent forms, and an electronic back-up file (i.e., a computerized location created with digital copies of all interview transcript data) were placed in locked storage in the researcher's home where only the researcher had key access. The transcript data will be stored in the researcher's personal computer for 7 years and then deleted. The forms and back-up file will be destroyed after 7 years. The audio tapes were returned to the researcher, erased, and destroyed after they were transcribed.

**Data collection and analysis.** The researcher created written journal entries and field notes of observations and subjective impressions of the participant in response to the interview process immediately following the conclusion of each interview. The journal

entries and field notes comprised secondary data and gave insight to the consistency of the primary data from the interview transcripts.

The open-ended unstructured interview with use of question probes was used to elicit the adolescents' descriptions of experience with Type 2 diabetes. The interviews were audio-taped, transcribed, and paper copies made for use in the data analysis. Each interview was reviewed initially by the researcher along with the paper copy of the transcript and then reviewed several times thereafter in the audio and paper copy formats. The data analysis of the interviews followed a process of identifying themes, shared and common themes, and essential themes revealing the essence and meaning of the phenomenon. The follow-up meeting with each participant was scheduled following an extensive review of the previous interview.

**Protection of human subjects.** This research study met all requirements of the protection of human subjects and approval to conduct the study was granted by the University of Minnesota's Institutional Review Board.

The study involved limited potential risk for the participants. There was a minimal risk of psychological distress for the participants if they were experiencing stress, or trauma in their lives. In addition, the researcher asked all participants to feel free to stop the interview if desired and they were informed of the availability of supportive health professionals such as counselors and specialists in American Indian health care, should the desire arise during the interview to make this referral. In addition, a spiritual leader and American Indian elder were available to consult on issues raised during the interview should the participant desire this contact and support.

To minimize psychological risk, participants were informed that at any time during the interview they could choose what they were to say. They were informed they could terminate their participation in the study without explanation or notice and it would not jeopardize any relationship. Participants were also informed that all information collected during the interview would be confidential and would not be shared in any way that would reveal their identity.

The potential benefit for participants involved in this study was the opportunity to share their experiences with an experienced health professional and within a supportive environment. Potential benefits included the satisfaction in contributing valuable information to an important health issue for American Indians and support to become involved in additional conversations and programs specific to their needs.

Within the findings, no participant identifiers were used to reveal the identity of the adolescent participants. In the consent process the researcher explained what would occur to the participant and risks involved as a consequence of the study in order for the participant and their parent or guardian to give informed consent. Participants and parents/guardians of the adolescent participant received study information and a consent form fully explained to them. Adolescent participants under the age of 18 years received an assent form fully explained to them in order to be part of the study.

The rationale for using adolescents as the focus of the study was very little is known about urban-based American Indian adolescent perceptions related to this disease, even though research has been conducted on various aspects of Type 2 diabetes among American Indians living in the United States. This study aimed to provide important

understanding about American Indian adolescents' views about Type 2 diabetes considering the family and cultural context.

In order to advance knowledge it was important to limit enrollment in this research study to adolescents from the American Indian community. Only American Indian adolescents living with Type 2 diabetes had the greatest potential to provide insight on experiences in living with Type 2 diabetes within the specific cultural and community context. Based on the final presentation of lifeworld comparisons, understanding cultural context can enhance understanding about this disease in American Indian adolescents.

**Time frame.** Participant recruitment began in 2007, data collection began May 2008, and interviews were completed in September 2008. Analysis and validation of the findings began during data collection. Theme analysis followed the first interview and was confirmed in subsequent interviews with each adolescent.

### **Phenomenological Writing**

Phenomenological writing is the final activity in van Manen's (1997) phenomenological method and occurred throughout the study. Reflection and ongoing re-visiting of the resulting data on the lived experience of urban-based American Indian adolescents was required to assure reliability and validity of the data. The study concludes with a description and discussion of the findings presented in Chapters IV and V. The writing of the final dissertation occurred between 2007 and 2011.

## **Reliability and Validity**

The conventional criteria for assessing the quality of a research study are reliability, validity, and generalizability. These criteria originated in the epistemology of positivism and experimental research. In assessing for strengths and limitations in the present study, it was important to adapt and translate the criteria to a qualitative, phenomenological study. Issac and Michael (1997) presented an adaptation of the conventional assessment criteria using Lincoln and Guba's (1985) criteria of credibility, transferability, dependability, and confirmability. These four criteria were utilized in assessment of study rigor, strengths, and limitations.

To further establish scientific rigor, the quality of the study was evaluated with use of Lincoln and Guba's (1985) four criteria. Collaborative work occurred with American Indian urban community experts to ensure transferability of the study design and data collection methods. Collaboration with key members and stakeholders of the urban community was essential and invited involvement from the community.

## **Credibility**

Qualitative research and the phenomenological method are not used for research requiring statistical control of bias or researcher detachment from the study participants. In the present study, detachment from participants would not have allowed for a culturally sensitive approach to American Indian culture within the urban community. Therefore, credibility was addressed through journal entries and field notes created by the researcher with life experience and a cultural background similar to the participants. The researcher's credibility in these areas provided important contributions to the study



design, interpretation, and results. These considerations were included in the study design and contributed to a higher level of study credibility.

Another area of strength in the study's credibility was appropriateness of paradigmatic and epistemological foundations of the research approach to the cultural community served. First, the phenomenological design was appropriate to the level and the type of existing knowledge in this area. In addition, developing and preserving ongoing relationships with key community members and stakeholders was maintained throughout the study. Cultural appropriateness was realized in the frequent inclusion of community participation throughout the study design, and in so doing, the community was enabled and empowered to give insight to the findings. The appropriateness of the overall approach and ongoing collaboration with community members increased the credibility of the study.

Finally, a potential limitation in the study was that the adolescent participant may have withheld information, would not share what they knew in regards to the research question, or may have given false or misleading information in the researcher's presence. In this study it was important to develop trust between the researcher, the community, and the study participants, to recruit the participant and to assure participants were comfortable with and informed about the study. Trust development decreased non-participation or the possibility of providing misleading information. To minimize this limitation, the study design included repeated in-person visits, phone calls, and emails at different times of the year, all to demonstrate the researcher's commitment to the community and to establish trust and understanding with the participants and community

stakeholders. This level of involvement required greater time and financial resources; however, the prolonged and repeated community engagement minimized this potential threat to credibility and increased the effectiveness of the study to address the aims.

### **Transferability**

To address transferability, identical methods and questions were explored with each study participant who selected to be part of study. A possible study limitation was that the urban-based American Indian adolescent participants may not have represented the American Indian adolescent population as a whole. With the use of a purposive sample, the representation of the adolescent population was not achieved at random and was not intended to support generalized conclusions on the adolescent population or on American Indian adolescents. Generalizations would not be possible without further research designed to involve planned comparisons. These elements minimized potential limitations and increased the transferability of the study findings.

### **Dependability**

In the time frame of the study, the adolescent participants continued with their daily lives, experienced development and maturation, and unanticipated life circumstances. A strength in the study design was its ability to be flexible and accommodate such events. The study methods could be arranged to occur at a time that was optimal for the participant, the community, and the researcher. A strength of the design was its flexibility to allow for contingencies that developed over time. The study demonstrated use of a research design for future American Indian adolescent health

research. Dependability in the study was strengthened when the design could accommodate life changes for the participants over time.

### **Confirmability**

Maintaining the ability to audit the study was accounted for in collection of evidence on the study processes, data collection, and analysis. Morse's (1994) cognitive processes of qualitative research were used to guide the data analysis and to create an audit trail (Lincoln & Guba, 1985). Records were maintained on, (a) appropriate IRB procedures, (b) raw data, (c) field notes, (d) journal entries, (e) transcripts, (g) data analysis products, (h) notes on study decisions, rationale, and (i) drafts of all written documents. In the event of an audit, the ongoing creation of the study's complete historical record increased study confirmability in its processes and products.

### **Summary**

In this chapter a general description of phenomenology, hermeneutics and use of qualitative research within the American Indian culture was provided. The background and purpose of hermeneutic phenomenology was detailed further and the chapter included an introduction to Max van Manen's approach in hermeneutic phenomenology. van Manen's (1997) four courses of action - turning to the nature of the lived experience, the existential investigation, phenomenological reflection, and phenomenological writing - used in the study and outlined. Through van Manen's methods and Morse's (1994) cognitive processes of qualitative research, the essential themes of meaning of urban-based American Indian adolescents' experiences of living with Type 2 diabetes in the study were discovered.

Steps of phenomenological data collection of the adolescent's experiences of living with Type 2 diabetes were included. A description on the use of a purposeful sample, definition of qualitative research and sample size, how the urban-based American Indian adolescents were recruited through contacts with community stakeholders for the study, and interview setting and format were explained.

Storage of data and the time frame of data collection were listed. Interviews were transcribed and stored in digital format. Participant recruitment, data collection, and analysis took place over a four year period from 2007-2011. The chapter concluded with a discussion on protection of human subjects, confidentiality, and data protection.

## CHAPTER IV

### Results

#### Introduction

This chapter begins with a demographic description of the American Indian adolescents living with Type 2 diabetes who participated in the study. Study data were collected in five one-to-one interviews with the adolescents on their lived experiences in living with this disease. Data analysis utilized Morse's (1994) qualitative research cognitive processes to guide an abstract thematic analysis within and across the interview transcripts. Following identification of theme statements, a hermeneutic interpretation was created using Max van Manen's four existentials as an interpretive guide in order to consider deeper understanding of the findings.

Max van Manen's (1997) four existentials are known as the fundamental life world themes and in the human experience the themes are considered separately, yet they exist simultaneously (p.103). The four existentials are fundamental to human life as they, "are the themes that pervade the lifeworld of all human beings (van Manen, 1997) and "represent an intricate unity of the lifeworld that can be differentiated, but not separated" (p. 104). Husserl (1970) described the lifeworld as the world people experience immediately, or the experience of the world that already exists.

Four existential themes compose the lifeworld: spatiality, corporeality, temporality, and relationality. Spatiality refers to the experience of a person whenever they become aware of their surroundings or environment, before language is used to structure and identify what is seen or felt. Spatiality refers to how the environment

influences a person. “In general, we may say that we become the space we are in” (van Manen, p. 102). For example, in a large stadium a person may feel small, part of a greater whole, or perhaps exposed. The experience of a large environment such as this can be contrasted to a smaller environment, such as a cafe, where a person may feel surrounded by others, confined, or comforted, perhaps aware of every movement of self and others.

Corporeality, or lived body, refers to the experience of embodiment, or the experience of the body in the world. Each person lives within a physical body and it is from this realm that they interact with others and the world. Through interaction the body becomes recognized and what may exist internally can open to possible discovery. The experience includes what manifests in and through the person’s body. In corporeality, there is discovery and the revealing of one’s self.

Temporality, also known as lived time, is the experience a person has of time. Lived time is multidimensional. In some experiences, a person may forget to follow objective time, also known as clock time. When this occurs, the person can be living in the moment, where objective time has little meaning to what they are experiencing. Additional aspects of lived time included the person’s perception of the past, present, and future. These aspects of time occur within temporality and include a person’s experiences of the present, memories of the past, and thoughts or hopes of the future. All aspects exist within the lived experience of time and are used by the person to form their understanding of what was, what is now, and what will be.

The fourth theme, relationality, or the lived other, involves the experience of another person or persons that share the same interpersonal space. A relationship is formed with an individual, family, or community. The relationship provides meaning and value to the individual's experiences as they are lived.

The study's analysis focused on discovering themes of importance to the participating adolescents and themes that were essential to living with Type 2 diabetes. In the creation of thematic statements, the analysis also considered the unique linguistic characteristics for each adolescent, present in their reflections. The study findings were revealed further through the hermeneutic phenomenological interpretation including review of supporting text from the adolescents' interview transcripts.

### **Participant Demographics**

Two female and three male adolescents participated in the study. All participants were between the ages of 12 and 19: One, 12 years of age, one, 16 years of age, and three, 19 years of age. Two participants lived in foster care settings; one lived with extended family, one lived with immediate family. Two female participants were mothers (Table 11).

The five adolescents lived in the Minneapolis/St. Paul, Minnesota, urban area. One participant was originally from Canada, now a resident of Minneapolis/St. Paul Minnesota for eight years and therefore met the sample inclusion criteria. All other participants were US citizens. Each adolescent reported they met the study inclusion criteria at the time of study recruitment. Information on the occurrence of Type 2 diabetes

in their lives and on their overall state of health was also shared by the adolescent. No other source was accessed to verify health information.

*Table 11: Participant Profile*

Gender	2 female; 3 male
Age in years	12, 16, 19, 19, 19
Time since diagnosis	1 to 8 years
Primary supporting family member	1- Mother 1- Grandmother; 2- Foster parent; 1- Roommate
Tribal affiliations of participants	Standing Rock, South Dakota Red Lake, Minnesota White Earth, Minnesota Rama, Ontario

All adolescents appeared to participate openly and comfortably during the individual interviews. The interviews ranged in length from 30 to 70 minutes. No adolescent participant requested a referral to a health professional or a traditional medicine or spiritual person for topics discussed during the interview process.

### **Hermeneutic Phenomenological Description using Lifeworld Themes**

#### **Lived Other (Relationality)**

Max van Manen (1997) included in his definition of the fundamental lifeworld of the lived other, or relationality, relationships with others within a shared interpersonal space. The lived other includes how people meet, approach, or connect with others in a



common space, such as reaching out for another's hand, a pat on the back, or an embrace. The experience of the lived other can begin in an indirect manner where individuals form a physical impression of another such as through a letter, by a phone call, or email. This impression is later confirmed or negated through face-to-face conversation. The reality that emerges allows transcendence of initial impressions of the other, and of self; and through this transcendence a sense of purpose, identity, support, and belonging can be discovered. The lifeworld of the lived other also applies in a larger context where humans search for the absolute other, or God, such as in a religious experience (van Manen, 1997) or spiritual realm of understanding.

The adolescent's recollections on what used to be came from memories of the past, and were used by the adolescent to consider the present diabetes diagnosis, a changed self-image, and lifestyle. A primary finding in the study was that the lifeworld of relationality was essential to the meaning of the experience of living with Type 2 diabetes for the adolescent participants. Community and family experiences from the reservation were a frequent component of the adolescents' reflections and experiences. These experiences often involved memories of a past relative or a community member on the reservation who had lived with Type 2 diabetes.

I: You mentioned other family members who have diabetes as your mom—

R: And my dad.

I: And your dad. And how about your grandparents?

R: They have it. My grandma has it.

I: Grandma has it. Anyone else?

R: My mom's younger brother has it. And he got diagnosed when he was 30.

I: Oh, ok.

R: With type 2.

I: Ok. Alright. Well...how has diabetes affected your life?

R: It was pretty scary, finding out when I was 17.

I: Ok, when you lived on the reservation?

R: Yes. Since we were born, all the way up till I was 11. Then we moved [to the Minneapolis/St. Paul urban area] when I was 11.

It runs in our family. My mom has it. I went with her to her classes to know more about it, and so if anything happens, 'cause she's a type 2 diabetic too. And she takes pills, so we gotta make sure everybody [text unclear] family members. My two brothers, me, my boyfriend and my dad went with her to the classes to know more about it.

It [Type 2 diabetes] was affecting [name of reservation removed] like, there were—how would I say that? Like how I lost my motivation, lot of people I noticed too that they just lost their motivation, you know.

I know a couple people back where I come from [name of reservation] that have diabetes, and mostly what a lot of people do—mostly everybody you see at a pow-wow or something has diabetes. Some of 'em are worse, and some of 'em are not that bad, but—like [relative's name removed], he has diabetes too.

When the adolescent was diagnosed with Type 2 diabetes, family involvement became even more important. The ability of the participant to manage their diabetes was dependent on the understanding and cooperation of their family, be it the immediate family or a foster family. Most adolescents' reflections took into consideration family experiences, as they reflected on a changed view of self - a person living with the diabetes. Relationality included reflections on, what used to be or specific reflections on family members' experiences from the past on the reservation as they lived with diabetes. What used to be provided a context for the adolescent to understand their own diabetic symptoms and experiences as they lived in the urban environment. Family relationships and experiences were reflected in their present day experiences in the urban environment including aspects of American Indian culture, and for some, fear and anxiety for the future.

It is proposed that adolescent mothers in the study had an additional level of relationality, being an adolescent living with and responsible for children. The two participants who were mother's were not only reflecting on their own experiences living with the disease, but also most likely focused on the impact of the disease on the relationship with their children. Mothers would typically be concerned for their children's well being in response to the disease and how life might be impacted by the disease in the future.

Relationality while being the essential lifeworld theme to all participants in the study, often co-existed with the lifeworld theme of temporality in the experiences represented. Most interview transcripts included themes of relationality entwined with

themes of temporality. Most participants realized a change had occurred in their physical body, their health, and in their identity as an adolescent now living with Type 2 diabetes. They sought support for these changes through direct communication with family and community, and also through their recollections of family members on the reservation who had lived with and perhaps died from the disease. These experiences were essential to adolescents living with the disease and created meaning as the disease became part of their life.

Type 2 diabetes is hard to live with. When I started giving my own shots [on the reservation], [name removed] he showed me how, right through his shirt. He was like; this is how you do it. My grandpa, he had diabetes. When I got diagnosed, he was at the hospital, I guess. My mom would always call my grandpa, and, [name removed] ain't taking her insulin, and did this—I don't know. It's a hassle. My grandpa had complications of diabetes that led to his death. And—yeah.

If I did change everything, it would eventually come back, because it runs in my family, you know. It's like in the traits of our family of all the ladies, you know, somebody—there's something wrong with so many in all the females, and I don't know, it's just—. You know my grandma has cancer, and my auntie has thyroid problems, and then she's—it's scary. The diabetes comes early, but they started getting sicker with cancer and thyroid problems when they're older. And, I don't know, it just seems like—I'd always talk to my mom and I had told her, you know, I feel like I'm gonna be one of them persons out of my aunties and my grandmother, that's gonna be one of 'em that gets sick just like them. And she's like, no, no, no, that won't happen to you. I said yeah. They started out like me, started out with diabetes, and end up going on to a lot of other things.

It feels like everybody's—I don't know, like, I have no friends that have diabetes, and it's like I'm the only one. And I'll go to my doctors and they'll be like well, you can meet people with diabetes, and it's mostly elders. And so I get really frustrated because elders is not the same as kids. Elders, they have a different mindset, and they're on top of their stuff. While kids are still growing up and still wondering—you know what I'm saying? Wondering what to become if their diabetes or whatever is in the way. I don't know. It's really, really frustrating. Sometimes I just feel like giving up.

### **Lived Time (Temporality)**

Lived time is the experience a person has of time and is variable in a person's awareness based on the ability to recall and to be receptive to their life experiences. The experience of lived time involves an individual's focus within the realm of time. In the experience of lived time, a person can be focused on the subjective experience of time, versus the objective experience of time, or clock time (i.e., 12 noon, or 8pm). In order to understand this lifeworld further, one must understand where is a person focused and how a person may regard time at any given moment of their day.

In addition to the experience of time, lived time also includes how a person is oriented in the world - past, present or future, or in combination of these areas. The dimensions of lived time - past, present, future - influence one another. Lived time involves the individual's placement of past memories within the present and how the present affects the outlook to the future. Whatever has impacted the past, traces of these experiences are retained in how the person exists in the world and are realized through habits, lifestyle, and the use of words or language. As a person lives in the present, hopes and expectations are created that either give the motivation to live in the future, or create the absence of motivation to live, all influenced by what has been experienced.

Adolescents typically experience temporality with a hopefulness for the future; a youthful expectation of the world to come. This perspective can be contrasted to the perspective of elders, who have lived many years and typically experience a temporality involving the past. While either group may have hopes and expectation for life to come, both may experience desperation or non-expectancy for life in the future, because of past

experience. This could result in a lack of will to live, or lack of a perspective to help visualize a hopeful future. An important finding in the study was that when it came to discussing the future, most participants did not experience hopeful expectation. Most had experienced the death of family and of community members due to diabetes and could imagine a similar future for themselves.

In the lived experiences of the urban-based American Indian adolescents involved in the study, temporality was second in importance to the lived other or relationality. Yet, perspectives on temporality were consistently used by participants and the two lifeworld areas were represented together throughout the transcripts. Most participants when asked the grand tour research question of what their experience had been in living with Type 2 diabetes could review their life history from an early age, through the time of diagnosis, what they were doing in the present time, and what they saw for the future.

R: So, I would go with [relative's name] when I was younger, cause I had nothing else to do, so I went with [relative's name]. And you can already tell like what diabetes was doing to their body. And a couple people were getting close to getting their legs amputated. And it was pretty scary.

I: So you definitely saw it affecting [reservation name], then.

R: Yeah, the elders. Mostly the elders. It's kind of scary.

The only thoughts I have is I wish it would go away, or I'd rather be dead than have this and live with this. That's like my thoughts. Every morning when I wake up I—I think that there's no point in—like what am I getting up for? I understand there's school—you know what I'm saying? I'm in that kind of—I don't know—that kind of state.

I: Can you say more about what you were thinking or feeling in that regard?

R: Just that I have to really be careful what I do now. Especially when I get older.

If I can get it under control, and possibly go away. But if it doesn't, then I gotta really watch what I do. Because, you know what I'm saying, is that, if I really did die or something, then that <would>—I don't know. That doesn't scare me.

People always tell me—cause I kinda don't care for my diabetes. And as I'm getting older now, it's kind of catching up to me, like my legs are hurting. If I just sit there, my back hurts a lot. And like, I just hate when people tell me to take my insulin, or [name removed] did you check your blood sugar? It's like, leave me alone. You know what I'm saying? And it gets really hard, and depressing, and it just—I wish I could do my diabetes my way. But you have to follow doctor's orders and—I know people are scared.

### **Lived Body (Corporeality)**

The lived body or, corporeality, is the understanding a person has gained through their lifetime about the physical body, its characteristics and capabilities. Importantly, the experience of the lived body involves appraisal, perspective, and ascribed meaning by the individual to the physical body. For example, to one person, a body may appear asymmetrical, or awkward; to another, the same body may appear graceful and inspiring.

Another example of the lifeworld of the lived body can be seen in the perspective of the body between individuals, for example in a romantic relationship, or the perspective of the body between a child and parent. In the latter, the child's physical body may appear separate, yet the same or similar as the parent's body (van Manen, 1997). In all examples, the lived body experience evolves from perspective and interpreted meaning.

Reflections from adolescents in this study revealed an orientation to the lived body as it was prior to diagnosis of the disease, compared to the lived body in the present, living with the disease. For some participants this reflection was communicated as a comparison between past abilities and the present inability to participate in traditional activities, such as pow-wows and singing, due to symptoms of diabetes (e.g. vision changes, fatigue, vertigo). To others similar to other lifeworld areas, the adolescents' experiences revealed specific reflections and identification with family members' corporeality experiences as they lived with diabetes on the reservation. In the lived body experience, adolescents also included reflections on sensations in their physical body related to diabetes.

After I started noticing changes too, is that I didn't have much energy no more like I used to. I wasn't motivated on running and jogging. 'Cause I used to jog and I used to lift weights and stuff. I was tired, and I'd just do one set, you know, work out, and I'd just be tired. Usually I don't get tired like that. Another thing too that kept me kinda healthy too, that which I'm still doing right now is I'm going to pow-wows and dancing and stuff like that. It kept me in shape and healthy and stuff. One thing I was worried about that was—after I started noticing, cause I haven't danced in about a year when I start noticing those symptoms. And my grandma passed away too, so I was kinda going through some stuff. And I got out of shape and start drinkin' pop and stuff like that. One thing I noticed too, I couldn't dance no more cause I was so outa shape. I'd spin around too fast and I'd almost black out and stuff. So after that I just quit dancing.



I think they (blood sugars) got high cause how I was eating. Cause it seems like when you eat certain foods or drink certain things it makes it like go super high. And they say when your sugars go high that's when you feel like you ain't got no energy, you know. Just makes you feel like really run down. I didn't really believe that until I felt that way that day. That's how I knew. And I don't know, my grandma said when she feels like that she eats something sweet, but that doesn't work for me. I don't think it does. I don't think she takes her medicine like I do.

So when I found out when I was 17, I kind of stopped and thought about it. And then when I was pregnant, too, when I had salty food my feet were just swollen. My legs would get real swollen, and I just didn't feel good. And [name removed] told me not to—watch out for salt. Cause she said that would happen. So that's what happens to her when she eats a lot of salt.

Most adolescents in the study experienced the lifeworld of the lived body through eating and drinking. The participants experienced an increased awareness of the body through use of foods and beverages that typify youth, for example, soda, potato chips, and energy drinks. The lived body experience included substituting foods and beverages which they saw other adolescents, their peers, and family using, for new and healthier choices. They frequently compared what they had been able to eat and drank in the past, to what they could not eat and drink in the present because of the disease.

Making diabetic diet changes was important to the corporeality experience for the participants. The process of eating is connected to enjoyment, affiliation with others, and identity. One way to achieve identity change as a person living with diabetes is learning new ways of eating and food substitutions. For the participants, this change required time, effort, and support from others who knew how to successfully manage Type 2

diabetes. Once food substitution was learned, most had less difficulty in managing their diabetes and attained a new understanding of the lived body.

Well I think you get diabetes from eating too much sugar and all that, and eating too much. Well, now I'm working out, but I played football. I think you just get it from eating too much and not exercising that good.

I used to be a heavy pop drinker a lot. I used to drink a lot of pop, like most every day. Like any kind of pop I'd drink, and I used ta make my tea with a lot of sugar and stuff, and I—I always used to be healthy before, and I could do all kinds of stuff—run, and I could do back-flips and all that. And I—like later on down the road I would know that it'd affect me, and I heard about people getting diabetes, and I never thought that'd happen to me. Like, right now it's like, like—cause see I just—like I think I still like get those stars in my vision and stuff like that. It's like whenever I jump up too fast or something like that.

Yeah, and [name removed] too. She kind of thought about it, <about> buying a whole bunch of stuff, like pop, and like a whole bunch of sugar stuff—a lot of stuff she gets me. Sometimes it's sugarfree and only like 100 calorie <potato chips>. I remember she got those once. But she only gets stuff that I'm available to eat. And if I get a pop, it's like a treat to me. The hardest part is not being able to eat the stuff that I want.

I: What did you have to give up that you used to eat?

R: Pop, a lot of chips, .. kind of a lot of sugar stuff.

I: And what do you eat now, compared to what you used to?

R: Well, I have breakfast, lunch and dinner, but I'm only allowed to have like one snack per day.

The lived body experience also involved adolescents' experiences in adding medication to the daily lifestyle. To the participants, medication was seen as important and with it, life could return to normal.

I: So what kind of things are helpful to you in dealing with diabetes?

R: I would have to say just the medication. And you know, they have all these little programs you can go to and like little meetings and stuff, to talk about it, but you know I don't know, I don't go to them groups or anything. A lot of things – what's helpful to me is my medicine. That helps me feel better and gets you better when you feel sick. So, I would have to say the medicine.

I don't know. I was kind of like shocked, or somethin, cause [name removed] had it when he was younger, and it made him really sick. Like he got like really super sick, and that's all I was thinkin about when, you know, they told me. Everybody says it makes you sick, but I don't know, I guess when you take your medicine it doesn't make you that sick. When you take it everyday like you're sposed to.

It started off when I got pregnant with my baby, and I got diabetes when I was pregnant with her. And then after, it never went away. It just stayed with me. And ever since then I been on medicine, and I'm taking medicine, and going to the doctor regularly, but I don't know, it just seems different from—you know, it seems like from when before I had (child's name). I felt different. But now it's just, I feel—I don't know, I feel sick sometimes from it I guess. Oh, my face got really tingly, and I was sweating all the time and just feelin' sick. And I didn't know what was wrong, and I went in and they checked my sugars and they were like super high. So, they put me on medicine, and it seems like as soon as they did I felt better.

The experience of the lived body also involved perceptions of the future. Evidence of identity change as a person living with diabetes was present in most adolescents' statements regarding the future and what they saw occurring to the body as a result of living with Type 2 diabetes. Most participants verbalized fear related to knowing about a relative's experiences that had lived with Type 2 diabetes. These perceptions either involved accepting or denying the future with the disease. While some participants were aware that the disease could cause serious complications such as blindness, amputation, diabetic coma, or death, others thought disease complications would not occur to them. Some participants revealed beliefs that the disease was reversible and it was possible to return to the previous life without the disease. Some participants related death to their personal future.

I: Ok, when you think about this in your life, what affect do you think diabetes will have in your life, in the years to come?

R: I don't know, like, with it when you get older and they say if you don't take care of yourself it can make you blind, and theres certain types you can loose your fingers and toes, you know. If you don't take care of yourself. And that's just what scares me. Causes theres a lot of my family members that did get sick off of it you know.

I: When you think of your future, what do you think about in living with diabetes?

R: I think that I won't make it past 25. But, when I was younger I used to think well, I'm not going to make it past 15 and now look I'm nineteen and I don't know.

One thing I was really scared of is how diabetes, the worst one, is where you can lose a part of your body or somethin, get your foot cut off. That's what scared me. Hopefully, that won't happen. I've got worried about it a couple of times. But then sometime I try to cheer myself up telling me that I was going to be o.k. So, I really didn't care, whatever. I went into a diabetic coma and I had six death experiences. That still didn't scare me, though. Because you know what I'm, saying, is that if I really did die or something than...I don't know, it doesn't scare me. And like, I just hate when people tell me to take my insulin, did you check your blood sugar? It's like leave me alone, you know what I am saying? And it gets really hard and depressing and it just – I wish I could do my diabetes my way.

I: What do you know about diabetes? What happens?

R: It can cause death.

Well, it's kind of scary, just hopefully if we keep doing what we're doing hopefully it will be able to get under control.

### **Lived Space**

Max van Manen (1997) explained lived space as, "...the existential theme that refers us to the world or landscape in which human beings move and find themselves at home". The initial consideration of lived space is usually the objective qualities or manifestations of a space, such as how large or small the room is, its physical appearance, and dimensions. However, similar to other lifeworld categories, lived space also refers to the experience of the space that surrounds a person before words can describe what is seen, heard, and felt.

Lived space can also refer to a person's desired experience where certain environments are sought out to support a specific experience. For example, a person may look for a certain space or environment to read a book, or a specific space to have an in-depth conversation with a friend or family member. Another consideration of lived space is that public spaces such as an office are experienced differently than a private space such as that of a person's home. A private space such as a person's home is a space directly related to who the person is, a space where the person can retreat and be who they are.

Adolescents experience lived space differently than adults. Adults often have a learned understanding or interpretation on the meaning of the space that directs their interpretation of the experience in it. A learned understanding or interpretation may also be influenced by cultural and social expectations typically associated with a space. In general, an adolescent can experience space without or with fewer learned associations.

While a majority of America Indian people now reside in urban areas, the lifeworld of lived space was not well-represented by the participants in this study, and was therefore incidental in meaning to the experience of living with Type 2 diabetes. In this study, participants' reflections on their physical environment included current living conditions, reference to their urban residence or housing circumstance, or that fact they were residing in an urban area. For several participants, perceptions of space included the idea that the reservation was home, or the lived space, where they were from, and the urban area was not referred to as such.

I: And you live here in Minneapolis? Are you here with any other of your family?

R :<Another relative's name>.

I O.K., And you are originally from Minneapolis?

R: I'm from Canada.

I: O.K, how about at <reservation name>? Do you know the community? Do you know teens there?

R: Yeah, my family's from there. I have a couple of cousins that got it.

I: Now, you mentioned you are from the <reservation name> area?

R: Yeah...

I: And so you lived there when you were younger and you go back and see things in that community. Do you see diabetes affecting <reservation name>.

R: Just their weight, like everybody's betting really big. Now, they've been – their weight can have something to do with diabetes too.

I: ... and where are you from?

R: I'm from <reservation name>

I: O.K., and how long have you been in the Twin Cities?

R: About a month now.

I: So, you lived on <reservation name>?

R: Yes, since we were born, all the way up till I was 11. Then we moved to Minnesota when I was 11.

Finally, access to health care was referenced by most participants stating they had obtained diabetes-related care from health clinics and providers specifically serving American Indians in the metropolitan area. Recollections on this experience involved individual and group instruction on diabetes, how the disease was diagnosed, and for one participant what the health professionals specifically communicated to respond to the adolescent's concerns.

### **Linguistic Characteristics of the Adolescents' Experiences**

Throughout the individual interviews characteristics of the adolescents' use of language and voice shed light on the findings and added another dimension to data analysis unable to be captured in the transcript. The use of voice, syntax, intonation, discourse markers, and use of specific words or language added meaning to the story the participant was sharing. The linguistic properties of the interviews could reveal for some participants their subconscious presence in the interview. How the participant used their voice and language to mark points of emphasis of the story or variations in the



participant's mood about subjects being discussed provided evidence on what the adolescent was truly feeling as they recalled the experiences they were sharing.

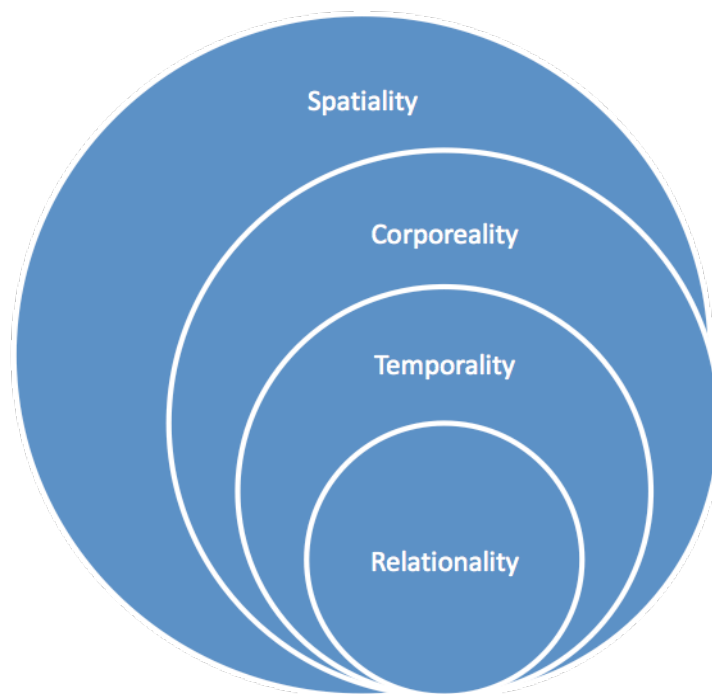
Some interviews included linguistic characteristics indicating a response to perceived oppressive circumstances. For example, linguistic characteristics in some interviews were noted when describing Type 2 diabetes as an experience and its persistence over time. For these participants, considering the stage of oppression the participant may have been experiencing as described in the study's philosophical overview was helpful. Some participants also included a historical view of the oppressive qualities of the diabetes experience, and referenced a legacy of oppression in their family as the disease had taken lives of several relatives through multiple generations.

In applying the philosophical stages of oppression created in the study's philosophical perspective, a focus for most participants' linguistics was not on overcoming, re-creation or renewal, but on survival. Also for some, themes of hope and a return to a previous time when the disease was not a part of their life were part of the linguistic expression.

### **Conceptual Organization**

A schematic diagram representing the study's findings reveals the placement of essential and incidental lifeworld categories related to the meaning of the urban-based adolescents experience in living with Type 2 diabetes (Figure 1). The essential theme relationality discovered in the study is at the center of the diagram, with incidental themes temporality, corporeality and spaciality progressing upward.

*Figure 1: Conceptual Organization Representing the Lifeworld of the Urban-based American Indian Adolescents Living with Type 2 Diabetes.*



### **Summary**

Chapter 4 presented demographic information on the adolescent participants and findings from the study data that representing the adolescents' experiences. The essential themes spotlight the essence of the youth voice and to validate the method. The findings were highlighted and explained, with essential themes identified that encompassed the essence of the meaning represented in the adolescents' experiences.

The chapter concluded by proposing a conceptual organization representing the lifeworld of the urban-based American Indian adolescents living with Type 2 diabetes for further research and programmatic consideration. The study brought forward a conceptual representation on the lifeworld themes the adolescents ascribed to their life with Type 2 diabetes and attempted to broaden understanding on this topic for health professionals of various disciplines. The findings were highlighted and explained, along with reflections on the philosophical framework of oppression emerging from the data.

## **CHAPTER V**

### **Discussion**

#### **Reflections on the Phenomenological Method**

The goal of this study was to understand what it meant for urban-based American Indian adolescents to live with and experience Type 2 diabetes. The specific aims of the study were: 1) to describe the lived experience of the urban-based American Indian adolescent with Type 2 diabetes living in Minneapolis/St. Paul, Minnesota, and, 2) to understand the role of family and community for the adolescents. The study discovered adolescents' personal meanings in living with the disease and theme statements were formed representing the essence of their experiences. Max van Manen's (1997) four existentials or fundamental lifeworld themes- spatiality, corporeality, temporality, and relationality - were used to consider a theoretical perspective on the theme statements.

Conducting a research study on the lived experiences of urban-based American Indian adolescents living with Type 2 diabetes involved making a choice to explore a topic where little was known. Narrative data from the adolescents' lived experiences was indeterminate and required the researcher to be comfortable with complexity and uncertainty. The researcher selected the phenomenological research method because of (a) the synchronicity of the method to American Indian culture, (b) the method's appropriateness to explore the research question, (c) the possibility of discovering meaning of American Indian adolescents' experiences in living with this disease, and, (d) the promise of contributing useful insights in developing age and culturally sensitive

diabetic health care. This inquiry obtained actual stories from the participants, articulated their experiences, and amplified their voices through theoretical lifeworld categories.

The use of the phenomenological method provided an opportunity to discover pragmatic and existential experiences of the participants living in an urban area, not previously discussed in the literature or described as in this inquiry. The intention through this research approach was to create greater understanding for future health research and programmatic efforts. When a research process can embrace the qualities of complexity and uncertainty, the findings promise greater levels of knowledge and comprehension on the topic for future research endeavors.

### **Reflection and Interpretation of the Findings**

This study found that lifeworld categories of relationality and temporality were integral to the experience of urban-based American Indian adolescents living with Type 2 diabetes. Adolescents who participated in this inquiry maintained connection with family and reservation community members from the past and in the present, in order to find meaning and to understand life with the disease. Adolescents revealed how these relationships assisted to meet their needs, and how they impacted their worldview and quality of life with the disease.

Applying the fundamental lifeworld themes to the findings, the theme essential to the lived experience was relationality, or lived human relation, also known as the lived other. “The lived other, or relationality, is the lived relation we maintain with others in the interpersonal space that we share” (van Manen, 1997, p. 105). The lived relation is highly personal with a high level of interpersonal significance for the individual (van

Manen). In the current study the importance of the lived other was revealed in each adolescent's experiences with significant connections to past and present relationships in their lives. It was within this lifeworld that participants conveyed a sense of identity and family support, which ultimately allowed each to become a more independent person, and to develop confidence and trust that without which, they could not move to a new level of understanding managing their disease. From the perspective of the lived other, human beings develop a conversational relationship with others. The data revealed that all adolescents in the study engaged with and learned from others in their environment, each living in communal and conversational experiences.

Radius et. al. (1980) found, in general, adolescents are not normally concerned with their health, or do not associate with alterations in health status as most perceive themselves to be healthy. When an adolescent is diagnosed with Type 2 diabetes, the related health issues are combined with the typical stage of adolescent confusion and uncertainty at this time of life. Unhealthy behaviors can be used (i.e., smoking, over-eating, substance abuse) as a way to demonstrate maturity without connecting to the future effect or consequences of the behaviors. According to Radius (1980) most adolescents fail to associate dysfunctional health behaviors with unhealthy outcomes to their own health, both physical and mental.

Radius (1980) also found that family/guardian support is needed to bridge the adolescents' world of non-association and the need to change their identity to a person living with a health condition. From their family/guardian relationships, the data in this study revealed adolescents' transcended perceptions of health and with the support of

their family/guardian developed their own understanding of living with disease. The realm of the lived other also involved the participant's ability to interpret health information, manage daily life with Type 2 diabetes, incorporate new eating and activity habits into daily life, and for most, to consider a revised outlook on the future.

A study by Khurana and White (1970) found adolescents were less likely to disclose their diabetes diagnosis because they perceived it would separate them from peers, interfere with school, restrict their diet, and necessitate the need for medicine (i.e., insulin injections). A specific challenge in adolescent health promotion will be connecting with such perceptions in order to achieve youth involvement in their own health approach and successful diabetic management. The present inquiry revealed the presence of supportive family/guardians and community in an adolescent's life could decrease these potential barriers to successful disease management.

Adolescents who are mothers or fathers have a relationship with their young children to further consider as they learn diabetes disease management. An additional level of relationality is proposed for participating adolescents with Type 2 diabetes who were parents. Some participants lived within their own stages of adolescent development, and at the same time directed and responded to their children's needs in a parent role. Some participants were single adolescent parents, coordinating assistance from family/guardians and the community to meet the needs of their young children. Their experiences as a parent and consideration of the dual role experiences were revealed through the researcher's use of additional interview question prompts about the well being of their children and how they envisioned the future in living with the disease.

In this study, temporality was also a lifeworld category represented by most participants' experiences that helped create meaning for the disease in their lives. Participants responded to the research question with reflections on the lived other entwined within the lifeworld of temporality, also known as subjective time. Results showed adolescents oriented to the past, the present, and the future in terms of understandings how to live with the disease.

### **Findings Involving the American Indian Worldview**

Aspects of American Indian culture were represented throughout the findings. All participants lived in the Minneapolis/St. Paul, Minnesota urban area, and had vivid and meaningful recollections in regards to a reservation community. In the interviews, characteristics of life on a reservation were not recalled, but rather experiences with family on the reservation living with Type 2 diabetes or with family members who had passed on after living with the disease.

Specific to urban life, all participants sought diabetes health care at clinics focused on serving American Indians. Most adolescents transformed Western medical references and language specific to diabetes care learned through their health care provider to language, words, or phrases familiar to what was used in their home environment. In one example, one participant used the word medicine in place of the word insulin. The idea of medicine in American Indian culture involves a broader holistic perspective. Therefore, use of the word medicine perhaps provided greater meaning to the participant as it involved aspects of healing and spirituality to the adolescent's experience of administering insulin.



Three doctoral dissertations created by American Indian researchers provided background and perspective towards the aims of the study. Martin (1988) looked at the modernism preferences and participation patterns among American Indian adults, staff, and board members in two types of community service agencies in Minneapolis, Minnesota. The study emphasized modernization developing within urban American Indian adults through the process of urbanization and assimilation. Martin provided perspectives to the American Indian worldview, historical factors, cultural factors, and societal structures that have influenced Indian adults to modernize in the American society.

These ideas were applied to the present study, to consider varying degrees to which American Indian adolescents and their families accept modernistic or Western health care approaches. In Martin's study a presentation of modernism versus traditionalism was used to describe a basic difference between non-Indian board members and American Indian adults they served. "To understand these differences is one step toward a solution to fundamental problems faced by agencies which work in pluralistic setting" (p. 65). Martin's study offered to the present inquiry a consideration of the participant's modern or traditional preferences and a perspective on how urbanization may impact American Indians choosing to retain traditional perspectives in non-traditional environments.

The second dissertation study influencing the study was conducted by Moss (2000) involving ethnographic research with Zuni tribal elders in New Mexico, focusing on the aging experience within a southwest North American Indian tribe. Like Martin's

(1988) study, the findings revealed differences in the American Indian elder's worldview and that of Western nurses and health care providers. This study supported the conceptual basis of the present inquiry and recommended developing greater knowledge on the differences in American Indian and the Western worldview in order to deliver culturally competent health care.

Also influential to the present inquiry was Struther's (1999) dissertation study using the phenomenological method. Struthers (1999) conducted a phenomenological study on the lived experiences of Ojibwa and Cree tribal women healers. With use of the phenomenological approach, Struthers explored the participants' experiences through traditional storytelling in response to the research question on the lived experience of being an American Indian woman healer. In many American Indian tribes and other indigenous cultures, storytelling and talking circles are traditional methods used to share important life teachings and for health education and promotion between generations, also referred to as oral history (Anderson, 2001; Hodge, 1996; Hodge, 2002; Strickland, 1996; Struthers, 2003). Four American Indian women healers were interviewed to recall their life experiences in being healers. In Struthers's study, the phenomenological approach allowed the study participants "an opportunity to utilize their traditional, native story telling process" (p.39). Struther's study provided an example of a hermeneutic phenomenological method sample size and in the use of the actual voice of the participant and their choice of words. The study contributed to development of the present inquiry by revealing how the healers' hidden as well as explicit life interpretations could be accessed

and shared with respect and sensitivity. This was an important finding to apply to future research efforts in American Indian health research.

Findings from the literature on American Indian adolescents with Type 2 diabetes were also evident in the study results and within the life circumstances of the adolescents who participated. The literature revealed that co-morbidities of being overweight and inactivity occur in a growing number of cases of Type 2 diabetes during adolescence (Bennett, 1999; Fagot-Campagna, 2001). In this study, participants spoke of their understandings of activity and being overweight and what they did each day to address these health issues. Most were aware that in order to live with diabetes, healthy eating and increased physical activity were the foundations of success. For most, this awareness was initiated through a health care provider and maintained through family/guardian support, and interpretation of health care recommendations to the daily life at home.

Previous literature has looked at disordered eating and protective factors specific to American Indian adolescents. It was observed in one study of American Indian adolescent females, that high family connectedness was a significant protective factor for disordered eating behaviors (Croll, 2002). The present study findings revealed prevention and treatment efforts existing at individual, family, and community levels and the relationality finding, as the essential lifeworld category, was consistent with Croll's finding for both male and female adolescent participants.

Adolescents with Type 2 diabetes are particularly vulnerable to poorer outcomes related to diabetic metabolic control because of the necessity for family involvement in daily disease management and the potential for family conflict in this area (Grey, 2005;

Rosenbloom, 1999). The findings from the study revealed the adolescents' families, while being geographically separated or fragmented, continued to play an important and influential role in the support of the adolescent living with the disease. The findings also revealed the lives of family members who had passed on continued to be influential to the adolescent's experiences, highlighting the American Indian cultural value placed on ancestors.

The topic of family conflict was absent from reflections for most participants. Possible insight to this finding is that typical to the culture, American Indian's think of "we" rather than "I" (Sutton & Broken Nose, 1996). Walters (1996) supported the contributions of cultural worldview, values, and diverse tribal experiences to the way American Indians express conflict. The adolescent's perception of cultural identity as an American Indian may have promoted identification with traditional values for study participants, one of which is traditional identification of "we", or a sense of belonging. Hill's (2006) research within the Flathead Nation underscored the importance of a sense of belonging, and its contributions to resilience, maintenance of mental health, and preservation of the American Indian culture, worldview, and beliefs.

Lastly, the literature supported the need to prevent and treat Type 2 diabetes in adolescents through a collaboration of health care providers, school personnel, community members, community organizations, and government agencies (Poupart, 2009). In the reflections of all participants, extended family and community were recognized within the network of support, including connection with American Indian organized collaborative health programs and clinics.

### **Implications for Research**

Implications from the study can guide future exploration of research in the area of Type 2 diabetes in urban-based American Indian adolescents. The findings of the study can help in framing the next steps or research with this population and to test further inclusion of the constructivist or critical theory paradigms. Further research could address differing worldviews, allow for greater inclusion of culturally-specific factors as well as adolescents' perspectives on living with this disease. It is also recommended that further scientific development in this area include utilization of mixed quantitative and qualitative methods, based on the constructivist or critical theory paradigms.

The researcher's views in this study were influenced by three factors, (a) knowledge on the low health status and dire outcomes that portray the current health of American Indian adolescents today, (b) American Indian cultural beliefs and world view, and, (c) the belief that adolescents can contribute valuable insights towards building a better future. The study findings supported the appropriateness of the research methods specific to American Indian culture. The literature supporting the study indicated urban, tribal or regional-specific disease occurrence was not well-known. Further research and development is needed to understand more on the scope, nature, and the increasing presence of Type 2 diabetes in American Indian adolescents.

In future research efforts, approaching an urban-based American Indian adolescent, family or community must be conducted through culturally appropriate methods such as those revealed in the sample recruitment approaches. What was essential to securing a sample for the present study was building familiarity of the researcher with

the urban community and building relationships with individual stakeholders to find eligible families. A prominent effort during this phase, was listening to stories from the community, of their experiences with other research endeavors that used the American Indian urban community for their own means and gave nothing back to the community for their participation. Part of the recruitment process was for the researcher to listen to the concerns of the community and address each respectfully and on a timely basis in order to develop trust. Trust was not created quickly and with this positive effort, the recruitment phase took years to complete. Considering the presence of historical oppression in the American Indian experience, building trust is an important part of cultural competence for future, similarly designed American Indian health research efforts.

Another key step in study recruitment was to communicate the goals and requirements of the study through a trusted community member and to allow for flexibility in the contact process. The researcher or the potential participant needed to communicate regarding the study as they desired, to explore possible participation in the study. Arranging IRB approval for this step was essential. Providing a desirable financial incentive for adolescents was appreciated by all participants and was also a key part of successful recruitment.

In developing future health care programs designed to meet the needs of American Indian adolescents use of a conceptual framework specific to culture values and beliefs is advised. A cultural framework that is holistic, relational, experienced in a circular manner, and based on the five characteristics of spirituality - relationship, unity,

honor, balance, and healing (Struthers, 1999) could provide important context for adolescents to understand the diabetes diagnosis, life events, and relationships past and present. Components of the five characteristics of spirituality; relationship, unity, honor, balance, and destiny could direction the adolescent to consider their disease in a holistic manner, and to transcend Western medicine boundaries of the disease (Struthers, 1999) to a broader culturally relevant framework for living with the disease. With the ability to incorporate traditional approaches to health such as the medicine wheel, working with medicine men or women, elders, ancestors, and ties to different reservation areas and ceremony, a cultural framework representing the relational/holistic worldview could also be used to guide culturally competent health care practice for a variety of health professions working with the American Indian population.

### **Limitations of the Study**

The study elicited descriptions from urban-based American Indian young people living with Type 2 diabetes and then analyzed and interpreted their meaning. The phenomenological method resulted in discovery of the essential themes of adolescents' experiences while meeting the adolescents' needs for increased understanding. When a credible discovery of meaning has been described and found informative, the reader is cautioned regarding making generalizations to all American Indian adolescents or to all adolescents. The participants were adolescents who had received encouragement from referral sources or family/guardians to share their experiences and stories. In volunteering for the study, it could be inferred that the participating adolescents found research an opportunity for sharing or further reflecting on their experiences. Therefore,

adolescents in this study may not have represented the larger population of adolescents and the meaning and experiences shared cannot be generalized to represent all adolescents with Type 2 diabetes.

### **Significance of the Study**

The study contributes to a broader understanding of urban-based American Indian adolescents' life experiences with Type 2 diabetes and other chronic illnesses. Even though the literature on adolescent diabetes has been emerging, qualitative aspects of the meaning of adolescents' experiences have not been well-understood. This study used a qualitative research method with the goal of contributing to greater understanding on culture and differences between worldviews for young people with diabetes. The method utilized adolescents' recollections and stories, such that the essence of the experience in living with the disease could be articulated and brought forth by the adolescents themselves.

A significant outcome in the present study is the potential to develop the phenomenological method further in order to lead to a longitudinal study of adolescents living with Type 2 diabetes. The phenomenology method lends itself to investigating prospective and future phenomenon related to the current topic and with other human experiences. The discovery of meaning and the essence of many significant experiences can lead to greater understanding of health, health care, and the role of nursing, and awaits future researchers to uncover in important human experiences.



### **Reflections on the Relevance to Nursing Practice**

Improving diabetes health care for American Indian adolescents requires a high level of expertise on American Indian culture, families, worldview differences, history, oppression, cultural traditions, adolescence, spirituality, and differences between American Indian tribes, their beliefs, and values. While Type 2 diabetes is being diagnosed in American Indian adolescents at alarming rates, most nurses and other health professionals do not have access to this expertise and therefore do not appreciate the full implications on the meaning diabetes has for American Indian people. Cultural norms value the oral tradition of communicating life views, a process also not easily accessed by those outside of the community.

However, today there is a great need for increased primary and preventive health care in this area, nursing can begin to improve health care to the population through (a) learning more on the American Indian worldview, (b) application of knowledge on worldview differences towards nursing practice, (c) focus on reversing oppression and hopelessness that continues in American Indian and other minority communities, and, (d) involving adolescents in the design and creation of solutions that address their own lives with Type 2 diabetes. With these changes, primary and preventive health care holds promise to address the health status and dire outcomes that portray American Indian adolescents living with this disease.

The conceptual basis and the findings of this inquiry encourage nursing and other health professions to continue providing healing health care to American Indian adolescents. The study points to the need for greater sensitivity to the complex nature of

culture, and the importance including adolescents' perspectives on what it is like to live with the Type 2 diabetes. The study addressed the hidden meaning, as well as what was visible or forthright in the adolescents' experiences. Nurses and other health professionals can begin to respond at the individual level by exploring topics of where the adolescent has lived in their lifetime, their understanding of oppression present in their life, what is most important to them, and inquiring on family members who have also lived with Type 2 diabetes. Overall, in order to influence and improve health, the study findings encourage the profession of nursing to continue to observe for the emergence of new data on human experience in living with a chronic disease. Nursing can also promote reflection from the client's perspective on the meaning of experiences in order to understand new pathways for health improvement.

### **Summary**

The aim of this study was to contribute to a greater understanding on how to improve the lives and health status of American Indian adolescents living with Type 2 diabetes. A hermeneutic phenomenological inquiry was utilized to uncover the meaning of the lived experience of living with Type 2 diabetes for the urban-based adolescent participant. The fundamental lifeworld themes of relationality and temporality were of primary importance, realized through connections with family, community, and American Indian. Culture the participants who had previously lived in a reservation community.

Chapter V reviewed the research goal and aims, and discussed literature and dissertation studies applicable to the findings. The discussion provided description and interpretation of the phenomenon through key literature.

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## Appendix A

### Example of Phenomenological Data Analysis

*Comprehending interview.* This step identifies sentences and phrases that represent re-occurring and prominent ideas on the experience of living with Type 2 diabetes. Listed below are the identified themes and transcript line numbers within interview one, where the supporting narrative data occurred. Themes with the highest frequency of transcript data are underlined.

1. Heavy pop drinking, drinking pop  
(21,23,23,24,33,33,34,34,35,125,127,127,127,152,204,209,210,211,214,216, 218,226)
2. “Used to be” (i.e. discourse marker) (20,23,23,24,25,29,98,127,127, 167,257,264)
3. “Back home”, uses “us”, “we” in regards to reservation community where participant lived in the past  
(43,75,138,171,231,234,234,235,235,236,237)
4. Haven’t been in shape for years(25,91)
5. Loss of motivation (67,99,139,174,174,)
6. Pow-wows, dancing (102,102,104,105,106,107,108,109,110,114,136,)

7. Uncle – past life of uncle and current status, what uncle went through living with the disease  
(46,47,48,49, 59,175,176,177,178,178,179,180,181,182,183,184,184,185, 189,190,191,192,193,194,195,196,197,198,256,257,258)
8. Exploration of symptoms – detailed description of symptoms, changes in physical capacity  
(30,31,32,33,34,35,36,37,55,57,83,84,85,86,87,88,93,96,97,98,99,100,101,104,105,106,108,101,104,105,106,107,108,109,110,125,126,127,128,129,136,137,138,139,140,146,147,148,149,153,154,155,156,162,163,164,165,166,167)
9. No trouble now in managing a diabetic diet (122,125,126,127,128)
10. Future is unclear (134,135,136,137,138,139)
11. Doesn't think the disease is serious (76,122)
12. Trying to return to the previous self, without diabetes  
(87,88,113,134,135,136,137,138,139,140,)
13. Reference to health services (54,55,56,57)
14. Loosing limb (40, 150)
15. Making substitutions with foods and eating  
(36,64,152,153,154,155,156,162,163,164,165,166,)
16. Visual messages are helpful in retaining information about diabetes  
(206,207,208,209,210,211,214,215,216,217,218,219)

*Synthesizing interview one.* Organizing supporting text into theme sections, organized by frequency and prominence in the narrative text.

Past to Present - Reflection on a past family member on the reservation.

Reflections on physical capacity in the past compared to the present life with the disease. Reflections on what the participant used to be able to do. "Back home"- using us/we when talking about the reservation. Reflection that the participant used to be a dancer at pow-wows before diagnosis.

Disease – Spoke often about being a heavy pop drinker and the experience of drinking pop. Exploration and description of diabetes symptoms. Was taught by family to substitute for beverages with less or no sugar and healthier eating practices. Detailed changes seen in physical capacity. The participant has no trouble watching diet now.

Future – Unclear. Believes disease is not serious to the participant's life. Thinks about returning to previous self without diabetes.

Health care – Neutral references to health services. Health care has contributed to understanding diabetes when visual teaching is used.

*Phenomenological theme statements.* The theme statements are an extensive description on how the lived experienced can be described and are developed from the synthesized theme statements. The phenomenological theme statements are written in response to the research question, “What is the lived experience of urban-based American Indian adolescents living with Type 2 diabetes?”

1. The lived experience of the urban-based American Indian adolescent living with Type 2 diabetes includes an orientation to the adolescents’ past experiences while living on the reservation, prior to living in an urban area. Community and family experiences were part of the adolescent’s environment when the adolescent lived on the reservation. The lived experience incorporates the adolescent’s recollections on “what used to be” with an orientation towards community, using “we” and “us” in recalling the past reservation life. What used to be includes specific reflections on family members’ experiences as they lived with diabetes on the reservation. These reflections include orientation to the physical body as it was prior to the disease, orientation to the physical body now living with the disease, as well as a comparison on the lack of participation in traditional activities such as pow-wows and singing, that the adolescent can no longer do because of the impact of the disease.
2. The lived experience of the urban American Indian adolescent living with Type 2 diabetes includes an association with foods that typify youth, for example, soda, chips, and energy drinks. The lived experience includes

needing to make choices and substitutions for foods and beverages which the participant sees other adolescents, their peers, or family using. The urban American Indian adolescent explores the disease through the experience of what is possible with eating and drinking. The adolescent compares what they have been able to eat and drink in the past to what they cannot eat and drink now with the disease. The process of making diet changes is at the center of the experience. Eating and drinking are connected to enjoyment, identity, and peer affiliation. The process of learning food substitution requires time and is best understood from family members who live with the disease and from family who are successfully managing their Type 2 diabetes. Once the process of diet substitutions has been learned, the adolescent has less difficulty watching what they eat and drink in order to manage their diabetes.

3. The lived experience of the urban American Indian adolescent living with Type 2 diabetes is paradoxical where the disease is regarded as not serious, or life lasting, at the same time recognizing the disease can cause deadly circumstances, such as amputations, blindness, and diabetic coma. It is difficult for the adolescent to associate long-term consequences with their personal future. There is belief that the disease is not serious and there is a possibility to return to the previous self without the disease.
4. The lived experience of the urban American Indian adolescent living with Type 2 diabetes includes recollection of health services that included

visual methods of teaching. Information provided to the adolescent from the health care provider is considered helpful. Helpful information includes visual models and association with adolescent peers.

*Recontextualizing.* Recontextualizing involves creating a linguistic transformation statement to represent select phenomenological theme statements. The goal is to develop a statement to transcend the world of the participant's text and re-create the theme area into a broader reflective statement. This statement is the hermeneutic interpretation or reflection of what it is like to live with this disease.

*Recontextualized Statement 1* - In order to understand the present symptoms with the physical body, the lived experience of the urban-based American Indian adolescent living with Type 2 diabetes includes an association with past experiences of cultural and family support.

*Recontextualized Statement 2* - The lived experience of the urban American Indian adolescents living with Type 2 diabetes involves a change in identity and acquiring knowledge on how to include foods and beverages that are supportive to the diabetic lifestyle in order to manage the disease. This knowledge is observed and learned from the adolescent's family and community and is key to accepting and managing the disease.

*Recontextualized Statement 3* - The lived experience of the urban based American Indian adolescent living with Type 2 diabetes exists in present life circumstances with a strong association to the self from the past.



*Recontextualized Statement 4* - The lived experience of urban American Indian adolescents living with Type 2 diabetes references health care that can be directly associated with the adolescent's environment and life circumstances.

*Theorizing interview one.* The analysis uses the four existentials or fundamental life world themes, spatiality, corporeality, temporality, and relationality to consider theoretical understanding of the recontextualized statements. The lifeworld themes are used to compare and contrast the recontextualized reflective statements to determine if the statements were essential or incidental to the lived experience as demonstrated below.

*Application of the fundamental life world themes and interview theme analysis*

	Similarities between re-contextualized statements	Differences between re-contextualized statements	Incidental to the lived experience	Essential to the lived experience
1	Past experiences with cultural practice and family	The physical body	Family/Relationality  Perception of time/Temporality  The physical body/Corporeality	Relationality
2	Change in identity	Foods and beverages that must be substituted	Identity/ Temporality, Relationality	Relationality
3	Change in life circumstances	Awareness of present and the past	Contrasting past and present/ Temporality	Temporality

## Appendix B

### Complications of Diabetes

Heart Disease and Stroke	In adults 20 years of age and older, approximately 65% of deaths among people with diabetes were due to heart disease and stroke, with the risk for stroke two to four times greater than adults without diabetes (Centers for Disease Control [CDC] National Center for Chronic Disease Prevention and Health Promotion, 2005).
Blindness, End-stage Renal Disease	Diabetes is the leading cause of new cases of blindness among adults aged 20 to 74 years of age and is the leading cause of end-stage renal disease accounting for 44% of new cases (CDC National Center for Chronic Disease Prevention and Health Promotion).
Nervous System Disease	Nervous system disease occurs in about 60% to 70% of people with diabetes and results often in impaired sensation to the feet or hands and other nerve problems like carpal tunnel syndrome (CDC National Center for Chronic Disease Prevention and Health Promotion).
Amputations and Dental Disease	Amputations and dental disease occur more frequently among people with diabetes, and among young adults, those with diabetes have about two times the risk of dental disease as those without diabetes (CDC National Center for Chronic Disease Prevention and Health Promotion).
Birth defects and hyperglycemia in newborns	Poorly controlled diabetes before conception and during the first trimester of pregnancy can cause severe birth defects and hyperglycemia among newborns (CDC National Center for Chronic Disease Prevention and Health Promotion).
Ketoacidosis and Coma	Uncontrolled diabetes can many times lead to a biochemical imbalance that can cause life threatening events such as diabetic ketoacidosis and coma (CDC National Center for Chronic Disease Prevention)

## Appendix C

### Individual Interview Question Prompts

1. What is the name you call this?

#### **Time of onset**

2. What can you tell me about when you found out about your (diabetes or pre-diabetes)?
  - a. How did you find out you had (diabetes or pre-diabetes)?
3. Why do you think it came on (started) when it did?

#### **Etiology**

4. What is the reason (cause) for your (diabetes or pre-diabetes)?
5. What family members have diabetes?
  - a. What about other teens our age; do they have this too?

#### **Course of Illness**

6. What does it feel like for you to have (diabetes or pre-diabetes)?
7. How does your (diabetes or pre-diabetes) affect your life?
  - a. What kinds of problems does it cause?
8. What have you heard of that can happen to a person who has diabetes?

#### **Pathophysiology**

9. Do you feel different in your body because of your (diabetes or pre-diabetes)?
10. Please show me the places on your body where it shows up.
  - a. Explain to me how diabetes works.
  - b. Is your blood sugar low or high? Please tell me more about your blood sugar.

#### **Treatment**

11. What kind of medical help do you get for your (diabetes or pre-diabetes)?
12. What kind of things would be helpful in dealing with (diabetes or pre-diabetes)?
13. What kinds of things are not helpful with your (diabetes or pre-diabetes)?
14. What would you like to see to help treat your (diabetes or pre-diabetes)?
15. What do you do everyday to help your (diabetes or pre-diabetes)?
16. You have (diabetes or pre-diabetes). When you think of your future, what effect can (diabetes or pre-diabetes) have?
17. How would you like your (diabetes or pre-diabetes) to be handled (treated) in the future?
18. Do you have any other health conditions or illnesses?
  - a. Which one bothers you the most?

**Diet and Exercise**

19. What have you been told about your diet – the foods you eat?
20. What have you been told about exercise?

**Prevention of diabetes or pre-diabetes**

21. What are some things somebody can do so they won't get (diabetes or pre-diabetes)?
  - a. What can children do so they won't get (diabetes or pre-diabetes)?

**Emotions**

22. What are some feelings you have everyday about your (diabetes or pre-diabetes)?
23. What are some things you do that help you solve (cope/manage) your feelings about your (diabetes or pre-diabetes)?

**History of tribal people**

24. Tell me about the history of the Indian people from your tribe.

**Culture**

Let's talk about the Indian culture

25. Are there certain cultural events or activities you take part in?
26. Do you participate in American Indian ceremonies?
  - a. What ceremonies/customs do you participate in?
27. You see things in your neighborhood. What effect does diabetes have on Indian people who live around you?

**Traditional healing**

28. Do you think an Indian traditional healer (medicine person) can help with diabetes?
  - a. Have you seen an Indian healer?
29. Do you know of any Indian traditional medicines that treats diabetes?

**Spirituality**

30. What is spirituality to you?
31. What type of religious or spiritual activities are you involved in?
32. As you see it, do you think diabetes has an effect on (influences) spirituality?

Is there anything else you would like to say?