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Indigenous Knowledge, Land, History, and Health: The Construction of Diabetes on the White Mountain Apache Indian Reservation

Tennille Marley

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**INDIGENOUS KNOWLEDGE, LAND, HISTORY, AND
HEALTH: THE CONSTRUCTION OF DIABETES ON THE
WHITE MOUNTAIN APACHE INDIAN RESERVATION**

BY

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B.A., Elementary Education, University of Arizona, 2002
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DISSERTATION

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DEDICATION

To Scott, my best friend and husband, who encouraged me and believed in me from the time we first met.

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ABSTRACT

American Indians and Alaska Natives are at an increased risk of developing type 2 diabetes and are more likely than the general population to suffer from diabetes-related complications. This study attempts to clarify the relationships between indigenous knowledge, land, local history/historical trauma, and diabetes on the White Mountain Apache Indian Reservation, using “place” as an anchoring concept. The concept of place is largely absent in sociological literature, and a growing number of researchers argue that place should be central to sociology. Further, many researchers argue that place and context matter for health and are necessary for a deeper understanding of societal inequalities.

I conducted an explanatory, single-case study research design of the White Mountain Apache Indian Reservation supplemented by in-depth interviews. This study is the first step for future work and will serve to develop a working methodology and establish preliminary findings. Quantitative and qualitative data, including interviews with community members, were collected to

examine the relationship between indigenous knowledge, land, the experiences of local history/historical trauma, and diabetes.

Findings suggested that historical experiences and losses associated with those experiences disrupted the Apache way of life, the effects of which are seen today. Historical experiences created changes that affected indigenous knowledge, including how people interacted with the land, how they prepared and consumed food, and their consequent activity levels. This research contributes to theory by highlighting the role of place, especially the role of place-based history to diabetes.

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Chapter 1: Introduction to the Study

These fields look after us by helping our corn to grow. Our children eat it and become strong. We eat it and continue to live. Our corn draws life from this earth and we draw life from our corn. This earth is part of us! We are of this place. We should name ourselves for this place. We Are *Gad'O'ááhn*. This is how it shall be. (On the origin of clans, in Basso, 1996, p. 21)

Land and history are closely associated with well-being among the people on the White Mountain Apache Indian Reservation. I am Ndee (or White Mountain Apache), born of the Biszaha (Cliff Bank People/Roadrunner) and of the Dlo' (Butterfly) clans. I grew up on the White Mountain Apache Reservation in a community called Yangongai, and it is all part of me. My cousins lived next door to me, and my grandmother was just down the road. My summers were spent swimming in the river and riding to the lakes in the back of my family's pick-up truck. I ate corn fresh off the stalk from my grandmother's cornfield and helped my grandmother sort ground acorn under her shade while she told stories about the time when we could talk to animals.

When I think of home, I think of my relatives and the landscape: rivers, streams, lake, trees, and mountains. When I'm home I get to dance to songs/prayers. My moccasined feet massage the earth to ensure the Creator hears our prayers. As an Apache, I strive for *gozhóó* (beauty/goodness), including an intimate spiritual connection with and knowledge of the natural world. I was taught that this connection is necessary to respect one's self,

others, and all living things. The Ndee word for land is *ni'*, which means “both land and mind”; that is, country and way of thinking (Welch & Riley, 2001, p. 2). This term *ni'* and the opening quote illustrate the significance of place for White Mountain Apaches and the connection between place and Apache knowledge.

Today, Apaches are dying from alcoholism, car accidents, cancer, and diabetes. I lost my grandmother to a complication in her dialysis treatment. She lived with type 2 diabetes for most of her life. I lost my cousin Esther to cirrhosis when she was merely 40 years of age. My brother struggled with alcohol and marijuana addiction for most of his life, and he is currently more than a hundred pounds overweight. Several years ago my sister-in-law almost died from alcohol withdrawal, having spent three weeks in intensive care. Since graduation from high school 18 years ago, I have lost at least 15 of 95 classmates. All of my aunts and uncles have diabetes and many of them also have high blood pressure. No one should have to lose friends and family from deaths that are preventable.

My “Apache-ness” is central to my work and my own indigenous knowledge is valid and integral to understanding health in Native communities. The concept of positionality is relevant to discuss. By positionality I mean that my identity is shared with my research subjects (Chavez, 2008); we are all White Mountain Apaches. Because I am conducting this research in my own community, I am both an insider and an outsider, which means that I must be aware of my position in this research context. By insider, I mean that I am an Apache who grew up on the reservation and conducting research with other

Apaches. As an outsider, I am a researcher with an advanced college education who has not lived on the reservation for 13 years.

Other Native or American Indians researchers have tried to reconcile their insider/outsider position and many have characterized the insider position as a strength to their research. For example, Swisher (1998), stated:

How can an outsider really understand life on reservations, the struggle for recognition, sovereignty, economic development, preservation of language and culture? Perhaps they can gain a high degree of empathy and act as “brokers” of sorts, but it takes American Indians and Alaska Natives themselves to understand the depth of meaning...to ask appropriate questions and find appropriate answers...The view from the outside remains the same; it’s the inside view that varies” (Swisher, 1998, p. 194).

There are many advantages to conducting research as an insider in terms of positionality and data collection (Chavez, 2008). In terms of positionality, for example, the relationship between research and participant are equalized, rapport building is expedient, and legitimacy is almost immediate. Advantages related to data collection included knowledge of history and practices in the community, stimulation of informal interaction and behavior, and knowledge of hidden behaviors, perceptions, and nonverbal gestures of embarrassment and discomfort.

Despite these advantages there were several complications that I encountered. For example, because of my positionality, I was faced with issues such as remaining unbiased with regard to tribal politics and value conflicts as a

research and as a community member. The value conflict was mostly a result of my age and gender. In a few of my interviews, because of the status of people as elders, I allowed some interview participants to control the interview. Another issue was with respect to my gender, generally in Apache culture, unmarried men and women do not interact. As a result, I interviewed many more women than men. Other researchers have acknowledged similar issues related to positionality such as bias in the field and in selecting participants and selective reporting of results (Chavez, 2008).

In order to navigate this insider/outsider status, I followed several of Smith's (2005) guiding principles for research with indigenous communities such as reflection, respect, resilience, reciprocity, responsibility, and revolution. Smith states that research with indigenous communities require researchers to reflect on their privilege status from where they operate, acknowledge the pain of Native communities, and develop empathy (2005). As an outsider, I have to reflect on my privilege as a researcher, as a college educated Apache, as a person in a higher socioeconomic class. This became apparent with a few of my participants when they expressed that they did not know anything, had only a high school education, and doubted that they knew anything useful. Hearing people talk about their inferiority was and is painful. As an insider, I feel the pain and understand it.

Respect is a core value of the White Mountain Apache and is essential in my research. In terms of respect, Smith (2005) states that researchers must value and prioritize indigenous epistemologies, knowledge and cultural protocols.

At the end of almost all my interviews, I was thanked. People were grateful that someone was asking them about what they knew and valued what they said.

Resilience of the community is another guiding principal (Smith, 2005). Researchers should recognize the strength and resilience of tribal communities. The White Mountain Apache continues to conduct many of its ceremonies, especially the puberty ceremonies for girls. The fact that much of the culture is still intact speaks to the resilience of the Apache people. Instead of looking exclusively at individual behaviors, I have acknowledged the contextual, structural, and historical factors that affect health.

In terms of my research, reciprocity and responsibility are two principles I have and will continue to practice (Smith, 2005). I have a responsibility to reciprocate by sharing my findings in a culturally meaningful way. Revolution, the last guiding principle, means to change research with indigenous communities by decolonizing and indigenizing research to benefit of all people (Smith, 2005). To decolonize and indigenize research is to start from the understanding of indigenous people. This research started from an Apache concept and strives to understand what diabetes means to Apaches. I recognize that Apache experiences and knowledge are central to understanding diabetes.

The focus of this research is type 2 diabetes. Type 2 diabetes is the most common form of diabetes. "Type 2 diabetes mellitus is characterized by hyperglycemia [high blood sugar], insulin resistance, and relative impairment of insulin secretion" (McCulloch & Robertson, 2012). Insulin is needed to move blood sugar (glucose) into cells, where it is stored and later used for energy.

Table 1.1.			
Types of Diabetes and Characteristics			
Characteristic	Pre-Diabetes	Type 2 Diabetes	Type 1 Diabetes
Definition	A person has blood glucose levels that are higher than normal but not high enough to be called diabetes. (Medline, 2013)	"Hyperglycemia (high blood sugar), insulin resistance, and relative impairment in insulin secretion" (McCulloch & Robertson, 2012)	The pancreas produces little or no insulin, a hormone needed to allow sugar (glucose) to enter cells to produce energy (MayoClinic, 2013)
Risk Factors	Overweight, inactivity, advancing age (+45), family history of type 2 diabetes (MayoClinic, 2013)	Overweight, fat distribution around abdomen; inactivity, age (45+), family history of diabetes, and history of pre-diabetes and/or gestational diabetes (MayoClinic, 2013)	A family history of type 1 diabetes; genetics (the presence of certain genes) (MayoClinic, 2013)
Symptoms	Most people do not have symptoms. (Medline, 2013)	Increased thirst; urinating often; feeling very hungry; fatigue; losing weight without trying; having sores heal slowly; having dry; itchy skin; losing the feeling in your feet or having tingling in your feet; having blurry eyesight. (MayoClinic, 2013)	
Treatment	Eat healthy foods, increased physical activity, loss excess weight, medication (in some cases) (MayoClinic, 2013)	Blood sugar monitoring, healthy eating, regular exercise, and diabetes medication or insulin therapy (in some cases) (MayoClinic, 2013)	Taking insulin, exercising regularly and maintaining a healthy weight, eating healthy foods, and monitoring blood sugar (MayoClinic, 2013)
Complications	Progression into type 2 diabetes, and development of heart disease, and stroke.	Heart and blood vessel disease, nerve damage, kidney damage, eye damage, foot damage, skin and mouth conditions, osteoporosis, and hearing problems (MayoClinic 2013)	

Insulin resistance occurs when a person's tissues, specifically fat, liver, and muscle cells, do not respond correctly to insulin and blood sugar does not get into these cells to be stored for energy. When sugar cannot enter cells, high levels of sugar build up in the blood (hyperglycemia) (McCulloch & Robertson, 2012). The number of people with diabetes and pre-diabetic conditions is growing across all population groups; however, it is more common in racial/ethnic minority groups, including American Indians (AIs¹). Table 1.1 lists the various types of diabetes and characteristics including definitions, risk factors, symptoms, treatment, and potential complications.

Background of the Problem/Study

There are 566 federally recognized tribes in the United States (Bureau of Indian Affairs, 2012). According to the 2010 U.S. Census, 0.9% or 2.9 million reported their race as wholly American Indian and 2.3 million as wholly American Indian or in combination with another ethnicity, for a total of 1.7% or 4.1 million of the total population. Although the number of AIs is relatively small, this population experiences disparities in many areas, especially in health. For example, the Indian Health Service (IHS¹, 2012a) indicates that AIs experience disproportionately higher mortality when compared to the non-Native population from diabetes (177% higher), tuberculosis (500% higher), alcoholism (514% higher), unintentional injuries (140% higher), homicide (92% higher), and suicide (82% higher).

¹ IHS refers to the Indian Health Service, an agency within the Department of

When it comes to diabetes, AIs experience higher rates of diabetes-related complications and mortality when compared to the non-Native population. The overall rate of diabetes for AIs is 16.1% versus 7.1% for non-Hispanic whites (CDC, 2011). AIs are more likely than the general population to suffer from diabetes-related complications such as kidney failure (3.5 times higher) and cardiovascular disease (3-4 times higher) (IHS, 2013). The death rate due to diabetes is 1.6 times higher for AIs as compared to the general population (34.5 versus 21.8 per 100,000) (CDC, 2011).

In order to address the epidemic of diabetes in Indian Country, Congress passed legislation in 1997 to create the Special Diabetes Program for Indians. The current annual budget for the program (\$150 million per year) funds 399 programs (IHS, 2011). Despite the amount of resources going into diabetes education and prevention, mortality rates are not decreasing. This plateau in rates suggests a need to examine diabetes from a different perspective.

Early diabetes research approached diabetes in American Indian communities from a deficit perspective, emphasizing “faulty” genes, diets, and other unhealthy behaviors: “The prevailing research focusing on obesity, nutrition, and individual health—although undeniably contributors to health outcomes—obscures social and historical issues that are even more fundamental to the etiology of the disease” (Ferreira & Lang, 2006, p. xix). Ferreira and Lang (2006) expressed the need to consider other potential contributing factors related to diabetes, including colonization, social inequality (including racism and ethnocentrism), and the “socio-political pathology” of diabetes. Although the link

between diabetes and diet is robust, the effects of colonization on AIs are devastating and cannot be ignored. Many AI health disparities are associated with colonization, including land loss and destruction, inadequate housing, poor living conditions, changes in lifestyles etc. (LaDuke, 1999; Gracey & King, 2009; Stephens, Nettleton, Porter, Willis, & Clark, 2005). Ferreira and Lang (2006) called for diabetes research that:

- “Reconsiders the diabetes epidemic with a broader semantic domain that extends well beyond the narrowly defined biologic and genetic condition into the realms of social relations, history, and the politics of Indigenous identity, which can lead us to ...
- consider diabetes as a reaction of the organism to adverse life conditions, rather than a morbid or pathological phenomenon superimposed on the organism.” (p. 16)

In this study, I will clarify the relationships between indigenous knowledge, land, local history/historical trauma, and diabetes on the White Mountain Apache Indian Reservation, using “place” as an anchoring concept. As evidenced by the beginning quote, the concept of “place” is important to White Mountain Apaches, who believe they were placed in the White Mountains of Arizona by the Creator in the beginning. It is where they learned to be *Ndee* (“the people”) and how to live on their land. As Vine Deloria, Jr. states (2003): “American Indians hold their lands—places—as having the highest meaning, and all their statements are made with this reference point in mind” (p. 61). AIs are also situated in several different “places”—socially, geographically, politically, and contextually. Given

the distinct “places” that American Indians occupy, coupled with the health inequalities they experience, there is a need to examine how these places and contexts relate to health.

Importance

The work I am proposing will contribute to the sociological literature by conceptualizing “place” and connecting it to health. In the field of sociology the concept of place is largely absent (Gieryn, 2000; Urry, 2004; Cheyne & Binder, 2010). However, an increasing number of researchers argue that place and context matter for health and are necessary for deeper understanding of societal inequalities (Popay, Williams, Thomas, & Gatrell, 1998 & 2003; Macintyre, Ellaway, & Cummins, 2002; Cummins, Curtis, Diez-Roux, & Macintyre, 2007; Burton, Kemp, Leung, Matthews, & Takeuchi, 2011; Kemp, 2011; Walters, Beltran, Huh, & Evans-Campbell, 2011). Previous theoretical work and empirical analysis of place suggest a need to develop multifaceted conceptions of place that include geographic location, material form, infrastructure, and meaning (Gieryn, 2000; Macintyre et al., 2002; Cumins et al., 2007). Further, Walters et al. (2011) call for “work in the area of place and health, specifically examining how AI health outcomes can be contextualized and understood in light of historical losses and disruptions tied to place or land” (p. 166).

Sociological research does not consider indigenous notions of place. Few sociologists examine indigenous knowledge and its connection to health from a sociological perspective. The work I am proposing will contribute to the sociological literature by doing what few have done: conceptualizing place and

examining how it may be related to health. I conceptualize “place” for AIs as a position in the greater social hierarchy, a place where history and colonization (and tremendous change) has occurred and continues to occur, and where indigenous knowledge is maintained (and/or lost), and as an important determinant of diabetes. This study may help inform policy by highlighting potential points of intervention for diabetes prevention.

Purpose of the Study, Research Questions, and Hypothesis

In this study I look at the association among the “places” AI are situated. I examine the connections of land and place, knowledge and place, history and place, and their relation to diabetes. I expand on the theory of Popay et al. (1998) on place and health and incorporate Krieger’s (2005) conception of “embodiment” as the mechanism underlying these associations.

The theorization of health inequalities by Popay et al. (1998 & 2003) calls for the “conceptualization and measurement of ‘place’ within a historical location in which macro social structures impact on individual lives” (2003, p. 399), and asks us “to consider how ‘places,’ conceptualized in this way, are understood within lay experience of ‘the everyday life-world’” (1998, p. 634). They state: “There is much to be gained from adopting an historical-sociological perspective which defines inequalities in health neither as a category nor a structure but as an historical phenomenon, something which in fact happens in human relationships” (2003, p. 386).

“Embodiment” (Krieger, 2005) is the mechanism underlying the association between place (macro-, meso-, and micro processes) and diabetes.

According to Krieger (1999), “Eco-social theory” posits “ ... that how we develop, grow, age, ail, and die necessarily reflects a constant interplay, within our bodies, of our intertwined and inseparable social and biological history. ... Taking literally the notion of ‘embodiment,’ this theory asks how we literally incorporate biologically—from conception to death—our social experiences and express this embodiment in population patterns of health, disease, and well-being” (p. 296). In other words, place and what happens in place impact the body.

Specifically, my research questions are:

How is diabetes constructed by the White Mountain Apache?

How does place, including indigenous knowledge, meaning of land, and the experiences of local history/historical trauma, relate to diabetes on the White Mountain Apache Reservation?

I hypothesize that “place” is related to diabetes on the White Mountain Apache Indian Reservation. Welsh and Riley (2001) state: “A more recent threat to the land and its connections to the people is seen in the growing distance between people and place ... [However,] the Ndee homeland—as it has nurtured countless Apache generations and been shaped both physically and conceptually through actions, reflections, and oral traditions—holds the key to restoring much of the harmony and health of the White Mountain Apache community” (Welch & Riley, 2001, p. 8).

I see a growing distance between land and people that is evident by Apaches neglecting their cornfields. Stories are no longer used to teach and guide people. I also see that people generally no longer know the history of the

tribe, and I see failure in the transmission of the Apache language, knowledge, and values from one generation to the next. There are consequences for drifting away from what is essentially an Apache worldview. I think the consequences are social, emotional, spiritual, and physical. The neglect of Apache tradition and knowledge is related to the health status of Apaches today.

Dissertation Overview

There are six chapters in this dissertation. In this chapter I presented an introduction and overview of the study. I started with how and why the concept of place is important for the White Mountain Apaches and why the topic is important to me. Then I presented a brief background of the problem—diabetes in AIs—followed by a statement on the current study. I subsequently reviewed why the study is important, including contributions from the sociological literature. Later presented was the purpose of the study, my research question, and my hypothesis. Finally, I provide an overview of all the chapters in the dissertation.

Chapter 2 contains a review of the literature on sociological theory and indigenous theory and the conceptual framework for my study. A rationale for this research is presented based on current AI diabetes research; afterwards I move on to discuss the concept of place in sociology and the role of place in health research, including a discussion of the social determinants of health. I then discuss place and its relation to history and historical trauma, as well as its relationship to indigenous knowledge. Finally, I present my conceptual framework.

In chapter 3, I give a brief overview of Apache history, focusing on the White Mountain Apaches. Then I provide a profile of the tribe today. Chapter 4 consists of the research design and methodology. In this chapter I provide an overview of the study: my research design and rationale; sampling, site selection, and nature of interview participants; data collection, including recruitment and data gathering; and, finally, data analysis.

Chapter 5 focuses on research findings. Presented are a few stories followed by a few diabetes anecdotes, and then thematic findings. Findings from the interviews suggest that place-based history and the experiences of that history—including colonization, confinement, distribution of rations, and historical trauma—are related to diabetes today. Additionally, indigenous, or, specifically, *Apache* knowledge is affected by historical experiences, exhibited by a diminishing relationship with the land, loss of language, and loss of respect, all of which contribute to the diabetes problem today. Finally, findings related to individual behaviors and contextual factors such as the physical environment and knowledge and access with respect to healthy food are presented.

Chapter 6 concludes the dissertation. In the last chapter I provide a summary of the findings and connect them to the conceptual framework. I end with a discussion of how I anticipate to advance theory in sociology and indigenous studies and consider implications for policy and further research.

Chapter 2: Sociological Theory and Indigenous Theory

Type 2 diabetes remains a major health concern among AIs. Much of the AI diabetes research, prevention, and intervention efforts target individual behaviors such as diet and exercise, as well as clinical outcomes such as blood sugar levels and cholesterol (IHS, 2011). However, there is a long history of works analyzing social conditions that contribute to ill health (Durkheim, Spaulding, & Simpson, 2010; Chadwick, 1842; Virchow, 1985). For example, Durkheim's work highlights social phenomena and social-structural determinants of suicide. Durkheim studied suicide across groups; specifically he studied the character of the groups, their characteristic ways of bringing about cohesion and solidarity among their members, and not the psychological traits or motives of the component individuals.

More recently, other researchers have also highlighted the impact of social conditions on health (Link & Phelan, 1995; Navarro & Shi, 2001; Marmot, 2001; Marmot & Wilkinson, 2006; Commission on the Social Determinants of Health (CSDH), 2008). For example, Link and Phelan (1995) argue that social conditions, particularly socioeconomic status, are fundamental causes of disease. Socioeconomic status influences disease outcomes, is connected to risk factors for disease, and affects access to resources including "money, knowledge, prestige, power, and beneficial social connections that protect health no matter what mechanisms are relevant at any given time" (Phelan, Link, & Tehranifar, 2010, p. S28).

In addition, overall, income and wealth are largely believed to be the greatest predictors of health (Wilkinson & Pickett, 2011). Compared to other countries the U.S. has the greatest income inequality and the worst health inequalities. The social gradient, present in most societies, is the hierarchy of individuals in terms of social, political and economic advantage. Many studies, particularly psychosocial comparison approaches, have suggested that the steeper the social gradient the worse the health outcomes (Raphael, 2006). Individuals lower on the social gradient are more likely to experience serious illness and premature death when compared to individuals who are positioned higher in society. Those higher on the gradient experience more financial security and access to resources that promote better health (Wilkinson & Pickett, 2010).

Emerging research demonstrates that disease and ill health are the result of the “circumstances in which people grow, live, work, and age, and the systems put in place to deal with illness. The conditions in which people live and die are, in turn, shaped by political, social, and economic forces” (CSDH, 2008, p. iii). For AIs, the places in which they “grow, live, work, and age” are intertwined with history and colonization, including land loss and destruction, breakdown in social structure, and change in lifeway (LaDuke, 1999; Ferreira & Lang, 2006; Gracey & King, 2009; Walters et al., 2011).

This chapter contains the theoretical framework for the study. After I identify needs based on the diabetes literature, I begin to build my theoretical framework of place to examine diabetes and its relationship to place. First I

examine and analyze the concept of place in the sociological literature. Then there is a discussion of the role of place in health research with an emphasis on the social determinants of health and place-based history and health. Afterwards I introduce indigenous notions of place, land, as well as indigenous knowledge *per se*. The chapter concludes with a presentation of my framework: Place, a Core Determinant of AI Health.

American Indian Diabetes Research

Als experience disproportionately higher rates of diabetes and diabetes related complications when compared to the non-Native population. According to the IHS, the rate of diabetes for Als is 16.1% compared to 8.3% for the general non-Native population (IHS, 2012). Als are also more likely than the general population to suffer from diabetes related complications such as kidney failure (3.5 times higher) and developing cardiovascular disease (3-4 times higher) (IHS, 2012). In order to address the epidemic of diabetes in Indian Country, the U.S. Congress passed legislation in 1997 to create the Special Diabetes Program for Indians (SDPI). Current annual funding for the program is \$150 million per year for 404 programs (IHS, 2013).

The Diabetes Prevention Program (DPP) is perhaps the most influential study on AI diabetes research, prevention, and intervention efforts (Diabetes Prevention Writing Group, 2002). The DPP was a clinical research study whose aim was to determine whether weight loss through dietary changes and increased physical activity, or treatment with the diabetes drug metformin, could prevent or delay the onset of type 2 diabetes. All of the study participants were

overweight and had pre-diabetes (a precursor to diabetes). Forty-five percent of the study participants were from high-risk groups, including African Americans, Alaska Natives, American Indians, Hispanic/Latinos, and Pacific Islanders. Results from the study indicate that modest weight loss through dietary changes and increased physical activity is associated with reduced risk of developing diabetes (DPP, 2002).

The DPP was so influential that in 2004 the Special Diabetes Program for Indians established demonstration projects (SDPI-DP²) that adapted the DPP lifestyle intervention for AIs. The intervention included group classes and individual coaching sessions (IHS, 2011). Results from the SDPI-DP mirrored results from the DPP. AIs enrolled in the SDPI-DP experienced changes in risk factors such as weight loss and lifestyle behaviors, including increased consumption of healthy food, decreased consumption of unhealthy food, and increased exercise at follow-up (IHS, 2011). In addition to the SDPI-DP, the SDPI also funded a similar program that focused on cardiovascular disease (SDPI-HH³), obtaining similar results.

In addition to the SDPI-DP and SDPI-HH, the SDPI also funds community directed diabetes programs (IHS, 2011). One component is grant funded

² SDPI-DP refers to the Special Diabetes Program for Indians Demonstration Projects, funded by the Indian Health Service.

³ SDPI—HH refers to the Special Diabetes Program for Indians (SDPI) Health Heart (HH) demonstration program.

programs that allow communities to design and implement interventions using best practices, such as adult weight management, breastfeeding, cardiovascular disease, chronic kidney disease, nutrition and physical activity (IHS,2011). The other components are interventions that target clinical outcomes, such as blood sugar levels, cholesterol levels, and blood pressure. The 2011 SDPI report to Congress states: “The SDPI Community Directed Programs, now with more than a decade of experience, have implemented and sustained diabetes interventions that have significantly improved clinical outcomes for AI people” (p. 16).

Despite the success of the SDPI, its attempts to address diabetes in Indian Country are misguided for several reasons. First, the SDPI focuses solely on individual behaviors and clinical outcomes. Many of the health issues on reservations are created by structures and society, including issues such as colonization, inadequate housing, segregation, and poor working and living conditions (LaDuke, 1999; Marmot & Wilkinson, 2006; Gracey & King, 2009). Another issue with the SDPI is that its funding is not guaranteed; funding for the SDPI expires in September 2013 unless Congress takes action. The SDPI states that its programs have sustained interventions; however, what happens to the programs if funding is not reauthorized? The final problem with the SDPI is that its programs do not consider alternative or cultural explanations for diabetes such as social inequality, colonization, racism, and social and/or historical etiologies (Ferreira & Lang, 2006).

In addition to the DPP and SDPI, much of the diabetes research with AIs and AI communities continues to focus on Western medical notions of diabetes,

with a continued focus on individuals. Research that examines or attempts to understand alternative explanations for diabetes, as with most diabetes research, continues to recommend individual level points for interventions or recommends more research (Weiner, 1999; Olsen, 1999; Smith-Morris, 2004; Henderson, 2010). Ferreira and Lang (2006) state: “The prevailing research focusing on obesity, nutrition, and individual health—although undeniably contributors to health outcomes—obscures social and historical issues that are even more fundamental to the etiology of the disease” (p. xviii).

Diabetes is a complex disease whose etiology is neither universally agreed upon nor understood (Weiner, 1999; Olson, 1999; Ferreira & Lang, 2006). In this study I seek to understand how diabetes is related to indigenous knowledge, land, and placed-based history/historical trauma on the White Mountain Apache Indian Reservation, using the concept of place as an anchoring concept.

Theoretical Framework

Place in Classical and Contemporary Sociological Theory

The concept of place in sociology is usually just as an implicit element of research and is largely absent in classic sociological literature (Gieryn, 2000; Urry, 2004; Cheyne & Binder, 2010). Gieryn (2000) states: “Sociologists have given the appearance of not being interested in place—perhaps preferring to leave the matter to specialists from geography, or fearing that environmental determinism would rob social and cultural variables of their explanatory oomph, or worrying that the particularities of discrete places might compromise the

generalizing and abstracting ambitions of the discipline” (p. 464).

Urry (2004) argues that space and place should be central to sociology. Marx, Engels, Durkheim, Simmel, and the Chicago School make some distant and ambiguous references to space, but not necessarily place. In more contemporary sociological literature, some theorists such as Massey, Harvey, Giddens, and Bourdieu do refer to space, but not place, explicitly. However, Gieryn (2000), Cummins et al. (2007), Labao, Hooks, and Tickamyer (2007), and Popay, et al. (1998 & 2003) refer to place. In this section I review and analyze the concept of place in classical and contemporary sociology.

Marx and Engels do not address space or place but only make ambiguous references. In *The Manifesto of the Communist Party*, Marx and Engels (1848/2000) discuss how relationships fade. In the many arguments they make, Marx and Engels cite capitalism as breaking the feudal ties between people and their “natural superiors”: the bourgeois are forced to expand their markets, destroying local and regional markets; the mass of laborers or proletariat work in factories, creating their own class; and improved transportation and communication helps the rise of trade unions. In *Das Kapital*, Marx (1867/1999) refers to space and time when he analyzes capitalist accumulation built on the obliteration of resources across space and time, creating changes in agriculture, industry, and populations.

Durkheim (1893/1997) alludes to space and place in *The Division of Labor in Society*, when he argues that societies and its accompanying components form solidarity either mechanically (based on similarity) or organically (based on

differences). Societies transform from the former to the latter as the division of labor and specialization increases due to either increased material and moral density or to increased density of social interaction. As the division of labor increases, so does population density. Societies lose individuality as people have more contacts and interactions with others. The end result is an organic solidarity of mutual interdependence (although social pathology can also result). In *The Elementary Forms of Religious Life*, Durkheim (1912/1995) presents a social theory of space. The first element of this theory is that everyone within a society represents space in the same way, and the setting is essentially social. A second element of the theory is that occasionally the spatial representations mirror dominant patterns of social organization.

Of all the classical sociological theorists, Georg Simmel is probably the greatest contributor to sociological thought on space (Frisby & Featherstone, 1997). Simmel offers five basic properties of space: 1) uniqueness of space; i.e., social space varies by the occupying groups; 2) space is divided or “framed” in boundaries for social purposes, as boundaries provide structure for experience and interaction; 3) localizing of social interaction in space influences social formations; i.e., a fixed space brings people together; 4) social interactions are characterized by the degree of proximity and distance among individuals and groups; i.e., how people interact is dependent on physical nearness or distance; and 5) location of space can change; i.e., the space that people inhabit can change, as they become travelers (Frisby & Featherstone, 1997).

“Urban sociology,” established at the University of Chicago between World War I and II, was an attempt to develop ecological approaches to study the city (Parker, Burgess & McKenzie, 1925; Wirth, 1938; Zorbaugh, 1926/1961). For example, Wirth (1938) argues that the difference in social patterns between urban and rural areas had three causes: size, density, and heterogeneity. Size produced segregation, indifference, and social distance. Density made people relate to each other in terms of specific roles. Heterogeneity means that people participate in different social circles, resulting in discrepant and unstable status.

Researchers from the field of geography have also contributed to sociological understanding of space and place. For example, Massey (1984) takes a Marxist approach to space, arguing that spatiality is an integral and active feature of the processes of capitalist production and includes region, distance, movement, proximity, specificity, perception, symbolism, and meaning. Harvey (1989) mentions “time-space compression,” and states that capitalism requires different “spatial fixes” within different historical periods. He argues that space is organized to facilitate production growth, reproduction of labor, and maximization of profit.

Time and space are central to Giddens’ (1984) structuration theory. Structuration theory explains and integrates agency and structure—i.e., it explains how social systems are produced and reproduced in social interaction. Giddens (1984) defines structuration as “the structuring of social relations across time and space, in virtue of the duality of structure” (p. 376), which means that people create society but that people are also constrained by society. Structures

can be thought of as traditions, institutions, moral codes, and other sets of expectations. People are part of the structure, and peoples' actions cannot be analyzed without considering structures. Structures have rules and resources. Rules constrain peoples' actions, and resources mediate action. In this theory, people and structures are linked (Giddens, 1984).

Bourdieu (1989) presents a notion of social space, a spatial metaphor where the distributions of social characteristics are geographically situated, much like an X-Y axis. A person's position in the social space indicates where an individual is situated in society with respect to the types of capital (cultural, economic, socially symbolic, etc.) they have access to or possess. The position of an individual in the social space, relative to other individuals, is signified and retained by capital, such as cultural and economic capital, and by practices or how people act, as represented by style of dress, taste or preference for certain foods or entertainment, etc. (i.e., *habitus*) (Bourdieu, 1989).

Gieryn (2000), states that three features are necessary for place: 1) geographic location; 2) material form; and 3) investment with meaning and value. Geographic location is "a unique spot in the universe ... [From] a room building, neighborhood, district, village, city, county [and Indian reservation]" (p. 464). Material form refers to place as having physicality, or, simply put: "Place is stuff." Finally, "place" should have meaning and value: "[Space becomes] place only when it ensconces history or utopia, danger or security, identity or memory" (p. 465). Gieryn (2000) makes a further distinction that place is not space or "just a setting, backdrop, stage, or context for something else" (p. 466).

Cummins et al. (2007) propose a relational view of place for the study of place and health. First, there is a reciprocal relationship between people and place; in other words, people interact with their environment. They also suggest that people's personal geography is important. People may live in multiple contexts or places for different periods of time and knowing that information may help researchers understand how location and duration at a location mediate health. Finally, place should consider scale, meaning researchers should consider not just the immediate site of place (neighborhood, community, etc.), but also larger regional, national, and global scales. This "scaling" allows for thinking about the appropriate point for intervention.

Labao, Hooks, and Tickamyer (2007) discuss the differences between "place-in-society" and "society-in-place" conceptualizations of place. A "place-in-society" approach "centers on the distinct character of place in a society and in light of social theory" (Labao et al., p. 11), while a "'society-in-place' approach starts at the societal level and then moves to specific places. In the 'society-in-place' approach, places are specific instances of intersecting social relations" (Labao et al., p. 12). How a researcher uses theory and research affects how place is conceptualized. "Since social processes cut across scales, one way to view place is as a particular articulation of those processes ... place represents a particular mix of social relationships originating from sources at different scales, both internal and external to that place" (Labao, et al., p. 33).

The theorization of health inequities of Popay, et al. (1998 & 2003) calls for the "conceptualization and measurement of 'place' within a historical location

in which macro social structures impact on individual lives” (2003, p. 399), and ask us “to consider how ‘places,’ conceptualized in this way, are understood within lay experience of ‘the everyday life-world’” (1998, p. 634). They state: “There is much to be gained from adopting an historical-sociological perspective which defines inequalities in health neither as a category nor a structure but as an historical phenomenon, something which in fact happens in human relationships” (2003, p. 386).

In conceptualizing my framework of place for Als, I consider several sociological theories of space and place. The most relevant theories are from Bourdieu (1989), Gieryn (2000), Labao et al. (2007), Cummins et al. (2007), and Popay et al. (1998 & 2003).

Bourdieu’s (1989) notion of social space helps to highlight the marginalized places that Als inhabit. Als, in general, have lower economic and symbolic capital; and capital can limit or encourage access to resources. The concept of social space can also be expanded to include groups or places such as a reservation or tribal government. For example, despite their status as sovereign nations, tribal governments have low symbolic capital and many also have low economic capital. The social space AI governments occupy limits access to resources such as funding for health care, education, and economic development. In my conceptual framework I borrow from this concept of social space: individuals on reservations, as well as reservations and their tribal governments, represent place in the social hierarchy or a place of marginalization.

Another theory I consider involves Gieryn's (2000) features of place: geographic location, material form, and meaning and value. In my conceptualization of place, geographic location is literally the reservation and the land on the reservation. The reservation also has materials such as houses, stores, schools, and other physical objects. Finally, the land on the reservation has specific meaning to the people who live on it. That meaning includes history, respect, and identity.

In my conceptualization of place, the notions of "place in society" and "society in place" are relevant. (Labao et al., 2007) In terms of the "place in society approach," the reservation serves as the place. I focus on distinct characteristics of place, including contextual factors and processes such as indigenous knowledge. In the "society in place" approach, I recognize larger societal processes such as federal Indian policies and segregation that impact the reservation.

From Cummins et al. (2007), scale and reciprocity between people and place is relevant to my conceptualization of place. In terms of scale, reservations (the place) are embedded in larger societal structures, including counties, states, regions, and the nation. In other words, reservations are impacted by policies and actions implemented by larger scales. Reciprocity between people and place mean that people interact with the "social and physical resources in their environment" (p. 1835). This notion of reciprocity can be expanded to include the relationship between people and place.

Finally, the historical aspect of place expressed by Popay, et al. (1998 &

2003) is relevant to my conceptual framework of place. To Popay, et al., health is a historical phenomenon and the historical dimensions of place impact health. Given their histories, this idea that history impacts individuals is especially important for AIs.

From the sociological literature my conceptualization of place for AIs includes the reservation (literally a geographic place) as a place of marginalization. The reservation also has meaning for its inhabitants, has characteristics such as the physically built environment or material form, and has history. Finally, the reservation is nested within larger structures.

Place in Health Research

The concept of place, broadly defined, has been present in public health literature since its beginning (Chadwick, 1842, Virchow, 1985). An increasing number of researchers argue that place and context matter for health and are necessary for a deeper understanding of societal inequities (Burton, Kemp, Leung, Matthews, & Takeuchi, 2011; Cummins, Curtis, Diez-Roux, & Macintyre, 2007; Popay, Williams, Thomas, & Gatrell, 1998 & 2003). Place is gaining significance in health disparities research. (Burton, et al., 2011; Macintyre, et al., 2002; Cummings, et al., 2007) “Where people live [i.e., place] affects their health and chances of leading flourishing lives. Communities and neighbourhoods that ensure access to basic goods, that are socially cohesive, that are designed to promote good physical and psychological wellbeing, and that are protective of the natural environment are essential for health equity” (CSDH, 2008, p. 60).

Place impacts health through several mechanisms or pathways. One of the ways place is conceptualized is through the social determinants of health (SDOH). The SDOH are “the conditions in which people are born, grow, live, work and age, including the health system” (World Health Organization (WHO), 2013). The SDOH are the result of the unequal distribution of resources, power, income, goods, and services, leading to unfair circumstances in people’s lives and ultimately diminishing their chances of a flourishing life. The SDOH focuses on the “causes of the causes” (CSDH 2008, p. 17): the fundamental structures of social hierarchy and the socially determined conditions in which people live, work, grow, play, and age (CSDH, 2008).

Recently, the Commission on the SDOH (Solar & Irwin, 2010) created a conceptual framework that highlights the social, economic, and political mechanisms that affect a person’s social position and result in stratification in terms of income, education, occupation, gender, race/ethnicity, and other factors. Socioeconomic position (through structural determinants) shapes specific determinants of health status (intermediary determinants) reflective of one’s place in the social hierarchy, one’s social status, and one’s experiences with respect to exposure and vulnerability to health-compromising conditions, consequently shaping specific determinants of health status (intermediary determinants). Illness or disease can then “feedback” on one’s social position. Context, in this framework, are the “social and political mechanisms that generate, configure, and maintain social hierarchies, including: the labour market, the educational system, political institutions, and other cultural and

societal values” (Sorlar & Irwin, 2010, p. 5). The structural determinants are mechanisms that generate and maintain stratification in society and affect an individual’s access to resources. These determinants are important to consider for AI health; however, these determinants are not enough to explain AI health disparities.

Place, history, and historical trauma. History is essential to any examination of AI health. In Kemp’s (2011) review of place, history, and memory, she encourages scholars to connect place and history in health disparities research. Further, Chowkwanyun (2011) argues that:

... the major shortcoming in racial health disparities research is an absence of an historical perspective that would enable exploration of historically rooted ‘fundamental causes.’ What is missing ... is a deeper understanding of how and why these social determinants of racial health disparities matter so much, the long- term process through which they came into being (p. 254)

Als experience place-based histories, and histories are important to consider in health conditions today. In the case of the White Mountain Apaches, they continue to live where they were colonized. Reminders of the past remain, such as Fort Apache, originally a fort used by the U.S. during the infamous Apache wars, but now a boarding school. Related to the concept that place has history is that of historical trauma. The legacy of past policies, including the combination of federal government programs that interrupted natural diets of AI people and the introduction of commodity foods, has contributed to the rise of

poor dietary habits among Native people.

Across “Indian Country” and AI health literature, historical trauma is the most widely recognized and/or accepted explanation for poor health outcomes, especially mental health issues such as depression and substance abuse. Brave Heart & DeBruyn (1998) define historical trauma as the “cumulative emotional and psychological wounding, over the lifespan and across generations, emanating from massive group trauma experiences” (p. 7) and the impact of a “generation’s trauma on subsequent generations” (p. 7). In addition, historical trauma include the following postulations: 1) trauma was methodically and purposely inflicted on AI; 2) trauma is not limited to past injustices but continues in the present; 3) traumatic experiences are universal to a group and echo all the way through that population; 4) traumatic experiences from the past disrupted the natural historical course and have created physical, psychological, social, and economic disparities (Sotero, 2006); and 5) psychosocial, social, and physical consequences that result from historical trauma are passed on from previous generations and continue through subsequent generations (Brave Heart & DeBruyn, 1998).

Relevant to local history and historical trauma are a few tenets from Tribal Critical Race Theory (TribalCRIT) (Brayboy, 2005):

- Colonization is widespread throughout society.
- U.S. policies toward AI are entrenched with imperialism.
- AIs have a desire for tribal sovereignty, tribal autonomy, self-determination, and self-identification.

- Als are both political and racialized identities.
- Government and educational policies aimed at Als are intimately linked around the problematic goal of assimilation.

TribalCRIT emerged from Critical Race Theory (CRT) and “is rooted in the multiple, nuanced, and historically- and geographically-located epistemologies and ontologies found in Indigenous communities” (Brayboy, p. 427). Typically, critical race theory has a focus on race and racism and other forms of subordination (such as gender, class, etc.). However, Tribal CRIT, as a theoretical framework, was developed to examine the relationship between Als and the federal government and to make sense of Als as a racial group, as legal/political groups, and as individuals (Brayboy, 2005).

In my conceptual framework, I recognize that place-based history and historical trauma continue to impact AI health. In addition, Als continue to experience colonization through assimilation and government policies. Also recognized is that Als are members of sovereign nations that strive for sovereignty, autonomy, and self-determination.

Land/place and indigenous knowledge. Native people expressed a relationship to the natural world that could only be called ‘ensoulment’ ... which for Native people represented the deepest level of psychological involvement with their land and which provided a kind of a map of the soul. The psychology and spiritual qualities of Indigenous peoples’ behaviors ... were thoroughly ‘informed’ by the depth and power of their participation mystique with the Earth as a living soul. It was from this orientation that Indian people developed

'responsibilities' to the land and all living things, similar to those that they had to each other. In the native mind, spirit and matter were not separate: They were one and the same (Cajete, 2000, p. 186).

Walters, Beltran, Huh, and Evans-Campbell (2011) state: "Indigenous knowledge recognizes place as integral to one's sense of being which is also central to both individual and collective spiritual health and wellness ... loss of place (i.e., displacement) is akin to loss of spirit or identity ... Many Native scholars have noted that place and land are directly tied to indigenous identity and health ... Place literally means us" (p. 173). They argue that connection to place is protective. For example, Watkins (2001) states:

AIs also share a cultural-historical relationship with the land. Their past and future is intertwined with it, as the fabric of their culture is woven of threads tied to places. The sacred locations are the foundation of threads of the fabric, the warp, while the cultural connections are the weft threads. The four sacred mountains which form the boundaries of the Navajo world are the edges of the blanket, and every local landscape threads within the blanket. Thus, all individual Navajos wear a multi-patterned protective blanket of their culture around them (p. 42).

Land for many AIs, including the White Mountain Apache, is central to identity. Loss of land is and was devastating: "The government's confiscation and redistribution [from roughly 14 million acres to 1.6 million acres] of vast tracts of once sovereign Ndee [White Mountain Apache] territory, caused serious and still-painful injuries to the Ndee." Elder

Raymond Kane said that his grandfather describes the loss as an “unanaesthetized amputation” (Welch & Riley, 2001, p. 7).

The connection to the land is also evident in the origin of clans for the White Mountain Apaches. “Clans” are literally the names of places. “Groups of people named themselves for the places where their women first planted corn. That is how they were known, to others and to themselves. They were known by their places. That is how they are still known ...” (Basso, 1996, p. 21). To be indigenous is to have a sacred connection to the land.

Many indigenous people have respect for the land because respect for the land is respect for one’s self. Also, if the land is not healthy then people are not healthy. Land is the connection to indigenous knowledge, to the past, to traditional ways of living, and for many Native Americans or AIs, land is the economic base.

According to TribalCrit, tribal philosophies, beliefs, customs, traditions, and visions for the future are central to understanding the empirical realities of AIs. Stories are not separate from theory: they embody theory and are real and legitimate sources of data and ways of being; and, finally, theory and practice are connected to ways towards which scholars must work (Brayboy, 2005). For many AIs, including the White Mountain Apaches, “the worldview is one in which the individual is part of all creation, living life as one system and not in separate units that are objectively relating with each other” (Duran & Duran, 1995, p. 15).

Land is central to AI identity and indigenous knowledge. The way of life for AIs has undergone changes since colonization. Research conducted with AIs

must recognize indigenous knowledge. To ignore indigenous knowledge is to dismiss AIs as legitimate people. Cultural continuity is important for health, and moving away from indigenous knowledge is problematic because indigenous knowledge is alive and organic, not static. To distance one's self from indigenous knowledge is removing the self from language, culture, and ceremonies. In my conceptual framework, I emphasize indigenous knowledge as an important "determinant" of AI health.

Place, a Core Determinant of AI Health

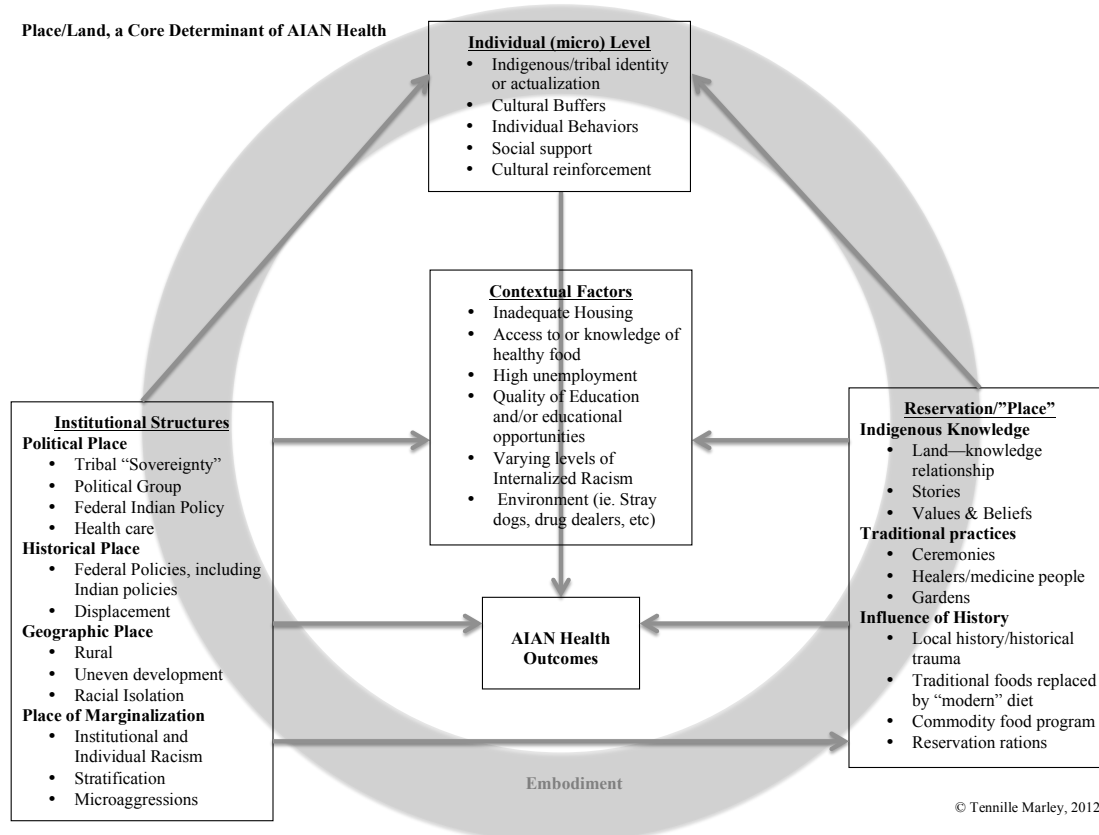
Although the conceptual framework created by the Commission on the Social Determinants of Health may be useful for the wider population, it does not consider unique aspects of AI communities. AIs are a colonized people who have undergone a traumatic history and tremendous change and continue to transition as a colonized people. Given their distinctive history, possession of indigenous knowledge, and unique political status as members of "sovereign" nations, additional determinants or alternate ways of examining health may be necessary. Taking into account the experience of place may provide insights into why health disparities persist.

My conceptual model of place for AIs considers the unique places AIs occupy. AIs are situated geographically on reservations. Reservations (literally a place) have distinct histories where colonization took place, continues to take place, and where indigenous knowledge is maintained and/or lost. Reservations and their tribal governments are situated in a distinct place of marginalization (with respect to position in the social hierarchy) within a political place (status as

“sovereigns” nations). The figure below (and in Appendix A) illustrates my conceptual framework with place as a core determinant of AI health.

Figure 2.1

Place, a Core Determinant of AI Health



In my conceptual framework, borrowing from Krieger’s eco-social theory (1999 & 2005), embodiment is the mechanism underlying the association between places (macro-, meso-, and micro processes) and diabetes. Eco-social theory posits “that how we develop, grow, age, ail, and die necessarily reflects a constant interplay; within our bodies, are our intertwined, and inseparable social and biological history ... Taking literally the notion of ‘embodiment,’ this theory

asks how we literally incorporate biologically—from conception to death—our social experiences and express this embodiment in population patterns of health, disease, and well-being” (p. 296). In other words, the body is directly impacted by place and what happens in place. According to Walters, Mohammed, Evans-Campbell, Beltrán, Chae, and Duran (2011), the concept of embodiment is consistent with AI’s spatial and relational worldviews. The environment, mind, body, and emotional health are intimately linked to human behavior, practices, wholeness, and, hence, wellness.

The theory of embodiment attempts to illustrate how bodies interact with the environment to produce and reproduce health. Krieger and Smith (2004) state that bodies are “biologic organisms” that “reproduce, grow, interact, exist in time and space, and evolve”, and also are “social being” that experience “social context, social position, social production, social consumption, and social reproduction” (p. 94). Krieger and Smith (2004) state, “This new scholarship [embodiment] emphasizes how actualization and suppression of people’s agency, that is, their ability to act within their bodies, intimately depends on socially structured opportunities for, and threats to, their well-being. The notion of ‘embodiment’ accordingly embraces biologic processes while avoiding the trap of equating ‘biologic’ with ‘innate’...In the case of social inequalities in health, it is likewise presumes that observed differences reflect biologic expressions of social inequality” (p. 95). In other words, the body responds biologically to society (Krieger, 2011).

Research that examines the connections among historical trauma, embodiment, and health is needed. Walters et al. (2011) attempt to explain how historically traumatic events are embodied; they state, “[Krieger’s] embodiment acknowledges that while bodies tell [his]stories, they reveal stories that are also not conscious, hidden, forbidden, or even denied by individuals or groups. Studying the embodiment of historical trauma and corresponding health consequences allows us to determine forces driving intergenerational patterns of health and disease among American Indians” (Walters et al., 2011, p. 184). Further Walters, et al (2011) state, “With this framework [embodiment], the high rates of chronic diseases [including diabetes], accidents, and suicides in indigenous communities can be viewed as bodies telling the stories of the catastrophic upheavals imposed upon them by colonial processes” (p. 173).

Despite the scarcity of research that provides a direct link between embodiment, historical trauma and health, researchers have theorized the connections. For example, much of Brave Heart’s (1999a, 1999b, 2000; Brave Heart & DeBruyn, 1998) work explores the impact of historically traumatic events on mental health among the Lakota. She calls the effect, historical trauma response, and the symptomology includes unresolved mourning, feeling numb in response to current traumatic events, anger, and depression. Additionally, Evans-Campbell (2008) argues that individual responses to historical trauma affect mental and physical health, with individuals exhibiting symptoms such as posttraumatic stress syndrome, guilt, anxiety, grief, and depression. Stress and depression are risk factors for type 2 diabetes and other health risks (McEwan,

1998; Brotman, Golden, & Wittstein, 2007; Mezuk, Eaton, Albrecht, & Golden, 2008).

The study of historical trauma and epigenetics holds promise but is beyond the scope of the current study. Walters, et al (2011) state, “The debate about which has the strongest or combined net effect on poor health outcomes and the persistence of health disparities remain open to ongoing empirical verification; however, the preliminary evidence for intergenerational transmission of stress has critical implications for the study of [historical trauma] among [American Indians]” (p. 184-185). Walters and her colleagues (2011) theorize that historical trauma may be “embodied” through epigenetics, the “mechanisms by which social influences become embodied” (Kuzawa & Sweet, 2008, p. 2). Epigenetics is a growing field of research that investigates inheritable changes in gene expression caused by mechanisms other than changes in DNA sequence (Stowers Institute for Medical Research, 2009).

In sociology, macro-level structures are the overarching or large-scale social processes whose effects affect all aspects of society from communities down to individuals (Ritzer, 2007). At the macro level, federally recognized AIs are members of a unique political group, have experienced a distinctive history, are usually geographically rural, and are subject to racism. These macro level processes represent the political, historical, geographical, and marginal “places” that AIs inhabit. As “sovereign” nations, AIs are a distinct political group that has access to health care through the federal government and fall under specific federal policies. Historically, AIs as colonized people have experienced a

tumultuous history whose effects continue today. The rural aspect of many tribes results in racial isolation and “uneven” development. Finally, the racism that AIs experience includes marginalization in the social hierarchy, institutional racism, legacies of past policies, and microaggressions (everyday stressors that serve to invalidate).

AIs are situated in a place of marginalization socially, politically, and economically, and, as a result, experience “uneven development.” According to Harvey (2006), uneven development in the environment is due to the historical practice by capitalist nations of the north of exploiting those at the margin, including AIs, creating a chronic state of underdevelopment that results in differences across geographical areas. Development does not happen evenly in all places, globally or locally. In relationship to American Indians on reservations, uneven development is widespread across the United States, resulting in measurable variability in resources such as access to healthy food, access to quality education and health care, and access to employment opportunities.

In addition to uneven development, there are other experiences of place that AIs encounter as a people of color. Leung and Takeuchi (2011) describe the geographic, social, and psychological process of place, focusing on race and health: “Place is where the processes of various health determinants interact to create health outcomes. The racial and ethnic hierarchy and racism that exist in the U.S. are crucial to analyzing location, landscape, and awareness of place” (p. 74). AIs residing on reservations, especially geographically rural reservations, experience the effects of racial residential segregation, such as limited access to

resources, opportunities, and services, resulting in high rates of poverty, unemployment, diabetes, trauma, alcohol and drug use, and in lower life expectancy (Leung & Takeuchi, 2011).

An example of this place of marginalization and experience of “uneven development” in Indian Country is the chronic and persistent underfunding of Indian Health Services. Health care for AIs remains inadequate and underfunded. Per capita funding for the IHS is only approximately 60% of that of other federal medical programs, such as Medicare and Medicaid. Annual budget increases stay far below those for other components of the U.S. Department of Health and Human Services and have not kept up with the growth of either the AI population or inflation, especially medical inflation (U.S. Commission on Civil Rights (USCCR), 2003; Langwell, Anagnopoulos, Ryan, Melson, & Iron Rope, 2009). As a result of chronic underfunding, health care for AIs does not provide the full range of needed health services. Many IHS clinics operate under a “life or limb” policy, meaning that unless the patient's life or body is threatened, the IHS denies referrals for specialty care (Langwell, et al., 2009).

At the reservation (literally a “place”) level, AIs have varying levels of indigenous knowledge and traditional practices, as well as different local histories and consequently different levels of historical trauma. Indigenous knowledge includes the relationship with the land, stories, values, and beliefs. Traditional practices are the ceremonies and ways of living. Finally, the influence of local history includes the modern day experience of historical events, such as change in diet and other health practices, as well as historical trauma and displacement.

The reservation can be thought of as a meso-level structure since it is an organization that operates on a mid-scale; it is not a large-scale institution but a community (Ritzer, 2007).

These macro- and meso- structures affect the context of place and individual level processes. Many AI reservations experience contexts that have been shown to influence health negatively, such as through inadequate housing, limited access to high quality food, high unemployment, poor education and/or limited opportunities for higher education, varying levels of internalized racism, and environmental stressors (Solar and Irwin, 2010). At the micro-level, in everyday human interactions (Ritzer, 2007), individuals have varying levels of tribal identification, social support, “buffers” that are potentially health protecting, and individual practices that may influence health (Walters & Simoni, 2002).

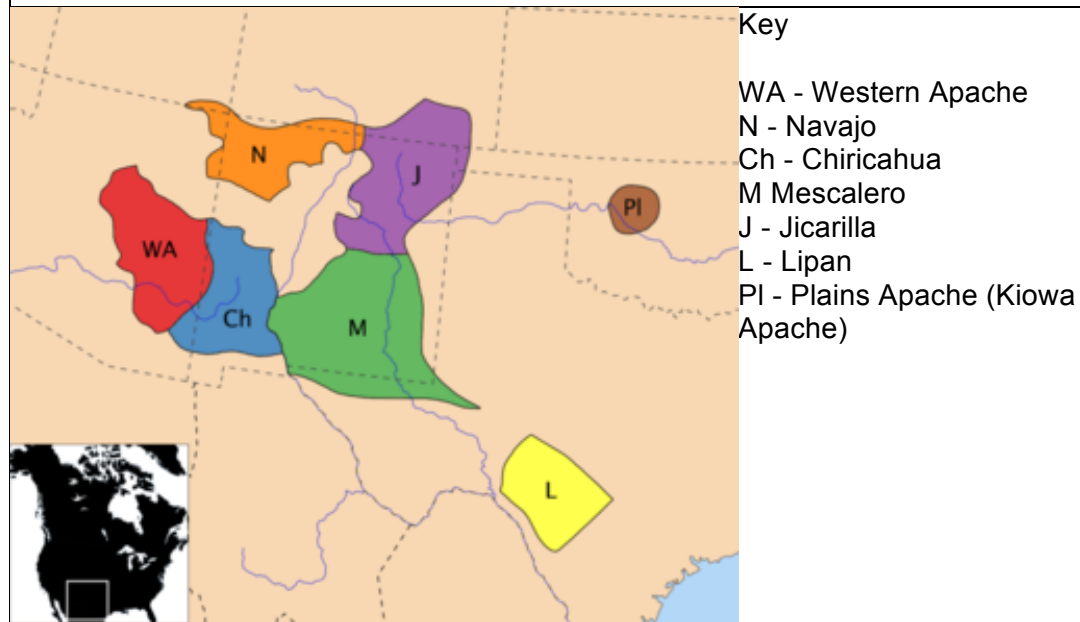
Chapter 3: White Mountain Apache Tribe Background and Context

This chapter is important to the study for several reasons. Place-based history and its effect on health is a central component in the theoretical framework. An examination of the history of the White Mountain Apaches highlights how it has affected life drastically and may provide insights into health today. This history and background also provides context for the interviews. The final reason why this chapter is important is personal. Prior to this research I did not know the history of my own people. In this chapter I provide a brief background of Apache groups, then a brief history of the White Mountain Apache, followed by a profile of the White Mountain Apache tribe.

Background on the White Mountain Apache Tribe

There are several distinct Apache groups in the United States. Anthropologists divide the Apaches into several ethnolinguistic groups: the Chiricahua, Jicarilla, Kiowa-Apache, Lipan, Mescalero, Navajo, and Western Apache (Spicer, 1989). The White Mountain Apache or Ndee are part of the Western Apache linguistic group. Another classification by Hoijer (1956) divides these seven bands into eastern and western groups. The eastern group consists of the Jicarilla, Lipan, and Kiowa-Apache/Plains Apaches. The western group includes the Chiricahua, Mescalero, Navajo, and Western Apaches (Cibecue, San Carlos, Tonto, and White Mountain). This classification is based on geography and subsistence practices. Figure 3.1 below shows the Apache groups and their territorial range in the eighteenth century.

Figure 3.1

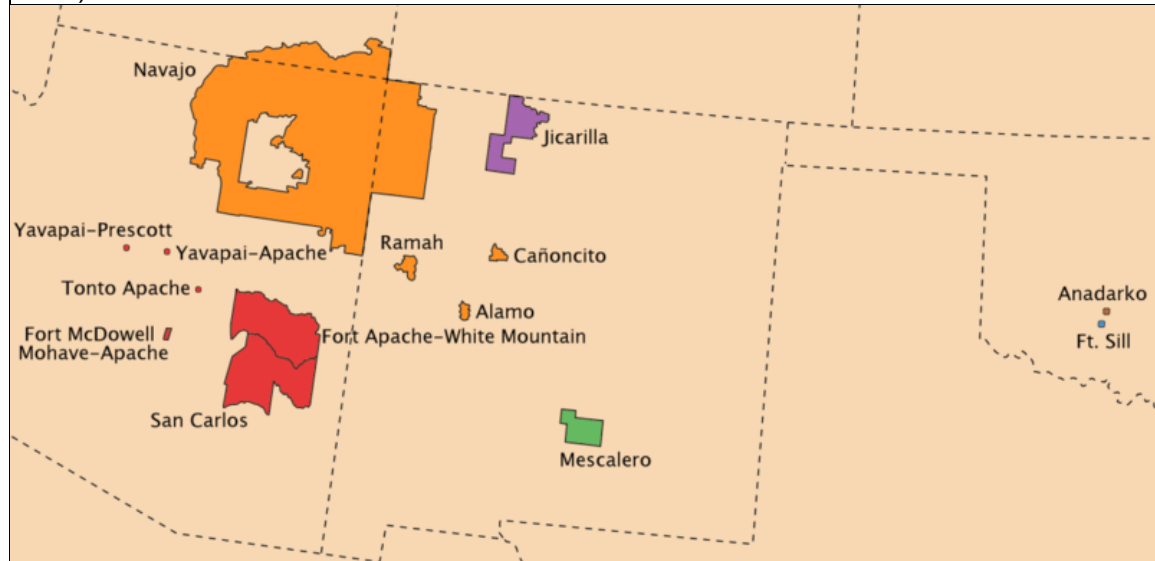
18th Century Apache Territories

Source: Creative Commons Attribution-Share Alike 3.0 Unprotected license, 2006

Today there are several Apache reservations in the Southwest: the White Mountain Apache Indian Reservation, the San Carlos Apache Indian Reservation, the Tonto Apache Reservation in Arizona, as well as the Jicarilla Apache Nation and the Mescalero Apache Reservation in New Mexico (see figure 3.2 below). Prior to the establishment of reservations, the Western Apache had a territorial range that extended across much of present-day central and eastern Arizona. The White Mountain Apache lived on the eastern section of the territory. Of all the Apache groups, the White Mountain Apache were the least nomadic and practiced the most agriculture (Goodwin, 1969).

Figure 3.2

The present-day primary locations of Apachean peoples (including reservations and cities)



Source: Creative Commons Attribution-Share Alike 3.0 Unprotected license, 2006

In the maps, note the pre-reservation and post-reservation territory change. A comparison of the two maps illustrates land loss experienced by the Apache groups. As stated in the previous chapter, land loss was devastating and “loss of place is akin to loss of spirit or identity” (Walters et al., 2011).

Pre-reservation life. Prior to the creation of the reservation, the White Mountain Apache wintered in camps near the Salt River Valley and spent the rest of the year on farming sites located in the mountains (Kaut, 1957). The practice of returning to permanent farming sites was connected to the clan system. Each campsite or farming site was “owned” by a group of related women (Goodwin, 1969), and their farming site indicated their clan place name. This matrilineal clan system facilitated the cooperation and performance of a variety of domestic and subsistence activities. Men were also important to the clan. Brothers and

male relatives related to one another on their mother's side cooperated in various activities, such as hunting, trading, and the building of residences. These men would also occasionally raid or, in other cases, settle disputes (Goodwin and Basso, 1971).

The clan system is significant to the White Mountain Apaches. The clan name of which an individual is a member is that of the place where his/her ancestors first planted corn. The clan system functioned to regulate marriage, sponsor and support the ritual activities of their members, and to aid in the day-to-day work of cooperative groups (Goodwin, 1969). Today the clan system continues to operate, but on a more limited level. Many Apaches continue to recognize the prohibition against marrying within their own clan, and clan members continue to support each other. However, a growing number of Apaches no longer identify with their clan. Apache society is potentially impacted by diminishing clan identification through loss of relationships with the land and through loss of the reciprocal aid relationship of the clan system.

The Western Apache lived in *gowas* or *wikiups*, domed or conical shaped structures built from a framework of long slender branches and covered with heavy grasses (Goodwin, 1969). At the turn of the 20th century, the *wikiups* were built with framed doors and vented so that a wood stove could be used. Married couples and their children usually built and lived in their own *wikiups* and oftentimes they would live in the camp or *gotah* of the wife's mother, father, and sisters (Goodwin, 1969). The husband would be expected to perform tasks for his wife's family. Oftentimes, the husband would also maintain close ties with his

own family and clan, and it was not unusual for couples to reside between the husband's and wife's *gotah* (Goodwin, 1969). Different families living in close proximity to each other were associated in "local groups," and larger, regional confederations were known as "bands" (Goodwin, 1969). These groups worked together in tasks such as gathering food, working agricultural lands, performing ceremonies, as well as joining together to form raiding parties.

The *gotah* or small "neighborhood" served several purposes. It maintained close family connections and facilitated cooperation. However, the *gotah* became increasingly uncommon first with the implementation of the reservation system, and nowadays because of housing policies. The breakdown in the *gotah* is essentially a breakdown of the social structure of Apache way of life. Today it is not uncommon for families to live far apart and for communities to be made up of strangers from different clans and from different parts of the reservations.

Traditional Western Apache diet. Prior to European contact, the Western Apache engaged in raiding, hunting, gathering, and farming, for subsistence. However, among all the Apache groups the White Mountain and Cibecue Apaches practiced agriculture more than other groups. Buskirk (1986) stated that prior to the establishment of the reservation about 60% of White Mountain Apache families farmed and up to 80% of Cibecue Apaches farmed. Early scholars such as Opler (1983) and Goodwin (1942) have estimated that the Western Apache diet consisted of 35% up to 65% non-meat food such as food from agriculture and gathering.

Gathering. The White Mountain Apache gathered many different wild plants for food. Plants such as mescal (agave), mesquite pods, cacti fruit, yucca fruit, wild potatoes, and juniper berries were gathered. Seeds including acorn, walnuts, pinon, sunflower, and others were also gathered as sources of food. Greens comprised a common food source including wild onions and Indian spinach (lambsquarter). Additionally, salt was gathered (Buskirk, 1986).

Agriculture. In addition to gathering food, the White Mountain Apaches also practiced limited agriculture. Corn was the most important crop to the Apaches and was the most widely planted. However, the Apaches also grew pumpkins and beans (Buskirk, 1986).

Hunting. The White Mountain hunted extensively. Adult males were the only people permitted to hunt large game. Game, including antelope, elk, mountain sheep, and particularly deer, provided important food sources. Deer was most important for its meat as well as the hide and sinews, which were used for clothing. Small game such as cottontail rabbits, jackrabbits, prairie dogs, wood rats, field mice, ground squirrels, and tree squirrels were also hunted (Buskirk, 1986).

Today's Apache diet differs drastically from the traditional. The distribution of rations introduced new foods such as flour, lard, sugar, canned meats, potatoes, coffee and tea (Taylor, Keim, & Gilmore, 2005). Sharma, Cao, Gittelsohn, Ethelhah, and Anliker (2007) conducted a study on the White Mountain and San Carlos Apache Reservations. The survey group was tasked to describe food intake, identify foods for intervention, and to provide data to

guide nutrition programs. According to results from their 24-hour “food frequency” questionnaire, the top sources of energy (or calories) were potato chips, fried bread, soda, fried potato dishes, and Apache tortillas and burritos. The top sources of sugar were soda, juices (orange, apple, etc.), refined sugar, and beer. Finally, the primary sources of fat were from potato chips, fried bread, fried potato dishes, eggs, and hot dogs and sausages. Results also indicated that fruit and vegetable intake was low. (Sharma et al., 2007) The study by Sharma et al. (2007) illustrates the drastic change in diet from pre-reservation times.

History of the White Mountain Apache

The White Mountain Apaches still occupy much of their ancestral homeland; however, they are relative newcomers to the areas. Anthropologists believe that the Apaches settled in their present locale in the mid 1600s, where they practiced raiding (Opler, 1983). Initial relations between the Apache and Spanish were not hostile; however, in response to encountering more and more Spanish forces in the sixteenth and seventeenth centuries, Apaches increasingly engaged in raiding. Raiding was a form of subsistence and not necessarily an act of warfare or vengeance (Goodwin, 1969; Goodwin & Basso, 1971). Raiding activities helped the Apaches acquire materials they needed for their well-being. They sought resources such as horses, cattle, weapons, and goods such as metal tools and cookware. The Chiricahua, Mescalero, and Western Apaches conducted most of the raiding, and the most common targets were settlements in

the Sonora and Chihuahua provinces of Mexico, as well as the occasional Pueblo and Tohono O'odham settlement (Spicer, 1989).

In response to increased raiding the Spanish adopted a policy of pacification in 1786 (Spicer, 1989). Under this policy, Spanish military forces attempted to force Apaches to take on a *presidio* way of life in exchange for rations and domestic goods. Few Apaches took to a *presidio* existence and the Spanish were unable to voluntarily make Apaches give up their traditional lifestyle or join the Spanish empire, let alone surrender. The policy was eventually abandoned in 1810 as an insurrection against Spanish rule began in Mexico. The primary reason the Spanish had a difficult time trying to exert control over the Apaches was because the nature of Apache social organization did not lend itself to outside control. The social organization of the Apaches during this era was widely dispersed, decentralized, and had no governing body (Goodwin, 1969).

After independence from Spain in 1821, the Mexicans inherited the Apache problem. At first, the Mexican policy was assimilation, as the Mexican government attempted to incorporate Apaches into mainstream Mexican society as farmers or laborers. The use of missionaries was also employed towards this end. However, these attempts did not pacify the Apaches and eventually bounties were offered for the scalps of Apache men, women, and children (Spicer, 1989). This policy only intensified the problem, and violence increased in the region. The actions of the Mexican government, particularly the

implementation of bounties for Apache scalps, is an extremely obvious early indication of Apache historical trauma.

After the Mexican-American war in 1848, the United States acquired the territories of Arizona and New Mexico, as well as the Apache problem, from Mexico. One of the first encounters between the U.S. government and Apaches took place in 1850, when General Kearney and Colonel Kit Carson led an expedition to survey the newly acquired territories. As with the Spanish, initial relations were amicable. As part of the Treaty of Guadalupe Hidalgo, the U.S. government attempted to stop Apache raiding into Mexico, building forts and garrisons (Spicer, 1989). The Apache resented the government for preventing them the raids, and tensions mounted as white settlers, ranchers, and miners intruded onto Apache lands.

Throughout the 1850s, relations between the Apache, settlers, and the U.S. government were generally peaceful, but several provocations eventually led to war. In 1861, a U.S. cavalry officer, Lieutenant George Bascom, took the Chiricahua Apache leader Cochise and several others hostage while looking for a Mexican captive. Cochise was able to escape, but Lieutenant Bascom killed the other hostages. This event set off a cycle of conflict between the U.S. Army and the Chiricahua, as well as other Apaches, that would last over twenty years (Spicer 1989).

During this time most of the Western Apache, with the exception of the Tonto, managed to remain at peace with the U.S. In 1869, after a series of U.S. Army raids into their territory, Chief Diablo of the White Mountain Apache people

agreed to allow the army to establish a base on their land, Fort Apache (Goodwin, 1969). This fort eventually became the base for General George Crook's campaign against the Chiricahua Apaches. In 1872, General Crook took over army operations in Arizona and persuaded a number of White Mountain, Cibecue, and San Carlos warriors to join his forces as scouts (Goodwin and Basso, 1971). The scouts played a vital role in General Crook's campaigns against the Tonto and Chiricahua bands.

In 1873 the U.S. Government started to consolidate the Apache groups at San Carlos in eastern Arizona. Eventually the Chiricahua and most Western Apache, including the White Mountain and Cibecue, were moved there (Spicer, 1989). The Apaches' movements were restricted to prevent contact with white settlers, and they were forced to live near the fort. However, the confinement of the Apache people disrupted indigenous subsistence practices. People gathered what they could, but what was available was soon exhausted and they could no longer feed themselves. The army responded to the lack of readily available food by distributing rations. Nonetheless, many people died as a result of starvation due to food shortages and communicable diseases (Spicer, 1989). The conditions at San Carlos led to revolts by the Chiricahua in the 1880s, and eventually the policy to concentrate all the Apaches on the San Carlos reservation was abandoned.

The White Mountain and Cibecue Apaches were allowed to return to their lands farther north (Goodwin, 1969). Conditions at the White Mountain Apache Reservation were better than those in San Carlos; however, the people were still

forced to live under the watch of the Army and Indian Affairs Superintendent, and movement on and off the reservation was tightly controlled (Opler, 1983).

The government tried to make the Apache reservations economically self-sustaining in the latter part of the 19th century and early parts of the 20th century. After the creation of the reservation, the government tried to teach the people of White Mountain American-style farming, with some success (Spicer 1989).

In 1934, the Indian Reorganization Act provided that any Indian tribe, or tribes, residing on a reservation have the right to organize for common welfare. In other words, tribes could finally govern themselves. The first steps to self-determination happened during this time and tribal governments were made formal and constitutions were adopted. After the passage of this act, an anthropologist named Morris Opler submitted a report to the Bureau of Indian Affairs (BIA) on the White Mountain Apache's existing political system and the prospects of creating an elected governing body as federally mandated. He advocated for a transitional system that recognized existing nantans, or chiefs, while gradually instituting a democratically elected body (Opler, 1983).

Throughout much of this time, the White Mountain Apache were largely self-sufficient economically and socially. In the early and middle decades of the twentieth century the BIA Superintendent maintained a large degree of control over the policies and legislation enacted by the Tribal Council, but this arrangement began to change after World War 2 (Basso, 1983).

In the 1960's the White Mountain Apache began to exert more independence and control over their own affairs. The tribe continued

development programs initiated by the BIA such as cattle ranching and took control over others that depended on Apache resources but that were controlled by non-Apache interests, such as the local forestry industry (Basso, 1983). During this time the Tribal council invested in recreational and tourist industries and built a ski resort and motel.

The establishment of the reservation system, which restricted White Mountain Apache movement, had a profound and destructive effect on the local economy and society. Prior to the establishment of the reservation, the White Mountain Apaches lived in family groups and practiced raiding, hunting, gathering, and agriculture for subsistence. Because their movement was curtailed, Apaches were further no longer able to hunt or gather the materials on which they depended for survival and ultimately became dependent on government food rations for survival (Goodwin, 1969). Apaches also became more sedentary as a result of restricted movement. Many of these effects continue today, particularly with respect to physical activity and food practices.

Context: White Mountain Apache Indian Reservation

In my conceptual framework the reservation is a place where history and colonization happened, continues to happen, and where indigenous knowledge is maintained and/or lost. It is an important determinant of health, particularly with respect to diabetes. Information about the reservation provides an important context for the study by highlighting socio-demographic conditions and other factors that may impact health.

The White Mountain Apaches live on the White Mountain Apache Indian Reservation located in eastern Arizona, which covers approximately 1.6 million acres (over 2,600 square miles). The reservation is approximately 75 miles long and 45 miles wide. Throughout the reservation there are 9 major communities: Canyon Day, Cibecue, Carrizo, Cedar Creek, Hon-day, McNary, East Fork, Seven Mile, and Whiteriver. The reservation lies in portions of Navajo, Apache, and Gila counties. The elevation ranges from 2,700 feet in the Salt River Canyon to over 11,000 feet at Mt. Baldy (White Mountain Apache Tribe, 2012).

Geographically, the White Mountain Apache Indian Reservation is rural, and its communities are distanced far apart. Whiteriver, the largest community and the capital of the tribe, has a grocery store and two gas stations/convenience stores. The IHS hospital is approximately five miles away from the center of Whiteriver (*Google Maps*, 2013). The communities outside of Whiteriver have little or no services, with the exception of Cibecue that has a small grocery store. The nearest off-reservation full-sized town is 30 miles away, and the nearest Wal-Mart is 45 miles away (*Google Maps*, 2013). Many Apache who have the transportation and means travel to the border towns for food and other goods. Because the reservation is rural, Apaches have inferior access to health care providers, exacerbating health disparities in comparison to more urban dwellers. (Probst, Moore, Glover, and Samuels, 2004)

Socio-demographics. Residents of the White Mountain Apache Indian Reservation constitute a young population. The 2010 US Census reported 13,409 residents on the White Mountain Apache Indian reservation (US Census,

2010). 97.5% of the reservation population identified themselves as American Indian alone or in combination with another ethnicity. The reservation had a median age of 24.1, considerably younger than that of the general U.S. population (37.2). 42 percent of the population is 18 years or younger, and 8.5% are over the age of 60 (US Census, 2010). Als (including the White Mountain Apache), in general, are characterized by higher birth rates, as well higher death rates, in younger ages that explain the young population. The table below illustrates the population breakdown by sex and age.

In general, residents of the reservation experience lower incomes and more poverty than the general population. The median household income on the reservation was \$26,134 (versus \$52,762 for the U.S. general non-Native population); the mean household income is \$37,012 (versus \$72,555); and per capita income is \$9,738 (versus \$26,915) (US Census, 2011). Of the approximately 3,093 households on the reservation, 12.3% of the population received cash public assistance income (compared to 2.6% of the general population) and 47.4% of the population received Supplemental Nutrition Assistance Program (SNAP) benefits (compared to 10.2% of the general population) (US Census, 2011). 40.9% of families on the reservation live below the poverty level compared to 10.5% of the general population. For families with children the percentage that lives below the poverty level was 49.4% compared to 16.4% of the general population. For female-headed households, 49.4% live below the poverty level on the reservation.

Table 3.1

WMA Population by Age and Sex

Age Range	Total Population	%	Males	%	Females	%
Under 19	5,636	42.0	2,842	43.4	2,794	40.7
19 to 29 years	2,247	16.8	1,098	16.8	1,149	16.7
30 to 39 years	1,447	10.8	726	11.1	721	10.5
40 to 49 years	1,674	12.5	808	12.3	866	12.6
50 to 59 years	1,254	9.4	594	9.1	660	9.6
60 to 70 years	730	5.4	328	5.0	402	5.9
Over 70 years	421	3.1	153	2.3	268	3.9
Total Population	13,409	100.0	6,549	48.8	6,860	51.2

Source: US Census, 2011

In general, the educational attainment (see table 3.2) of Apaches on the reservation is lower than the U.S. population. Lower educational attainment places individuals at increased risk of poor health. For example, 28.0% of Apaches do not have a high school diploma compared to 8.5% of the general population. 7.9% of Apaches have less than a ninth grade education compared to 6.1% of the general population. The pattern of lower educational attainment remains for associate degrees, bachelor's degrees, and graduate/professional degrees. However, more Apaches are high school graduates (30.2% vs. 28.6%) and have some college (21.9% vs. 20.0%) than is the case in the general population (US Census, 2011).

The unemployment rate on the reservation is higher than that of the general population. According to the 2011 American Community Survey 5-year estimates, the unemployment rate was 30.9% compared to 6.5% for the general population. The most common occupations were services (29.5% vs. 18.3% for

Table 3.2		
Educational Attainment		
Level	White Mountain Apache Indian Reservation (%)	U.S.General Population (%)
Less than 9 th grade	7.9	6.1
9 th to 12 th , no diploma	28.0	8.5
High School Graduate	30.2	28.6
Some college	21.9	21.0
Associate's degree	5.7	7.6
Bachelor's degree	4.5	17.7
Graduate/professional degree	1.8	10.5
Source: US Census, 2011		

general population), sales and office (22.9% vs. 24.5%), management, business, science, and arts (20.4% vs. 36.0%), natural resources and construction (16.1% vs. 9.1%), and production, transportation, and material (11.0% vs. 12.1%).

Broken down by category of worker, the majority of reservation residents are government workers (67.8% vs. 15.0% for the general population), followed by private wage and salary workers (28.6% vs. 78.6%), and self-employed (3.6% vs. 6.2%) (US Census, 2011). The breakdown by employment indicates that the majority of people work for the government, which also speaks to the scarcity of jobs available on the reservation.

The majority of residents on the reservation continue to speak the Apache language. 41.1% of people on the reservation spoke only English and 58.9% spoke a language other than English, most likely Apache (US Census, 2011). Table 3.3 further breaks down language by age. The table indicates that people who speak a language other than English in the home are primarily adults.

The socio-demographic information in this section indicates that the Apache population is young, has a high birthrate, and experiences disparities

Table 3.3			
Language Spoken at Home by Age			
	Total	People who speak only English at home	Percent who speak a language other than English at home
	Estimate	Estimate	Estimate
Total population 5 years and over	11,828	4,858	6,970
AGE			
5 to 17 years	27.9%	45.2%	15.8%
18 to 64 years	66.3%	52.4%	76.0%
65 years and over	5.8%	2.4%	8.2%
Source: US Census, 2011			

compared to the general population with respect to income, poverty, educational attainment, and unemployment. Additionally, the Apache language continues to be spoken by many adults, although less so by those under 18 years of age. Poverty, low educational attainment, and unemployment are all associated with poor health outcomes (SDOH, 2010). However, the data also point to larger structures at work such as uneven development, segregation, and government policies.

Health status. In general, Als in Arizona experience worse health outcomes than other Arizonans. For example, compared to all Arizona residents, Als in Arizona experience 417.5% more alcohol induced deaths, 218.1% more motor vehicle-related deaths, and 192.5% and more influenza and pneumonia-related deaths (Arizona Department of Health Services (ADHS), 2009). When it comes to diabetes related mortality, Als in Arizona have higher mortality rates

Table 3.4

Diabetes Mortality on White Mountain Apache Indian Reservation, 2001-2009

Year	WMAT Diabetes Related Deaths	Percentage of Total Deaths Due to Diabetes	Crude Mortality Rate for WMAT	Diabetes Mortality Rate for Als	Diabetes Mortality Rate for all groups
2001	4	5.7%	32.3	72.8	19.9
2002	4	5.3%	32.3	80.8	22.3
2003	7	7.0%	56.6	55.8	20.3
2004	0	0%	0	59.0	20.7
2005	3	2.8%	24.2	69.9	20.1
2006	2	2.0%	16.2	43.9	18.9
2007	7	6.5%	56.6	51.1	17.0
2008	0	0%	0	49.9	19.8
2009	5	5.0%	40.4	54.2	15.7
Source: ADHS, 2001-2009					

than Arizonans in general. For example, the 2009 diabetes mortality rate for Als in Arizona was 54.2 per 100,000, while only 15.7 per 100,000 for all Arizonans.

In general, the White Mountain Apaches experience a lower rate of diabetes related mortality than other Als tribes in Arizona but a higher rate of mortality when compared to all Arizonans. Table 3.4 above compares diabetes related mortality rates across White Mountain Apaches, Als in Arizona, and all Arizonans. Diabetes related mortality on the White Mountain Apache Indian Reservation fluctuated yearly from lows of 0 in 2004 and 2008, up to 7 in 2003 and 2007. Over the nine-year period the average number of diabetes related deaths was 3.5 per 100,000, and the average crude mortality rate was 28.7 per 100,000.

In 2009, the leading causes of death for Als in Arizona were diseases of the heart, cancer, unintentional injury, diabetes, and chronic liver disease and cirrhosis. For all Arizonans, the leading causes of death were diseases of the

heart, cancer, unintentional injury, chronic lower respiratory diseases, and cerebrovascular diseases. However, for the White Mountain Apaches, the leading causes of death were diseases of the heart, unintentional injury, alcoholic liver disease, and suicide, followed by diabetes, cancer, and influenza and pneumonia (ADHS, 2010).

Health care on the White Mountain Apache Indian Reservation. The Indian Health Service (IHS) provides health care services on the White Mountain Apache Indian Reservation through the Whiteriver Hospital and the Cibecue Health Station. The 45-bed hospital is located in the town of Whiteriver and is accredited by the Joint Commission on Accreditation of Healthcare Organizations (JCAHO). The hospital offers general medical care, pediatrics, alcohol treatment, obstetric services, and ambulatory surgery. The health station is located in the isolated town of Cibecue. The health station provides outpatient urgent care and dental services (IHS, 2013).

Despite the availability of health services through the IHS, disparities exist in facilities, services, and personnel (IHS, 2012; ADHS, 2013). For example, when it comes to personnel, the ratio of population to provider was 2,791 to 1 for the tribe, 1,169 to 1 for the county, and 918 to 1 for the state (ADHS, 2013). Additionally, the IHS has been subject to severe resource limitation due to federal budget appropriations that have not kept up with either the increasing growth of the population or the cost of care (IHS, 2012). As a result, programming funds for health prevention measures and mental health outreach

are scarce, and the bulk of resources are used to focus on tertiary care and emergency services.

The Indian Self-Determination and Education Assistance Act (Public Law 93-638) and its subsequent amendments give tribes the option of taking on the administration and operation of health services and programs in their communities (IHS, 2012). Per the Act, the White Mountain Apache Tribe administers the Tribal Division of Health Programs, the Apache Behavioral Health Services (ABHS), as well as health education.

Health care access on the reservation remains inadequate due to underfunding and geographic isolation. Transportation is an issue for many residents. The transportation score for the reservation was 370, compared to 179 for the country and 135 for the state. The transportation score indicates adequacy of transportation: the higher the score, the greater the need for transportation (ADHS, 2013). The hospital is located 5 miles north of the town of Whiteriver, 9 miles from Canyon Day, 11 miles from East Fork, and 22 miles from Cedar Creek. Although health care services and access thereto are not explicit in my conceptual framework, they remain important consideration in overall health.

Conclusion

In my conceptual framework, place-based history is an important determinant of AI health. The historical experiences endured by the Apaches resulted in diminished identification with one's clan, loss of relationships, breakdown in social structure, and changes to diet and subsistence patterns. The health of Apaches continue to be affected by these experiences through

continued breakdown of the communal structure, largely because of current housing policies and the introduction of food that is now part of a “traditional” Apache diet (e.g., tortillas, fried bread, etc.). In addition to these historical burdens, White Mountain Apaches currently are subject to other factors that adversely impact their health. Geographic isolation, poverty, lower educational attainment, and high unemployment are all associated with poor health outcomes. (CSDH, 2008)

Chapter 4: Research Design and Methodology

Research Question and Design

In this study I attempt to clarify the relationship between indigenous knowledge, land, history, and diabetes, using “place” as an anchoring concept. Specifically, my research questions are:

- How is diabetes constructed by the White Mountain Apache?
- How does place, including indigenous knowledge, meaning of land, and the experiences of local history/historical trauma, relate to diabetes on the White Mountain Apache Reservation?

To answer the questions I used an explanatory, single-case study approach, supplemented by in-depth interviews.⁴ A stronger design would include an additional case for comparison. As a result of studying only once case, I cannot generalize beyond the White Mountain Apache reservation. The goals of this research were to refine my conceptual framework, to develop a working methodology, and to reach preliminary findings that can be used for comparison in my future work.

A case study is an appropriate approach to my questions since it is an empirical investigation that examines a “phenomenon in depth and within its real-life context, especially when the boundaries between phenomenon and context

⁴ In my proposal I planned to conduct focus groups to supplement the interviews. However, I decided that because of the political climate and concerns for my safety that focus groups were not appropriate.

are not clearly evident” (Yin, 2009, p. 18). According to Yin (2009), an explanatory case study has the following properties: a) an accurate rendition of the facts of the case; (b) some consideration of alternative explanations of these facts; and (c) a conclusion based on the single explanation that appears most congruent with the facts. The case study approach is most useful with questions that examine contemporary events and when behaviors cannot be manipulated. (Yin, 2009)

Site Selection

The White Mountain Apache Indian Reservation served as the case for this research. This site was chosen since it is an American Indian reservation and the tribal group continues to reside on their ancestral homeland. Another reason I chose this site is because the population is also undergoing changes. For example, many children and young adults no longer identify with their clans, and use of the Apache language is decreasing. The final reason I chose this site is because the local history of the tribe is unique. The White Mountain Apache suffered relatively less “trauma” and much less displacement than many other American Indian groups. Historically, the White Mountain Apaches were semi-agricultural and semi-nomadic; they grew crops such as corn, sunflowers, beans, and squash, and they encouraged select wild plant growth. They also hunted deer, elk and other game and collected wild plants. In 1869, when Brevet Colonel (Major) John Green encountered the White Mountain Apache, he made that observation that they were “perfectly healthy.”

Data Collection

The White Mountain Apache Division of the Health Programs Health Advisory Board, the White Mountain Apache Tribal Council, and the University of New Mexico (UNM) Human Research Protections Office (HPRO) approved my study before I began collecting data. On November 28, 2011, the Advisory Board agreed to let me conduct my study, and on January 4, 2012, the Tribal Council unanimously approved the study. Finally, on January 5, 2012, the UNM HPRO approved the research. I began collecting data on February 21, 2012, completing this by June 20, of the same year.

Interview guide. Interview questions can be found in Table 4.1. I pilot tested the interview guide with two members of my family who are considered elders in the community to assess whether my interview questions were appropriate for formulating answers to my research questions. Pilot testing allowed for refinement of data collection plans and relevant lines of questioning (Yin, 2009).

Table 4.1
Semi-Structured Interview Questions
<p>What do you think has caused so many Apaches to develop diabetes today?</p> <p>A lot of things have happened to us historically as White Mountain Apaches. How have these experiences affected our health, specifically in developing diabetes?</p> <p>The Apaches used to have a very close connection with our land. Do you think that is still true? Why or why not? How could this connection or loss of connection with the land affect whether people develop diabetes or not?</p> <p>We, as Apache people had our very own knowledge, Apache knowledge. Is that still true today? Why/why not?</p> <ul style="list-style-type: none"> • No: Is loss of Apache knowledge related to diabetes? If so, how? • Yes: How does having Apache knowledge affect a person in developing or not developing diabetes?

Selection of key informants. For this study I used purposeful sampling and snowball sampling (Maxwell, 2005) to select a non-probability sampling of key informants from members of the White Mountain Apache Tribe. Key informants included people who are elders, “medicine” men and women, and individuals who continue to grow corn, as well as those with cultural knowledge. Purposeful or criterion-based selection is “a strategy in which particular settings, persons, or activities are selected deliberately in order to provide information that can’t be gotten as well from other choices” (Maxwell, 2005, p. 88).

The initial participants were purposefully selected based on their status as elders, possession of indigenous or cultural knowledge, and lower likelihood of being influenced by Western, individually oriented explanations for diabetes. For example, I interviewed several people who work at the Apache Cultural Museum, people who serve as cultural consultants for the schools, and well-known elders in the community.

Procedures. I approached potential key-informant interview participants in person or by phone, provided a brief verbal description of the study, and asked if they would like to be interviewed. Individuals who expressed interest were given a copy of the written consent form. I then re-contacted individuals within a few days to see if they were still interested in participating. Interviews were scheduled at participants’ earliest convenience and at a location chosen by the participant. A secondary strategy for interview recruitment involved snowball sampling in which I asked participants at the end of the interview if they knew of

other people who may be interested or useful for the study. Recruitment occurred in person or by phone.

I interviewed participants using a semi-structured interview (see table 4.1 above for the questions and Appendix B for the interview guide). A semi-structured interview involves “specified questions you know you want to ask [and] you are prepared to follow unexpected leads that arise in the course of your interviewing” (Glesne, 2011, p. 134). Interviews were recorded with permission and administered by the investigator in the subject’s home or another agreed upon site. The semi-structured format allowed for probing after initial responses.

I attempted to assess the relationships between history, land, indigenous knowledge, and diabetes through the use of questions listed in table 4.1. The first question I asked was about the cause of diabetes today. Subsequent questions were more pointed. In the second group of questions I attempted to assess the relationship between place-based history and diabetes. Given the special relationship Apache have with their land, I asked a question about land and diabetes. Finally, I asked about indigenous knowledge and diabetes. During the interview I probed and redirected questions for clarification and/or for more information as necessary to assess the relationships.

At the time of the interview, I read through the consent form (see Appendix C for interview guide) and explained the purpose of the interview and procedures, including recording of the interview. The interviewee was given a copy of the consent form to read along with me. The consent form included information on the anonymous coding of the interviewee’s responses, the

transfer of interview information from audio to transcribed notes, and storage of interview information. The interviewee was given an opportunity to ask questions.

Inclusion/exclusion criteria and enrollment. I recruited study participants from January through June of 2012. My initial goal was to interview between 30 and 50 participants. Inclusion criteria for participants were as follows: 18 years of age or older, member of the White Mountain Apache Tribe, and English-speaking. Exclusion criteria included individuals younger than 18 years old, any enrolled member of the White Mountain Apache tribe, and any non-English speaking individuals.

Collection of case documents. In order to create a profile or context of the White Mountain Apache Indian Reservation (Chapter 3), I collected qualitative and quantitative data from several sources. Appendix C lists the data sources and type of data.

Data Analysis

Qualitative analysis, interpretation, and refinement of theoretical framework. I conducted 28 interviews to assess the relationship between history, land, indigenous knowledge, and diabetes. Saturation was reached after about 24 interviews. After that point responses become redundant and no more new additional information or viewpoints emerged (Schensul, Schensul, & LeCompte, 1999). Table 4.2 illustrates the demographics of the key informants.

The qualitative analysis plan included a number of strategies. I synthesized and analyzed data about the reservation using standard qualitative

Table 4.2					
Demographics of key informants					
Key Informant	Pseudonym	Age	Sex	Diabetes Status	Family History Diabetes
001	Velma	49	F	Borderline	Yes
002	Janet	69	F	No	Yes
003	Samantha	67	F	No	No
004	Melanie	60	F	Yes	Yes
005	Sonya	70	F	Yes	Yes
006	Ruth	41	F	Yes	Yes
007	Mark	26	M	No	No
008	Brian	45	M	Yes	Yes
009	Inez	51	F	Borderline	Yes
010	Catherine	43	F	No	Yes
011	Richard	70	M	No	Yes
012	Dale	44	M	No	Yes
013	Elsie	65	F	Borderline	Yes
014	Timothy	48	M	No	Yes
015	Tiffany	64	F	No	Yes
016	Mike	74	M	Yes	Yes
017	Sharon	63	F	Yes	Yes
018	James	52	M	No	Yes
019	Steve	45	M	No	Yes
020	Josephine	47	F	Yes	Yes
021	Gloria	25	F	No	Yes
022	Caroline	48	F	Borderline	Yes
023	Stanley	61	M	Yes	Yes
024	Rosalie	47	F	No	Yes
025	Cindy	54	F	Yes	Yes
026	Katrina	48	F	Borderline	Yes
027	Candace	19	F	No	Yes
028	Allison	52	F	No	Yes

research protocol (Maxwell, 2005). Interviews were professionally transcribed, verified for accuracy, and placed into ATLAS.ti (2012) for analysis. Interview transcriptions essentially were verbatim records; however, some quotations were slightly edited for comprehensibility. Even when an interviewee mixed tenses within a single sentences, their spoken dialogue was not altered in the transcription. Appendix C contains a table of themes I anticipated based on the

theoretical framework. However, since the goal of this research was refinement of the conceptual framework, a grounded theory approach (Corbin & Strauss, 2008) was necessary.

A grounded theory approach calls for thorough review of data (interview transcripts) without reference to a theoretical or conceptual framework (Corbin & Strauss, 2008). I read, analyzed, and interpreted the interview data. Categories or themes that emerged from the data were defined, coded, and response frequencies calculated (Corbin & Strauss, 2008). Throughout this process of data analysis and coding I created summary memos of observations and coding categories.

After analyzing the interviews using a grounded theory approach, I re-examined the interviews in terms of my conceptual framework and in terms of the overall research question. I then refined the conceptual framework through re-assessment of the empirical findings (Gibbs, 2007; Creswell, 2007). Data that did not fall within the range of responses in the conceptual framework were examined more closely. I then modified the framework to account for those findings.

Quantitative analysis. Quantitative data analysis was primarily descriptive. For example, socio-demographic data were descriptive, including cross-tabulations of population by age, sex, race, household type, social characteristics such as school enrollment, educational attainment, marital status, and language(s) spoken at home, and economic characteristics such as employment, income, and poverty status. Health data, including reservation

specific diabetes crude mortality rates for the years 1995 through 2009, was also descriptive.

Barriers to Research

There were several barriers that I faced during data collection. One of the first barriers was navigating tribal politics. On December 7, 2011, at the regularly scheduled tribal council meeting, a majority of 11 council members voted to suspend the chairman. This majority claimed the chairman “failed to carry out decisions of the governing body, refused to convene meetings as required by the tribal constitution, and unlawfully appointed a new chief judge” (Wagner, 2012). However, the chairman refused to give up his office, citing it as an attempt of government takeover in violation of Apache law. This incident affected the entire community, with residents taking sides in support or opposition to the chairman. My challenge was to remain neutral, desist from comments on tribal politics, and to distance myself from my parents and family members.

The issue of intra-council conflict and conflict in the community continued for the duration of the interviews. The conflicts intensified during and after tribal elections for a seat in the largest district on April 4, 2012. Two candidates who did not make the ballot sued the tribe. Allegations of corruption within the housing authority involving board members and tribal council members further contributed to community discontent. As a consequence of this intra-council and community conflict, I decided to drop the focus groups from the study. I did not want to unknowingly group people together who had taken sides in the dispute,

especially since, in some interviews, people brought up the issue of government dysfunction.

Besides community conflict, concerns for my safety contributed to my decision to drop the focus groups. A double homicide occurred in the community where I grew up. The people murdered lived on the same street as my parents, and the person who committed the crime lived behind my parents. I was frightened and realized that I no longer felt safe. Also, given the high unemployment rate and issues of alcoholism, along with the monetary incentive to participate in the focus group, I feared that I might unknowingly allow people under the influence to participate in the focus groups.

Another challenge I faced was securing a site for interviews. People were reluctant to have me in their homes for various reasons: no privacy, embarrassment, or inconvenience. I made arrangements with the Tribe's Department of Education and Northland Pioneer College (NPC) to acquire space in which to conduct interviews. The majority of interviews were conducted at NPC. This site was ideal, since it was centrally located in the community of Whiteriver. It was safe and secure and was open late into the evening. However, related to the issue of space was transportation. I started providing transportation to and from participants' homes and the interview site.

A further challenge faced was general distrust by community members and trouble in recruiting participants. Many people did not realize that I was from the community. However, once people realized that I had grown up on the reservation and attended the school there, they became more open. After a

while I started to introduce myself by my clan and by my parents and grandparents. When I had conducted research on the reservation back in 2005, recruitment was the biggest barrier. The same applied to this study. Recruitment became increasingly difficult as I attempted to conduct interviews in competition with the Sunrise Dance Ceremony season (April-September) and particularly school year-end activities. However, I was persistent and able to conduct enough interviews to answer my research questions.

Chapter 5: Findings

“Time has changed a lot of things.”

In the beginning the Dzil Lagai Ndee (White Mountain Apache) were placed on the earth by Usen (The Creator), and they were taught how to live. One of the gifts from Usen are stories and the ability to tell stories. In Apache culture the purpose of stories are to “enlighten, to instruct, to criticize, to warn, [and] to entertain” (Basso, 1990, p. 116). Ridington (1988) says, “Stories are windows into the thought world of Indian people ... Western social science assumes an object world independent of individual experiences. The language of Indians’ stories assumes that objectivity can only be approached through experience” (p. 70-71). Given the importance of stories in the tradition of my culture, I start this chapter by presenting narratives⁵ or stories from Samatha and Sony who have seen tremendous changes in their lifetimes, followed by narratives of diabetes, and finally findings according to themes.

Samantha was a 67 year-old elder. She continued to work as a cultural advisor in one of the local schools. Samantha told the following story at the time she introduced herself:

⁵ Most if not all interview respondents were primary Apache speakers.

Quotations are edited as little as possible. Most quotes appear as they were spoken by the interviewee.

Time has changed a lot of things. When I look back from the time I grew up ... I was born and raised in Cibecue. We lived in a *wikiup* up in the mountains ... it has been taught to you, the basic way of life. Back in those days, you were up at 3:00, ate breakfast, and your day begins ... [First,] we had to haul water ... we also had to gather wood. My mother will carry wood on her back and the two of us—my sister and I—will bring wood on our back. They'll put just a little bit on our back because it would be too much for us. The belief in that was [that you carry wood with yucca] ... so your neck will be stronger ... that your shoulder[s] will be strengthened; if you do work like this—carrying wood on your back—that you'll be able to endure.

Like many other people of her generation, Samantha's childhood chores were typical of the time period. Samantha talked about gathering wood with her mother. To transport wood, the women would use a strap of yucca across their forehead to carry the wood on their backs. Samantha's story illustrates how everything they did served a purpose. The strap across the forehead to carry the wood strengthened their neck, shoulders, and prevented injury later in life.

Samantha continued her story:

It seems like at an early age we were taught common sense—to think for yourself. Because in life nobody's gonna be there for you. You gotta think how important the value of life is—planning, thinking ahead. I think that's how we learned. Plan ahead. Everything there was a reason for it as I look back. Knock on wood—I'm not diabetic.

As Samantha reflected on her life, she expressed gratitude for an upbringing that taught her common sense and the importance of planning. She believes that because of the intentionality of her actions as a child and then throughout her life, she is healthy today. Her story illustrates how difficult life was, but yet how everything served a purpose. From an early age Samantha was socialized and taught to rise early, to stay busy, and to keep moving. She believed that because she was always moving and because she was strong, she does not have diabetes.

Sonya was a 70 year-old elder with diabetes who continued to work for the tribe in an administrative position. She held a bachelor's degree in business administration and had lived off-reservation for at least 20 years of her life. She told the following story of her upbringing in response to a question about historical experiences:

[A] long time ago we used to haul water with donkeys or [a] horse, bring the water back, build a fire, warm up the water, wash our clothes with the washboard in the tub. That was a lot of exercise. I was raised very, very traditional. When growing up myself, my mother and father were very traditional, and we can't sit around a lot. We cannot be idle. That's how I was raised.

Sonya had many chores as a child, and her story illustrates a common theme across many of the elders and those raised with traditional Apache values: always to move and to engage in some activity. She continued with an important event in her life:

When I was about 12 or 13, when I was about to become a lady, I was not allowed to sleep. I have to be up before dawn ... I live in North Fork at Alchesay Flats, and we have a big field where we plant corn. My mother would take me over there wearing the burden basket ... put it on you and then you have to hold it [on your forehead] ... I would walk in front of her ... [and] I have to grab the corn ... the stalk, and then break that off and throw them [in the basket]. If I do it slow, I would get hit on the wrist.

'Faster, faster. You've got to move faster.' Tears would be running down and she keeps pushing me, pushing me. It was awful. Then she would say, 'If you just sit around, you're going to become a very, very lazy and fat woman. It's no good to be fat. No. Only lazy people are fat.'

When Sonya reached puberty, she had to work, a common practice when a girl experienced her first menstruation. Apache people believed that during menstruation a woman will want to be idle. The requirement of work during a girl's first menstruation is supposed to prevent inactivity. Her mother tried to motivate Sonya by threatening her with becoming lazy and fat, likely perceived as undesirable qualities.

Samantha and Sonya's stories illustrate how from an early age chores, including gathering wood and hauling water, were required. Both stories reminded me of the Apache saying, "*Ch'ígoná'ái nítis dahsol'ees hela*," or "Don't let the sun step over you!" which means you get up early before the sun rises and prepare for the day. (Watt and Basso, 2004) To rise early, before the sun

rises, was a traditional Apache practice. As an Apache person you are supposed to wake up early, greet the sun, and pray as it rises.

Diabetes Narratives

“Diabetes is alive. It’s alive and it knows what its goal is. Its goal is to kill (Timothy).” In this section I present diabetes narratives from three people: Dale, Timothy, and Melanie.

Dale was 44 years old and was a husband and a father. He held a degree in business administration and worked for the tribe for most of his adult life. At the time of the interview he served as an administrator in a high profile office. His family, especially his mother and father, were known as “traditional” people in the community. Although he could not speak the Apache language, he sang in Apache. He told his story as part of his introduction:

I have a mother and father that are still alive. I have two brothers and a sister. As of today, Dad does not have diabetes. Mom does. Is it because Mom somehow got lazy? How come Dad didn't get it? My brother, Mike—second behind me—has diabetes. My brother Darrel doesn't have diabetes. Ruth ... I don't think she does. Me, Dale, Jr., does not, but I think it's coming ... With this job, I've become very stress[ed], and I don't have a chance to go be active and play sports or do things like I used to. It's today's world. I think [that] is what I'm getting at. My dad's always been active. Mom would always worry about the bills and maintaining family and the household. She had a stressful position.

Dale talked about diabetes in his family and wondered while most of his family has diabetes his father does not. He thought that modern society, including the nature of work, contributes to his own stress and creates time constraints related to the problem. He is not as active as he used to be, and time is a barrier to physical activities he used to enjoy. He is worried about his own stress level, especially since he suggested that his mother's diabetes is related to stress and his father's lack of diabetes to physical activity. He continued with his story:

I can feel it physically. There are days where I'm feeling shaky literally ... I want to live a long life ... I'm at the crossroads. I don't want to have diabetes. Diabetes is knocking on my door. I know it is. I'm staying a couple of steps ahead of it. I think a lot of people might not know if their bodies are changing enough to know that they're on the verge of it or not. I think I am. I think I know my own body where I know that that's [diabetes] coming. I'm right getting close to it. As we speak, I'm trying to fight it, and I don't think I have it. I don't want it

Dale was worried that he will develop diabetes, and he was convinced that he could feel diabetes coming. He continued to tell his story, but with hope:

We're having this [sunrise] dance [for my daughter]. Suddenly I'm becoming more active, more on my feet—rising up early—yes, we're doing that. Training more often—yes, than before. If we weren't having a dance ... God, God, well, I don't know ... I think it would be very bad for my health. So this dance couldn't have come at a better time.

Near the end of his story, Dale talked about returning to his traditional roots since his daughter would be having a sunrise dance or puberty ceremony in the coming year. He believed that this upcoming dance and the preparation would help him and his health. He specifically emphasized getting up early and training (exercising) for the physically challenging ceremony. In earlier times, training was not necessary because physical activity was embedded in everyday life.

Timothy, a 48 year-old male, is a husband and a father. He was unemployed, but active in the community. He lived his entire life on the reservation. He had a family history of diabetes. He told his this story when he introduced himself:

Everybody's kind of afraid to really say that this [diabetes] is killing us. Yeah, alcohol and drugs is doing that, but diabetes is doing it by itself inside. While we take alcohol in through our mouths to kill us and drugs to mess up our minds, we enjoy the cake and the cookies and all these things ... that we forget that in it [cake and cookies] there is a beast that's waiting to take control of your life, and when it does it destroys. That's what it did to my dad.

Timothy stated that people did not recognize that diabetes kills. He also suggested people see food as harmless compared to alcohol or drugs. He continued to talk about his father:

Back about maybe 20 years ago, my father was diagnosed with diabetes. He was [a] very healthy man. He worked in the sawmill, was a lumber grader all his life. He enjoyed it. When diabetes stepped in to his life it

changed everybody's life—it took control, it just took control. It was like that. Diabetes is alive. It's alive and it knows what its goal is. Its goal is to kill. That's all it wants to do. It knows how to do it.

Timothy became very emotional as he talked about the impact diabetes had on his family. His father worked and enjoyed manual labor, but developed diabetes after he stopped working. The life of his father and that of his entire family changed as a result of diabetes. He also talked about diabetes as if diabetes is alive, has a spirit, and a goal to kill. He proceeded to tell the story about his father:

The doctor told us, 'Your dad's not fine. There's something very wrong with him. He needs to get his leg amputated. If not, it's [the infection] [going to] go up [his leg] and it's [going to] kill him. It's [going to] kill him real fast if he doesn't get this done.' He doesn't want it done. I had to talk to him. He finally said, "okay," and he got it amputated. Years later the other side got amputated. Then it got to his heart. When it got to his heart there was really nothing we could do.

Timothy's father had both legs amputated and he eventually died of heart failure. His father did not want to have his legs amputated. Timothy also suggested that his father's heart failure was a result of diabetes. Timothy then talked about what he is doing to prevent diabetes:

Diabetes is at our door every day. My sisters, they have diabetes ... Both of my brothers are diabetic now. I have one sister and myself that aren't,

plus my mom. Since then I've been exercising a lot. Walking, jogging. I do that five times a day.

Timothy reflected on family members who have diabetes. He feared developing diabetes, especially after seeing his father suffer. He noted that he exercises in order to prevent diabetes. Timothy is relearning how to become physically active again, as evidenced by his daily walks. In earlier times, Apaches were physically active because physical activity was a consequence of life—necessary for chores such as gathering food, hauling water, and hunting. Because of many modern conveniences, such as indoor plumbing and stores, people now have far less physical activities to perform.

Melanie was 60 years old, and she was a wife, mother, and grandmother. She was known in the community for her cultural knowledge. Melanie told her story of diabetes in response to the question about diabetes among Apaches today:

In 2002, I got really sick. I got really sick, and I didn't know what was going on with me. Then I went in [and] they did the blood test. And then that's when they found out that I had diabetes too. To me, at that time, it just said like this is your death sentence. 'You're not gonna live very long.' That was my concept of that disease. I've learned to try to exercise and eat just a small portion and take my medications the way I'm supposed to. I feel like I'm doing okay. Maybe that's how they see it, too, that no matter what they do, it's gonna kill them.

She initially saw her diabetes diagnosis as a death sentence and suggested that other people also see diabetes as a death sentence and, as a result, don't take care of their illness. Like Timothy, Melanie has had to relearn how to be physically active. She has also had to relearn how to eat healthily through portion control. She then talked about what she is doing to prevent diabetes with her family:

I have a niece, a nephew ... two nephews, and then my brother that passed ... he had it [diabetes] first. I tried to tell my kids, 'Be careful, do what you can to exercise, 'cause I don't want you to get it. I get tired of eating the medicine every day, but in order to keep going I have to eat it.' It's really sad sometimes. I just hope that someday there'll be a cure for diabetes.

Melanie had family members that passed away as a result of diabetes, and she encouraged her family to be physically active in order to avoid diabetes.

Melanie's quote illustrates that physical activity does not occur naturally. It has to be intentional, as opposed to when it was forced by necessity in the past.

The stories about diabetes from Dale, Timothy, and Melanie, in comparison to the stories from Samantha and Sonya, illustrate the change in the way of life from earlier times. Whereas Samantha and Sonya's physical activity was embedded in everyday life, Dale, Timothy, and Melanie had to deliberately perform physical activities for exercise. Dale's physical activity was constrained by long work hours. For Samantha and Sonya, physical activity was associated with chores that ensured their needs were met, while Dale and Melanie sat in an

office all day to ensure their same needs were met. Dale, Timothy, and Melanie's stories all illustrate how physical activity is relearned. To get exercise, they had to seek it out.

Place and Diabetes

The rest of this chapter examines diabetes from the perspective of Apache community members and asks: how does place-based history, indigenous knowledge (because of its reciprocal relationship with land/place), land (literally a place), and contextual factors relate to diabetes? I present findings under three broad themes—place-based history, Apache knowledge, and contextual factors.

Place-based history and diabetes. In the theoretical framework I identify place-based history as an important determinant of American Indians' health. In addition, Walters et al. (2011) stress the need to investigate “place and health, specifically examining how American Indian health outcomes can be contextualized and understood in light of historical losses and disruptions tied to place or land” (p. 166). The history of the White Mountain Apache Tribe is a history of colonization that created disruptions whose effects continue today.

The White Mountain Apaches experienced several disruptions when they encountered the Spanish and later U.S. soldiers, when they were forced to move to San Carlos, and then when they were forced to live near Fort Apache. They were removed from their lands and then contained; they were not allowed to move from their winter to summer homes, to tend to their gardens, to gather, or to hunt. After the reservation was established, people were allowed to return to their summer sites if they were within reservation boundaries, but their way of life

was changed forever. Flour, lard, and sugar were introduced, trading posts appeared, and people moved from *wikiups*—Apache housing structures made from branches and heavy grass—to houses. This section covers the themes related to history—colonization, confinement, rations and diet change, and dependence—that have impacted the Apaches' experience with diabetes.

Colonization. When people were asked, “A long time ago our people did not have or rarely had diabetes; what do you think has caused so many Apaches to develop diabetes since then?” many of the responses referred to colonization. For example, Timothy, a 48-year-old unemployed community member stated:

When you're conquered by not necessarily a superior race, but when you're conquered by a stronger people, they dictate what goes on within your life. I believe that that happened here. It's sad, and you look at any conquered nation—whoever conquered them tries to make them be like them.

Timothy's response indicates that diabetes in Apache people today is related to colonization and assimilation. He indicates that the colonizers tried to keep Apaches from continuing their way of life and to mold Apaches in their fashion.

Diabetes was attributed to colonization in other responses. As Sharon, a 63-year-old elder and language advocate, stated:

Our people are descendants of ancestors that were here that did not have these types of disease before what we call 'The Arrival.' The ancestors did not have immunity against certain things that were brought over by the early Europeans—the Conquistadors and the colonizers. I believe that

our problems with diabetes go back to those times.

Sharon indicates that many diseases, including diabetes, did not exist prior to “The Arrival,” meaning that of the Spanish Conquistadors. She also stated that the Apaches did not possess immunity to diseases that the Conquistadors and colonizers brought with them. Immunity generally refers to infectious diseases such as influenza or chicken pox; however, Sharon conceived immunity more broadly to include non-infectious diseases, including diabetes. Sharon suggested that the roots of diabetes are connected to European contact.

Confinement. In addition to colonization, the establishment of the reservation and its boundaries that confined Apaches caused a shift in the way of life that continues to impact diabetes today. As Timothy, a 48-year-old community member stated, “They wanted to confine the people in one spot so that the Apaches would no longer be what they were.” Timothy cited confinement and assimilation (from Apache to Western ways) as factors related to diabetes.

The reservation affected physical activity and freedom. In this vein, Velma, a 49-year-old craftsperson and unemployed community member, stated:

We were [a] people that moved around. A long time ago ... we didn't always live in the valley. I'm talking about a time when we didn't have boundaries, because today we grow up and we know where the boundary is. We didn't have that mindset. We didn't know boundaries. Now, we're confined.

Velma cited a shift in physical activity levels due to reservation boundaries as a

potential cause of diabetes. She also indicated that the reservation boundaries changed Apache's mindset which, in turn, perhaps altered the Apache view of the land. Velma suggested that prior to the boundaries Apaches were free, but not any longer.

Rules and policies associated with the reservation also disrupted Apache way of life. Dale, a 44-year-old administrator for the tribe, stated:

When the reservation came, there was rule of law on paper. Just that alone caused a change in the normal life. You can't go raiding or you can't go do this or that without having some kind of permission or you might be violating some rule. You have an invisible line in which you needed to be in there, remain in there. The reservation life affected diabetes, I would say. It was just not being free and mobile like you once were in the past.

Dale attributed diabetes today to the establishment of the reservation and its accompanying rules and laws that caused a disruption in "normal" life. Dale's quote illustrates rules or policies during early reservation times that prevented Apaches from raiding, hunting, and gathering. Reservation boundaries also made it impossible for some families to migrate back and forth between their summer and winter homes. Apaches were required to stay within boundaries that did not exist prior to the reservation. To Dale, diabetes is related to Apache loss of freedom and mobility.

Self-sufficiency was also lost with the creation of the reservation. Timothy, a 48-year-old unemployed community member, recalled his parents telling him

about how things were different in the past:

They [Timothy's parents] said change was already taking place back then. When my dad passed away, he was hitting 70. When he was a little boy that was back in the '40s. He was telling me that the changes had already hit this place, because of how we were put on a reservation, when the reservation was implemented ... our self-sufficiency was already severed then. We could no longer do what we wanted. We were dictated to [as to] what we should do and how we should live. From that time our traditional way of eating food and our means of hunting for food changed.

Timothy's quote indicates that he and his parents understood the detrimental effects that resulted from the establishment of the reservation. According to Timothy, the reservation system affected Apaches' self-sufficiency, freedom to do what they wished, and the ways they ate and acquired food.

The reservation affected physical activity for Apaches. "Everything that our ancestors did required some type of physical activity," and, "We were people that moved around," were examples of typical responses to the question about history and health. Physical activity was a normal part of everyday life and was explicitly taught and encouraged. Brian, a 45-year-old tribal leader, stated:

You could say that in a pre-reservation day being a nomadic people, health-wise, everybody was ... just physical ... [it was] part of everyday life and part of teaching as a young one. I heard about how the young kids were awakened early in the morning, told go run down to the river and jump in the river and, after you wash yourself, run back home. After that,

[the children would] help the leader in the fields when there was still farming, or help their parents in any of the labor work that they did, but as the reservation days started we became accustomed to reservation life.

Brian stated that children learned from an early age to run, to maintain cleanliness, and to work. Physical activity was part of life and encouraged. However, reservation life changed activity levels as people became more sedentary.

Rations and change of diet. The White Mountain Apache were introduced to new foods with the arrival of U.S. soldiers and creation of the reservation system. The government distributed rations, foods items such as flour, lard, sugar, canned meats, potatoes, coffee and tea (Taylor, Keim, & Gilmore, 2005), to Apaches because they were no longer allowed to hunt or gather or to grow their own food. Many traditional Apache foods were replaced with poorer substitutes as a result of the rations

Rations were introduced at the inception of reservation life. For example, Melanie, a 60-year old elder, recalled: “My grandfathers were scouts here [at Fort Apache]. Back then the [Apache] people came out to sell feed [to the soldiers] for the livestock, and then they [Apaches] would get rations, flour and lard, coffee. Just staple items like that ... salt.” Similarly, Josephine, a 47-year old unemployed community member, stated, “Our chiefs were taken into custody or into camps. That’s when everything changed when they were forced to go into camps. We had to get rations ... I think that’s changed everything.” Melanie cited rations and Josephine pointed to rations and imprisonment as factors that

changed the historical life course of Apaches and ultimately contributed to the plague of diabetes today.

Rations also disrupted subsistence patterns. Ruth, a 41-year old unemployed mother, stated: “The government introduced rations to our people. Before, we were nomadic and we were hunter[s]/gatherers. We lived off the land. Then they put us on reservations and started giving us rations, which was flour and shortening.” Ruth indicated that prior to reservations and rations people were nomadic and lived off the land.

Rations also replaced traditional Apache foods. For example, Sharon, a 64-year-old elder and language advocate, stated:

It [diabetes] is because of the ... what became available to native people. Before that, we had different diets that were used by our ancestors [that] were the diets that we had [that] were from the natural resources that were available on our lands. After the military were here—in our lands here—they brought in foods that were not something that we were used to here. Previous to that, when the Apaches were here on their own on their own lands, we had various ... all types of edible plants and wildlife and other things that we gathered for our survival. Those [pre-reservation foods] were what our bodies were used to physically consuming.

Sharon attributed the diabetes prevalent today to the new foods that were introduced to the Apache. As other food became available, the Apaches ate fewer local indigenous plants and animals, which had provided superior nutrition.

people. She continued to elaborate on the non-indigenous staples that were introduced:

Then, when the military came in our area here, they [the government] brought in goods that were for the military. Our people became used to those types of foods. ... We got used to flour and things like lard ... Our Apache people began to make their own goods from what [was] distributed ... That's how our families got hold of those items. Then, we learned to make bread, tortillas, and fried bread from those things.

Sharon understood the history of the tribe and the role of the government in the introduction of new staples. She pinpointed the introduction of tortillas and fried bread back to the time when rations were distributed.

Dependence. Rations started a cycle of dependence on the government. For example, Catherine, a 43-year old community member and cultural advocate, stated, "We became dependent on rations and stuff like that. It changed how we prepared food and how we gathered." Similarly, Brian, a 45-year old tribal leader, stated: "Health wise, our lifestyle changed. They [our ancestors] became dependent on the government for the rations, which were something different than that they were used to, something that they would just have to take and use in order just to feed their family." Catherine cited a dependence on rations that changed food practices, including gathering and preparation. Brian indicated that rations changed Apaches' lifestyles because they were forced to take rations order to survive.

Rations created a dependency that continues today. Ruth, a 41-year old college educated and unemployed community member, echoed similar sentiments:

I still think that's [rations] a big part of it [diabetes today] ... We weren't going out and gathering berries and trying to eat right and eating meat and whatever the diet was at the time, but instead living off of what they've [the government] given us. It seems like through that system they've made us dependent on them.

Ruth believed that the introduction of rations caused people to give up traditional food access practices that ultimately resulted in dependence. She believed dependence continues today:

Right now. Right now you look at the unemployment rate here on the reservation. How many people are getting food stamps [now Supplemental Nutrition Assistance Program (SNAP)]? How many people are getting TANF [Temporary Assistance for Needy Families]? I feel that they have made us dependent on them for food [and] to live.

Ruth indicated that rations created government dependence in the past and that dependence continues today through social welfare programs such as TANF. And she further suggested that, as in the past, people are dependent on SNAP and TANF in order to survive. Ruth's remarks indicate social conditions on the reservation such as high unemployment and the large number of people who receive government assistance may be part of an issue of government-induced dependence.

Rations not only created dependence on the government, but also affected Apaches' self-sufficiency. For example, Timothy, a 48-year-old unemployed community member, stated:

What they [the government] were doing was making a group of people that were very, very self-sufficient, dependent on [them] for their survival ... They had to look to the US government. ... They would all come towards Fort Apache or San Carlos for rations ... Back then, that [way] they were already dependent on that.

Timothy stated that whereas Apaches had been self-sufficient the government created dependence. He suggested that Apaches therefore lost any self-sufficiency. He talked about how people would travel from Cibecue to Fort Apache or San Carlos, more than a day's travel in those days, to get rations on which they had become dependent. He continued:

Nowadays we're dependent on the tribe. We want the Council to give us money. We want the government to hand out money. I'm not against that. I'm not against it, but it's made it to where it's killed the drive in us. I no longer want to work. I no longer want to be self-sufficient. The government's giving. I want to kick back and they're gonna give and I'm gonna receive.

Timothy stated that Apache people became dependent on rations in the past for survival and that dependency continues today, affecting people's motivation and degree of self-sufficiency.

Historical trauma. Brave Heart and DeBruyn (1998) define historical trauma as “the cumulative emotional and psychological wounding, over the lifespan and across generations, emanating from massive group trauma experiences ... [and the impact of a] “generation’s trauma on subsequent generations” (p. 7). Psychosocial, social, and physical consequences that resulted from historical trauma are passed on from previous generations and continue through subsequent generations. (Brave Heart & DeBruyn, 1998) The concept of historical trauma is related to place-based trauma. Historical trauma was committed in a specific place for the White Mountain Apaches: on their ancestral homelands and at Fort Apache.

The findings presented in this section are from responses to the question about historical experiences and diabetes. Several people explicitly brought up the term historical trauma; however, many other people brought up experiences that were coded as such. When people spoke about historical trauma, it was primarily in terms of losses—of indigenous knowledge and of language. For example, Sharon, the language advocate, spoke about historical trauma in this way:

Psychologically, I believe our people have been affected. When you’re affected psychologically, and when genocide has happened to your people and the warfare that went on with Apache people here, of course, there’s gonna [*sic*] be symptoms that ... such as PTSD [post-traumatic stress disorder] ... this historical trauma is handed down intergenerationally from our ancestors ... even though our contemporary

Apaches might not be aware of that. They will deny it ... but they're not aware that our parents, our grandparents, suffered from [it] and ... how the mistreatment has brought these things down to us ... Genocidal policies by the U.S. government and by the Conquistadors strongly affect our health now.

Sharon's quote illustrates her knowledge of historical trauma and the history of the tribe. She noted that people suffer from historical trauma and are affected psychologically. She indicated that people may even suffer from post-traumatic stress disorder as a result of historical trauma. She suggested that some people in the community, unbeknownst to them, suffer from historical trauma.

Some respondents connected historical trauma with Fort Apache. For example, Catherine, a 43 year-old cultural advocate, stated:

Fort Apache, [for] example, was created so that they [the soldiers] could keep [a] watch on us, control us. That's how we became dependent on them. It was all related to [soldiers] taking what was ours for their benefit ... our cultural values ... the way we eat ... our traditions and our language and everything else. That caused historical trauma in our people.

Catherine identified Fort Apache, its purpose, and its actions against the people as traumatic. The fort created dependency and took away culture, food, tradition, language and "everything else." Catherine continued to speak about the fort that was later turned into a boarding school:

My mom went to T.R. School and talked about life in a boarding school and how they were told not to speak their language, and they couldn't do certain specific things, ceremonies ... We have lost touch with who we are. It's [the boarding school] taken things that are so precious to us, that we've always known in our way of life, our history [and] what was taught to us by our ancestors.

Catherine identified several actions on the part of the boarding school at Fort Apache and the role those actions had in diminishing Apache way of life, history, and ancestral knowledge. She further elaborated on the boarding school and its effects:

I know the trauma experience has to do with being beaten, having our hair chopped off, having our heads dipped in kerosene, and abuse for speaking the language. I think how it affected a whole generation of people ... in that age group ... I've seen my parents as them, that age group that stopped [being Apache] and who didn't know whether it was okay to be a native or ... adapt to white ways in order to survive.

In the last section of her quote, Catherine connected boarding school experiences with her parents and people of her parent's generation. She suggested that because her parents had negative experiences in boarding schools they struggled with Apache identity and may have lost considerable Apache knowledge. To Catherine, poor health today, including high rates of diabetes, is related to historical trauma.

Militarization. “Way back in the 1870s, Fort Apache was established... The reason they brought the soldiers in is to police the Apaches” (Mike).

Many people brought up Fort Apache when they responded to the question on historical experiences. People associate the fort with colonization, with soldiers, and with trauma. The fort also was the place where people were forced to live and the place from which the federal government distributed rations. Ultimately the principal factors that changed the Apaches’ way of life stem from the fort. The White Mountain Apache continue to live where they were colonized; they cannot move. Whitbeck, Adams, Hoyt, and Chen (2004) stated “the ‘holocaust’ is not over for many American Indian people. It continues to affect their perceptions on a daily basis and impinges on their psychological and physical health. There has been no ‘safe place’ to begin again.” (p.128)

Fort Apache is a reminder of the Apache past. It originally was a fort used by the U.S. during the infamous Apache wars but is now a boarding school.

Melanie, a 65 year-old elder, talked about how people felt about the fort:

Some people have real bad memories of Fort Apache, like being discouraged not to speak their language and being overworked. To this day some are like that. They don’t want to come here. We know that some people are still hurt by the way they were treated, especially the boarding school era.

Melanie’s remarks illustrate the historically traumatic aspect of the fort. People are still affected by what happened at the fort, and I believe simply seeing the fort reminds them of the pain.

Apache knowledge. “Our parents and our grandparents said to respect the land, to respect yourself, to respect your body. ... Nowadays it’s not like that. ...” (Timothy).

Apache knowledge was affected by changes as a result of placed-based history. Traditional Apache worldview is based on a spiritual connection with knowledge of the natural world and is a necessary corollary to respect of one’s self, of other human beings, and of all living things. Walters et al., (2011) state that “indigenous knowledge recognizes place as integral to one’s sense of being which is also central to both individual and collective spiritual health and wellness” (p. 173).

When you respect and take care of the land, the land, in turn, takes care of you. Richard stated: “Most elders, grassroots [i.e., traditional] people, they know that everything is connected.” Brian also spoke to the interconnectedness of land and people:

There are several songs that are sung during the summer's dance ceremony—corn songs—and it talks about the seed, the roots, the stalk, the silk, the pollen, and how it all connects to the ground, to the person, to the people. The realm of why it's there and how it helps the people ... and, in return, the people have to work the corn, that cycle of keeping it going. It's still there. It's just not taught as much.

Brian indicated how an Apache corn song describes the relationships between land, food, and people. Brian also suggested that the knowledge conveyed in the song is only passed on to the next generation on a much smaller scale. His

remarks also demonstrate the interconnectedness between Apache people and land or earth.

Land and respect. “Our identity is through the land because it is through that identity that’s who we say we are. Like with the White Mountain Apache tribe, the word, *Ndee*, the people ... and we tie ourselves to the land” (Gloria).

In this section many of the quotes are responses to the questions about land and diabetes. People were asked if Apaches still had a connection with the land. In the follow-up question people were asked whether having or not having a connection to the land was related to diabetes. For many interviewees, having respect for the land and having a relationship with the land was essential for health and may serve as a protective factor against diabetes. The connection between land and people experienced a disruption or disassociation. When people were asked whether they believed if Apaches still had a close connection with the land, many respondents said, “no,” “very little,” “only in the case of elders,” “not any more,” or “yes, but ...”

Apache people used to have deep reverence for the land; however, people nowadays have seemingly lost respect for it. For example, as Velma, a 45 unemployed community member and skilled Apache craftsperson, stated:

In terms with [*sic*] our ancestors, I think they identified with nature in a way that they understood it that it had life. They respected that. They didn’t desecrate it [the land] like today. I don’t think they really value the land like our ancestors did because they, their life depended [on it]. It was so

closely interconnected. They were able to appreciate the land in a way that our generation [doesn't].

Velma's quote indicates that she believes people no longer respect or appreciate the land. She seemed to suggest people currently do not understand the land in the way her ancestors did.

This loss of respect for land can be characterized as a disruption, an estrangement between land and people that has many implications for language, for diabetes, for health, and for other areas. In the following quote, Brian talked about how the alienation from the land and failure to share Apache knowledge can impact health:

I think it [lack of connection to the land] does impact our health by not sharing why to go out and plant corn or to use the ground to help feed your family. That connection of being who we are is fading away. Our clan is based on the land out there. I'm of the Tizsessin clan, which is "joining of the Cottonwood people" where the two river meets in City Creek by that school. My grandma's grandma's cornfield was there. One day she ... my grandma's story is BIA [Bureau of Indian Affairs] came and told her [to] sign a piece of paper. She did; then she was told, "You have to leave. We're building a school here now." That was a cornfield there. It identifies us of what part of the reservation that we come from ... [where you stayed] ... We had our family farm ...

Brian believed that lacking Apache knowledge and a relationship with the land can affect a person's health, specifically in the sense of failing to use the earth to

feed one's family. Growing corn connects people to the earth. Brian also talked about the clan system and that a person's clan symbolizes a person's origins. In his story he further talked about his grandmother's displacement and loss of land or place—her cornfield, her origins. What is particularly traumatic about Brian's grandmother's story is that she was likely a victim of manipulation on the part of the federal government, underlining the place of marginalization in which his grandmother had become situated.

Respect for land was a necessary corollary for respect of one's self and others. Gloria, a 25-year old mother and hospital employee, said:

[If] we don't have any respect for the land, and if we don't respect the land, we don't respect ourselves. ... Respect for yourself, it's not just physically; it's respect [for] yourself emotionally, spiritually. You have to have that balance where you do what's good for you, because if you don't take care of yourself, if you don't respect yourself, myself ... as a mother, I have to take care of myself. I have to force myself to eat healthy, to physically be active, in turn, so that way my kids will have a longer time with their mother. My husband will have more time with his wife if I'm happy and if I'm healthy. That, in turn, reflects in my children and my family and my surroundings.

Gloria's quote illustrates the relationship between people and land. She believed that in order to respect yourself you have to respect the land. If you respect yourself, then you take care of your physical, emotional, and spiritual health. Gloria also indicates that respect for one's self also means ensuring that one is

healthy for one's family so that the time the family has together is extended. She stated that if she is happy and healthy, then her family is also happy and healthy. To Gloria, respect is central to health.

Contextual and Individual Level Factors

In the theoretical framework discussed in Chapter 2, contextual factors such as living conditions, access to better quality and healthy food, quality of education, and individual behaviors were shown to be known contributors to the nature of a community's health. (Marmot & Wilkinson, 2006) Many behaviors are the result of institutional structures, such as the influence of history, disruptions tied to place, rurality, uneven development, institutional racism, and stratification. In addition to contextual factors, individual behaviors such as diet, physical activity, and alcohol and drug use—all embedded in contextual factors and larger processes—emerged in the finding as contributors to diabetes.

Living Conditions. Living conditions—including the environment, housing, neighborhood quality, and work/employment—are characteristics of place and influence health issues, including diabetes. Issues related to neighborhood quality or environment emerged in the interviews. Many of these responses were elicited from follow-up questions about Apache values, especially those concerning the breakdown in Apache values. The issue of safety was a prominent one.

Environment/neighborhood quality. Environment or neighborhood quality, in these findings, refers to the issue of safety. In the following quote, Sony, a 70- year old elder, talked about gathering nuts by the river:

My sister and I, we went to pick nuts, big walnuts [by her cornfield next to the river], but we were scared because there were young teenagers having a beer party right across the river. You really can't do that [i.e., gather food] any more. It's changing. It's just not safe, to me, like it used to be; too much break-ins and all of that.

Sonya stated that, in general, she does not feel safe and because of safety concerns she no longer gathers food. To her the issue of safety has risen from alcohol problems on the reservation. Many of the plants that Apache used to gather are found throughout the reservation in abundant quantities; however, the plants are found in isolated areas, often the same areas where people prefer to "party."

Housing. Housing characteristics can impact health concerns, including diabetes, and specific problems in neighborhoods were identified in the interviews. As Velma stated: "We no longer have [a] neighborhood watch. Back then, they [i.e., her ancestors] did. They looked out for each other." In this quote Velma referred to early Apache communal living arrangements such as the *gotah*. The Apache communal living structure was family based, neighbors were family members, and the neighborhood watch was incorporated in the living pattern. Nowadays, because of housing policies, people may not know their neighbors. Velma spoke to the actions she was forced to take:

We have become prisoners in our own home and I just hate that. Why [are] those criminals able to enjoy a home where they don't have bars? Why do I have to put up bars on my home? Oh, I just hated that thought.

I hated it and I just refused to do it, even though they would break in here.

[Then] there came a point ... I know I have to do it. I had to put up bars on my windows. It's all because of the breakdown in Apache values.

The frequent break-ins Velma attributed to a deterioration in Apache values, specifically the loss of respect for others. Velma's story of repeated break-ins is not uncommon on the reservation. Velma's remark highlights issues that can impact diabetes. Because of the break-ins, Velma does not trust her neighbors and she does not feel safe in her own home. These issues of trust and safety may impact health by increasing stress, a psychosocial factor.

Access to/knowledge of healthy food. "It doesn't take much education to be obese. It takes a lot not to be" (Timothy, 48 years old).

Knowledge of healthy food is a contextual factor that impacts health. Many interviewees recognized the role of nutrition in diabetes and many interviewees had knowledge of healthy foods; however, several interviewees did not. Allison, a 52-year-old homemaker stated:

We grew up on commodity [foods], and the food that they gave us back then [was] all healthy. It was mainly canned goods and cheese. Once in a while, they would give fruits.

As evidenced by the quote, Allison believed that the commodity food her family ate was healthy; however, the meat was likely high in sodium and the cheese, whose reputation was infamous in Indian County, was probably highly processed. Allison continued to talk about nutrition:

We never really grew up eating fruits ... When I was younger—way

younger—we lived ‘down below [by the river].’ We had an orchard, and we grew up eating apples, cherries, pears ... When we moved up from ‘down below,’ we didn’t have access to those kind of fruits. My mom was on welfare; so we didn’t grow up eating fruits. She only bought food that would last us the whole month; so that was the reason. I think fruits [are not] important.

Allison talked about how she rarely ate fruit as a child, as cost and availability restricted access. She implied that since she never really ate fruit, she does not think to eat it today.

Behaviors. Behavioral factors that impact health include nutrition, physical activity, and alcohol/drug use.

Nutrition/diet. “Historically, the bottom line is that [they were] healthy people—eating very healthy food—but, as time evolved, the diets started to change” (Dale, age 44).

Dale’s quote above summarizes what many Apaches expressed in the interviews. When asked the cause of diabetes, many interview respondents cited historical influences similar to those Dale mentioned, but many others also specified poor diet. Follow-up questions also revealed mechanisms that affect people’s food choices.

Time constraints due to work was cited as a common barrier to a healthy diet. Cindy, a 54 year-old full-time tribal employee, talked about feeding her family:

It’s just easier for me to [go to a] fast food place. If you work, there’s not

enough time in the day. Sometimes I am so tired from work that I just run home and make something easy, out of a box, instead of really cooking a nice, nutritional meal.

Cindy works a forty-hour week (a work condition) and cited time as a factor in choosing quickly and easily prepared but unhealthy foods for her family.

However, as Cindy continued her narrative, she mentioned additional barriers to eating healthy:

I know what I have to buy, my allowance for food. We live from payday to payday. ... When I'm really tight on the food budget, I just do shortcuts like, 'Oh, I'll get this cheap one.' Then, this one [that's] more healthy ... when you read the labels ... I even tried doing coupons. ... Wal-Mart does the price matching, [but] then you have to drive all the way up there.

Cindy's quote illustrates that food cost and distance affect her ability to feed her family nutritious and healthy food. Cindy's quote also highlights issues many families face on the reservation in accessing food: affordability, transportation, and geography. The town of Whiteriver is geographically rural, and the nearest Wal-Mart (an affordable food access option) is over 30 miles away. Cindy continued her narrative, and she mentioned issues other families face:

Here [at work] we know that parents need to survive. ... Our parents need to pitch in [for therapy costs for their child]. They would drop the therapy and go with what they really need—food, paying the bills. That's the problem we ran into. Some of them [Apache families] have like ten people in the home to feed. They [have] to prioritize what's more important,

what's needed now and what you can get later.

Cindy identified an additional barrier families face in feeding their household: the large number of people to feed. Cindy's remarks also illustrate a common problem on the reservation, that of overcrowded households primarily attributable to a significant housing shortage.

In the next quote, Catherine, a 43-year old tribal employee and cultural advocate, talked about food at sunrise dance ceremonies:

At the ceremonies, they're baking, they're cooking, but they're adding lard, and they're adding all this other stuff for flavor, even salt. I know that a lot of people use what's given to them; and it's funny [because] one time I asked my mom, 'Well, what do you take to somebody's camp?' She says, 'You take the traditional stuff.' I'm like, 'Well, what is that?' She was like, 'Well, you have to get macaroni, flour, coffee, sugar, lard, potatoes, pop ...' I'm like, 'Well, what's the tradition about it?' She goes, 'Well, that's just what we always give.'

Catherine's quote illustrates how people use food that's available to them. At sunrise dance ceremonies the families involved have the responsibility of feeding people who attend the camps. The ceremony is a communal event, and the families directly involved in the event accept donations from community members. However, the donations typically consist of what Catherine listed. These food items are inexpensive and go far. At the end of the event the families involved in the ceremony "gift" out leftover food items.

Physical activity. "A long time ago a lot of our exercise came from

[working the land]. We used to work. My mom had a garden and we worked in the garden. My grandma planted out at Carrizo every year, and we were out there picking corn when it was time to harvest” (Janet, age 69).

Janet, a 69 year-old elder, portrayed a life during earlier times when it was common for families to have gardens and cornfields. Gardens and cornfields, hunting, gathering food, and hauling water were all common chores that by nature are physical. Apaches engaged in these chores as a necessity essential to survival. Many of the interview respondents believe that, in addition to a drastic change in diet, activity levels have also altered perceptibly. The factors which have caused dietary changes and those that changed activity levels are related: confinement to the fort, reservation rations, and the introduction of conventional houses as opposed to *gotahs*.

In this section, the findings illustrate changes in activity levels and document issues that constrain physical activity among today’s Apache. Tiffany, a 64 year-old retired community member, stated:

[A] long time ago we used to haul water with donkeys or horse[s], bring the water back, build a fire, warm up the water, [and] wash our clothes with the washboard in the tub. That was a lot of exercise.

As a child, Tiffany had chores that required a lot of physical exertion. She continued:

Now we live in modern homes [with] running water. We don’t have to haul water. We have gas and not fire woods, and we’re idle a lot. It’s very

comfortable, but we don't exercise much any more.

Tiffany attributed the high rates of diabetes today to changing living conditions.

Tiffany believed that because of modern living conditions and technical advances individuals no longer get the physical activity that would otherwise occur naturally.

For many interview respondents barriers such as work conditions inhibited physical activity. For example, Cindy⁶ stated:

The tribe used to help. If you go exercise, you'd get an hour and a half lunch break, but we can't do that here because we are short-staffed. [My daughter and I] have a weight problem. I keep saying we're [going to] go to the gym and we're [going to] walk the treadmill, and we're [going to] go to Zumba, but time ... it's hard ... because I get off at 5:00; then it's already 6:00, and I'm tired.

Cindy cited time and work constraints as issues that prevent her from getting the physical activity she feels she needs. Cindy continued:

I'm [also] a taxi after I get out [of work]. I have relatives that don't have cars, and I don't want to say 'no' to them; so I drive them. I want to be helpful ... and I just think it's better to give, to help. I believe in that.

In this last remark Cindy cited a commitment to family that prevented her from exercising. Her quote also illustrates the geographic issues people face.

⁶ Introduced in previous section.

Alcohol/tobacco/drugs. “We were told not to take anything that will cloud your mind. ... Today it’s the alcohol that clouds your mind” (Richard, age 70).

Alcohol was frequently brought up in the interviews as a primary cause of diabetes, but also emerged as a topic throughout different parts of the interviews. Steve, a 45-year-old unemployed community member, stated: “We are not caring for ourselves. Alcoholism [is] breaking down our immune system.” Steve believes that alcohol is a cause of diabetes and that alcohol weakens the immune system, increasing an individual’s susceptibility to diabetes. James, a 52 year-old tribal leader who also thinks alcohol plays a role in diabetes, reiterated Steve’s sentiments: “I think the number one reason probably is alcohol. To me, I think the alcohol is to blame.” He continues: “All these [health] programs, I don’t think that’s enough. ... Yes, we can get alcohol off the reservation, but there’s Pine Top. Pine Top’s [going to] be selling. ... It doesn’t matter.” James’ comments reflect a frustration in restricting the availability of alcohol: whereas the tribe can restrict alcohol sales on the reservation, they cannot control the border town which chooses to allow these sales. The reservation is, in fact, “wet”, meaning that alcohol is sold, the tribe owns a package liquor store, and consumption is permitted on the reservation.

In the next quote, Richard, a 70 year-old elder, talks about alcohol and the issues surrounding it:

A white man has been drinking for the last 500 years, and he knows how to drink. He got used to it. He knows how to get a carton of beer and go

home. But for us ... it'll be bingeing, and that's what's really bad nowadays. Because of binge drinking, kids will get sick and become diabetic. There's a lot of young kids who are diabetic right now. Young kids are dying from alcohol because of the situation. It's bad.

Richard, like Steve and James, believes that alcohol is associated with diabetes and that youth are developing diabetes because of binge drinking. Richard's quote also suggests a lower level of physical tolerance among Apaches for alcohol as compared to whites, and he notes that Apache youth are dying because of alcohol.

Closing Statements on Findings

Our people had always prayed, which [is] who we are, the foundation [of] who we are. ... That [means] walking with true reverence: mentally, physically, [and] spiritually. It all ties in to one. ... Neglecting certain things in any one of those areas: your health—mentally, physically, spiritually—[you]'ll end up breaking down one way or another. ... [Our ancestors] walked with true reverence, liv[ing] long and strong. They were healthy—they were strong and healthy—but now not as much (Steve, 45-year old community member).

Steve's quote above illustrates what has happened to the Apache people. They are out of balance mentally, physically, and spiritually. However, as evidenced by many of the quotes and narratives, the Apache process involves a tremendous amount of wisdom, strength, knowledge, and resilience. Diabetes and its relationships to history, as well as Apache knowledge and contextual

factors, are complex and the complexity is reflected in the findings that overlap across the major themes of history, Apache knowledge, and contextual factors.

History—particularly place-based history—is an overarching determinant of diabetes for White Mountain Apaches. History influences health through several mechanisms: colonization, confinement, distribution of rations, and historical trauma. White Mountain Apaches experienced colonization primarily through the reservation system, and this system has affected the health of Apaches in several ways.

First, it confined people in a manner that robbed Apaches of their freedom and restricted their mobility. This, in turn, affected their ability to access food. Second, the government issued rations. Many Apache families were forced to accept them as a matter of survival, creating a dependency on the government in the process. As a consequence of confinement and the introduction of rations, traditional (and more healthy) Apache foods were replaced by a new diet that included tortillas and fried bread as staples. The balance sheet for the reservation system is essentially one of losses: loss of home/belonging, loss or restricted access to food sources, and loss of lifestyle and freedom. In addition to this history, Apaches also experienced historical trauma stemming from militarization, abusive school experiences, and losses associated with colonization.

Another determinant with respect to diabetes among Apaches is Apache knowledge. Apache knowledge encompasses how the Apache view and live in the world. Land is an important element of knowledge for Apache people. Land

and people have a relationship that is inseparable. If you care for and respect the land, the land, in turn, takes care of you in providing food, shelter, and knowledge. As a result of history and colonization, Apache people have varying levels of connection to the land: from deep connections to essentially no connection. People maintain a connection or relationship to the land by growing and tending their gardens. People also maintain a connection to the land through language. However, because fewer and fewer people are speaking the Apache language, the transmission of Apache knowledge is threatened. Apache people believe that if you respect the land then you can respect yourself and others, and that that results in health or balance. However, lack of respect for land or a severed relationship with it can destroy respect for both one's self or others. In general, Apache people feel that there is a growing distance from the land and a diminishing respect for land, self, and others. All of this contributes to the poor health experienced today.

Physical environment and housing, access to healthy/quality food, and health related behaviors are contextual factors that impact health. In regards to the physical environment, safety was an important issue, as people are reluctant to gather food and are exposed to unnecessary stress when they do not feel safe in their own homes. "Neighborhoods" have changed from earlier times, and are now composed of strangers who neither trust each other nor look out for one another. The reservation is geographically rural and has limited food access options, both in terms of geography and cost.

Regarding behaviors, nutrition, physical activity, and alcohol and drug use impact health. However, these behaviors are largely the result of history and institutional structures. Current dietary practices and activity levels can be traced to earlier reservation times. In addition, limited discretionary time related to excessive work hours and safety concerns creates barriers to physical activity. Nutrition is also influenced by cost and by geographic distance. Finally, alcohol is a serious issue on the reservation that contributes to diabetes and other social issues.

Chapter 6: Conclusion

There is a long history within the field of sociology examining societal determinants of ill health, dating to back to Durkheim (Durkheim, Spaulding, & Simpson, 2010), and more recently, Link and Phelan (1995). Despite this long history much health research, especially research on diabetes emphasizing prevention and intervention efforts, continues to focus on individual behaviors such as diet and exercise related to clinical outcomes.

Sociologists and other researchers need to revisit the tradition of classical sociologists, stop the continuation of reductionist approaches to ill health, and critique the “circumstances in which people grow, live, work, and age (CSDH, 2008, p.iii). Ferreira and Lang (2006) state, “The prevailing research focusing on obesity, nutrition, and individual health—although undeniably contributors to health outcomes—obscures social and historical issues that are even more fundamental to the etiology of the disease” (p. xix). For AIs, the conditions in which they “grow, live, work, and age” are entangled with history and colonization (LaDuke, 1999; Ferreira & Lang, 2006; Gracey & King, 2009; Walters et al., 2011). In this study I continue the tradition of in sociology that critiques reductionism. My work tries to break new ground by examining diabetes through a non-reductionist lens. The conceptual framework and findings from my research demonstrate the importance of using a societal level of analysis, especially regarding place, in understanding diabetes among American Indians and in developing non-reductionist strategies to combat this frightening epidemic.

The present study clarifies the relationships between indigenous knowledge, land, history and diabetes on the White Mountain Apache Indian Reservation, using “place” as an anchoring concept. In this chapter I review the theoretical framework for the study, present a summary of the results, and discuss the modified theoretical framework based on the findings. I then discuss how I advance theory, implications for policy, and the need for further research. Finally, I present concluding statements.

Theoretical Background

The concept of place is not overt in sociological research. Popay et al. (1998 & 2003), Gieryn (2000), Urry (2004), and Cheyne and Binder (2010) call for a more prominent role of place in sociological research, including a conceptualization of place that includes geographic location, material form, as well as meaning and value. Geographic location is a specific spot in the world; material form comprises the physical aspects or quality of a place; and meaning and value include facets of place such as history, identity, or memory (Gieryn, 2000).

In Popay et al. (1998) the authors stress the need to recognize the history and geography of places in the theorization of health inequities. They (Popay et al., 1998) argue that in order to understand how place impacts health, place should be conceptualized “within a historical context as the location in which macro social structures impact on individual lives” (p. 638)...Places have different histories and the history, and the present, of a neighborhood or locality

will mean different things to different people who have their own temporal and historical associations with the area” (p. 636).

Another consideration in the conceptualization of place is the idea of uneven development (Harvey, 2006). Harvey (2006) argued that places develop unevenly due to practices by capitalist nations who exploit the marginalized. In other words, in order to understand place, the implications of power relationships should be considered with respect to infrastructure: the way places are linked, the way areas are administratively defined, the way services are allocated, and the way places have developed as the result of social relations and power struggles. A growing number of researchers have connected place to health and argue that place and context are necessary for understanding health inequalities. (Williams & Collins, 2001; Macintyre et al., 2002; Cummins et al., 2007; CSDH, 2008; Walters et al., 2011; White, Haas, & Williams, 2012) For example, as LaVeist, Pollack, Thorpe, Fesahazion, and Gaskin (2011) state, “Racial and ethnic health disparities may be driven mostly by place” (p. 1880). One of the ways in which place can be conceptualized is as segregation. The effects of segregation include limited access to resources, opportunities, and services that result in high rates of poverty and unemployment, as well as lower life expectancy (Leung & Takeuchi, 2011).

The social determinants of health offer another relevant view of place. In 2010, the Commission on the Social Determinants of Health created a theoretical framework that demonstrated how “social, economic, and political mechanisms give rise to a set of socioeconomic positions, whereby populations are stratified

according to income, education, occupation, gender, race/ethnicity and other factors; these socioeconomic positions, in turn, shape specific determinants of health status” (Solar & Irwin, 2010, p. 49) that reflect a person’s position in the social hierarchy.

Indigenous knowledge and its relationship to land is another view of place. Duran (2011) defined indigenous knowledge “as ancient, communal, holistic, spiritual and systematic knowledge about every aspect of human existence” (p. 26). Walters et al. (2011) state: “Indigenous knowledge recognizes place as integral to one’s sense of being which is also central to both individual and collective spiritual health and wellness. ... Loss of place (i.e., displacement) is akin to loss of spirit or identity. ... Place literally means us” (p. 173). In Apache culture, as in most other indigenous cultures, indigenous knowledge and land are inseparable. For example, the Apache word for land, *ni’*, is the same word as that for mind, and the clan with which people identify is literally a place. Further, as an elder in my own tribe states: “A more recent threat to the land and its connections to the people is seen in the growing distance between people and place. ... The Ndee homeland—as it has nurtured countless Apache generations and been shaped both physically and conceptually through actions, reflections, and oral traditions—holds the key to restoring much of the harmony and health of the White Mountain Apache community” (Welch & Riley, 2001, p. 8).

Conceptual framework of place for American Indians. In order to examine the relationship between indigenous knowledge, land, history, and health, I created a conceptual framework of place. Geography, segregation, and

other macro structures such as governance, social and public policies, uneven development and history—specifically place-bound histories—are important determinants of health; however, for American Indians, additional aspects of place are necessary, including federal Indian policies with respect to tribes and tribal sovereignty, historical trauma, and indigenous knowledge. American Indians are members of a unique political group and are subject to specific federal policies such as access to health care through the Indian Health Services or other related programs. Federally recognized tribal governments have sovereignty that includes a government-to-government relationship with Washington.

Historical trauma is the “cumulative emotional and psychological wounding, over the lifespan and across generations, emanating from massive group trauma experiences” (Brave Heart & DeBruyn, 1998, p. 7). Historical trauma includes the notions that trauma was methodical and purposeful, continues today, and disrupted the course of history to create physical, psychological, social, and economic disparities (Sotero, 2006).

In my original conceptualization of place introduced in Chapter Two, it was stated that diabetes and other health outcomes are influenced by contextual factors and structures at the macro-, meso-, and micro- levels. At the macro level, the concept of place is symbolic. American Indians are situated in distinct political, historic, and geographic places. Political place includes tribal sovereignty, involves political rather than racial grouping, and is subject to government policies with respect to American Indians, such as access to health

care. Historical place includes displacement and the actions and policies implemented in the past that impact place. Geographic place includes location, the extent to which it is rural in nature, uneven development, and racial isolation. Finally, place of marginalization includes segregation, institutional and individual racism, microaggressions, and stratification. At the meso-level or reservation site—literally a place—indigenous knowledge, traditional practices, and the influence of history impact health, including diabetes. These macro- and meso-structures influence contextual factors such as inadequate housing, limited access to high quality food, high unemployment, and limited opportunities that are known to impact health. Finally, at the micro level, individuals possess varying levels of tribal identification, social support, and individual practices that may influence health.

The final part of my framework is the underlying mechanism that ties place to health, where I borrow from Krieger's (1999, 2001, & 2005) eco-social theory and embodiment principles. Eco-social theory states that our bodies interact with the environment and experiences influence health: "Taking literally the notion of 'embodiment' this theory asks how we literally incorporate biologically ... our social experiences and express this embodiment in population patterns of health, disease, and well-being" (Krieger, 1999, p. 296). In other words, the body is impacted by what happens in place.

Review of Findings

Findings from the interviews reflect some, but not all, aspects of my conceptualization of place for American Indians. The interviews reflect the

history of the tribe. Historical experiences and losses associated with those experiences, such as the establishment of Fort Apache and the creation of the reservation, disrupted the Apache way of life that created changes visible today. These historical experiences created changes in how the Apache interacted with the land, what they ate, how they prepared food, their activity levels, and created dependency on the federal government for survival.

With respect to history, many Apaches related stories that could be characterized as historical trauma. Many people mentioned Fort Apache when talking about historical experiences: why it was created and what it later became and remains—a boarding school.

The relationship between indigenous knowledge and diabetes remains unclear. Many respondents expressed the sentiment that Apaches continue to possess indigenous knowledge and that is important for health; however many could not explain how these factors are related. Many stated that having once had a relationship with the land and then an increasing disassociation from it has led to loss of respect for the land, as well as loss of respect for oneself and for others.

As discussed in the theoretical section, segregation and the social determinants of health highlight the ways in which macro structures affect health. Many interview respondents identified individual behaviors such as diet, physical activity, and alcohol use, as causes of diabetes. However, many of these behaviors are embedded in larger structural institutions. For example, although the White Mountain Apache Indian reservation covers 1.6 million acres with

approximately 15,000 residents, there is only one full sized grocery store for this population. Several people stated that they would not buy fresh fruit or vegetables there because of quality and cost concerns, but would rather travel to the nearest off-reservation grocery store.

Revised Conceptual Framework of Place

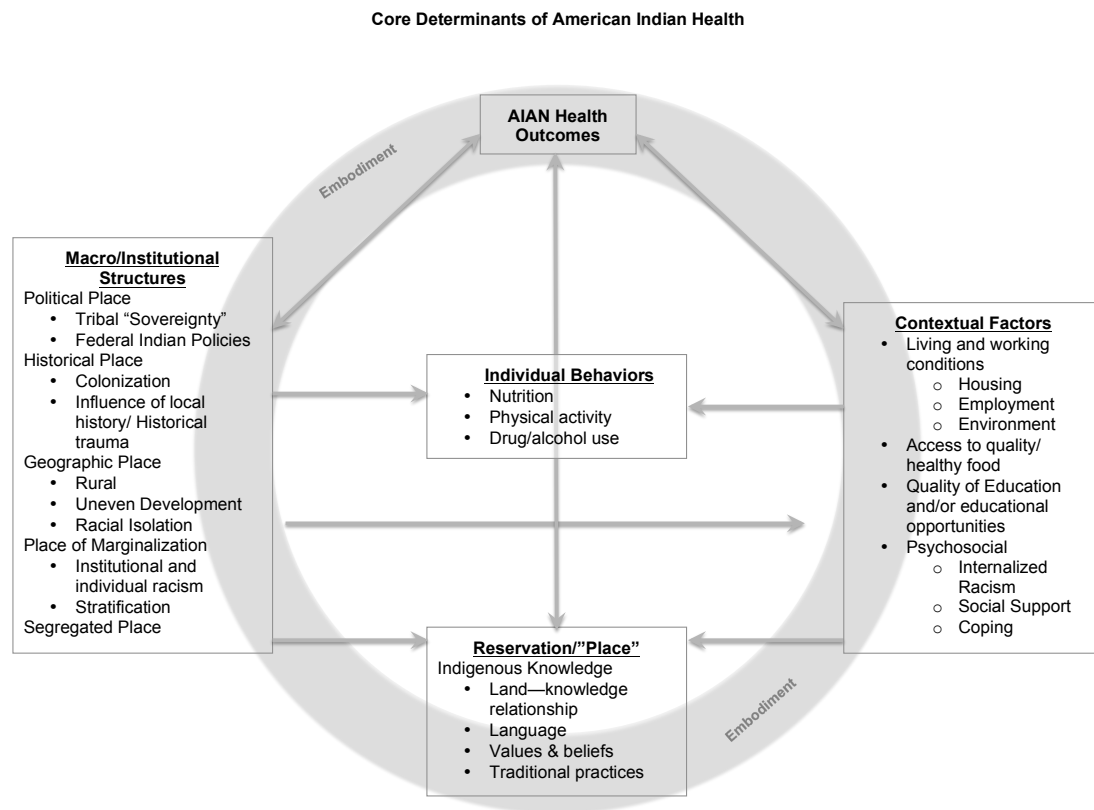
One of the goals of this research was to refine my conceptual framework of place and how it impacts diabetes for White Mountain Apaches based on the findings. Figure 6.1 contains the revised conceptual framework. The new framework functions much like the original framework with the concept of embodiment underlying the associations.

At the macro level are institutional structures and the predominant determinants of American Indian health. American Indians are a unique political group, have experienced a distinct history, and are geographically (usually) rural, segregated, and the victims of marginalization. These macro structures represent the political, historical, geographic, and marginal “places” that American Indians inhabit. As members of “sovereign” nations, American Indians are a distinct political group that has access to health care through the federal government, subject to its specific policies. American Indians, as colonized people, experienced a tumultuous history whose effects continue today. For example, American Indians were subject to policies such as reservation rations and the subsequent commodity food program. Many tribal groups also experienced historical place-based events, displacement or relocation, and other disruptions.

Geographically, many reservations are rural and experience racial isolation, uneven development, and the effects of residential segregation. American Indians also experience the effects of marginalization, such as institutional and individual racism, including micro-aggressions and confinement to a lower place in the social hierarchy. Macro level structures impact contextual factors of place, such as living and working conditions, including: housing, employment, and environment; access to high quality food; quality of education and access to educational opportunities; psychosocial factors such as internalized racism,

Figure 6.1

Place, A Core Determinant of American Indian Health



social support, and coping; and individual behaviors such as diet, physical activity, and alcohol/drug use. At the meso- or reservation level, literally a “place,” Als have varying levels of cultural buffers, such as identity attitudes, enculturation, spiritual coping, varying levels of indigenous knowledge, and varying levels of traditional practices. Apache knowledge has included the relationship with the land, ability to speak the language, and Apache values and beliefs. Apache people also participate in traditional practices (ceremonies, healing, gathering and use of herbs, and gardens). At this level, macro-structures and contextual factors may affect cultural buffers, indigenous knowledge, and practices, all of which can, in turn, impact health.

Rationale for modifications to framework. Given the salience of history and historical experiences across the interviews, the role of history is now more pronounced in the conceptual framework and operates at the macro-level. Historical experiences and losses associated with those experiences disrupted the Apache way of life and created changes in how the Apache interact with the land, affecting indigenous knowledge, what the tribe ate, how they prepared food, their activity levels, and their dependency on the federal government for survival.

Political place, which includes concepts such as tribal sovereignty and federal Indian policies, did not emerge in the interviews but remains an important determinant of American Indian health. Tribal governments, considered sovereign nations, exist in various forms across the United States. The U.S. Constitution, treaties, court decisions, laws, and other legal precedents over the past two centuries are the source of tribal governments’ authority (Wilkins 2007).

Tribal governments hold the authority to create laws and make decisions about taxes, govern fish and wildlife, and determine what activity is allowed or not allowed in “Indian Country,” a legal term that refers to lands under the jurisdiction of tribal governments. The power of tribal governments, however, remains precarious, so that tribes often struggle to establish and to maintain power relations and jurisdictional boundaries with federal, state, and local governments (Kalt & Singer, 2004).

Geographic place continues to play an important role as a determinant of health and is necessary for the conceptualization of place in the framework. Although not specific to American Indians, research investigating racial isolation and health suggests that racial isolation may be detrimental to health (Chang, Hillier, & Mehta, 2009; Acevedo-Garcia, Lochner, Osypuk, & Subramanian, 2003; Dinwiddie, Gaskin, Chan, Norrington, & McCleary, 2012). However, for American Indians, racial isolation may also function as a protective factor. Uneven development occurs on reservations and shapes the infrastructure that exists. As Jorgensen (1971) states: “The conditions of the ‘backward’ modern American Indians are not due to rural isolation nor [to] a tenacious hold on aboriginal ways, but result from the way in which United States urban centers of finance, political influence, and power have grown at the expense of rural areas” (p. 85).

At a place of marginalization, American Indians experience institutional and individual racism, including micro-aggressions. Several respondents talked about the anti-Apache sentiment of local churches and punishment inflicted for

speaking Apache as children. At the individual level, experiences of discrimination are a source of stress that adversely affects health. Exposure to discrimination is associated with increased risk of physical and mental illness, negatively affects patterns of health care utilization and adherence behaviors, and anticipates the risk of using substances as a coping mechanism (Williams, 2006).

Institutional racism did not emerge in the interviews; however, American Indians experience its effects. An example of institutional racism is through chronic underfunding of Indian health care. Health care for AIs remains inadequate and underfunded. Per capita funding for the IHS is only approximately 60% that of other federal medical programs such as Medicare and Medicaid. Annual budget increases remain far below those of other components of the U.S. Department of Health and Human Services and have not kept up with the growth of either the AI population or inflation, especially medical inflation (USCCR, 2003). As a result of chronic underfunding, health care for AIs does not provide the full range of needed services.

American Indians also experience the effects of residential segregation. Although segregation was not explicitly cited in the interviews, many of the contextual factors that exist on reservations result from segregation. Residential racial segregation is the primary institutional mechanism of racism and for creating concentrations of poverty, social disorder, and social isolation (Williams & Collins, 2001). Segregation can negatively affect health by restricting better SES attainment through limiting access to quality education and job

opportunities. Segregation also creates conditions of concentrated poverty and social disorder, with residents consequently unable to obtain either regular exercise or a nutritious diet. Institutional neglect and disinvestment in poorer, segregated communities contributes to increased exposure to environmental toxins, low quality housing, and criminal victimization. Further, segregation adversely affects access to quality health care. American Indians residing on reservations experience the effects of segregation, including limited access to resources, opportunities, and services, leading to high rates of poverty, unemployment, diabetes, trauma, alcohol and drug use, as well as lower life expectancy (Leung & Takeuchi, 2011).

The most drastic changes I have made in the conceptual framework include increased emphasis and inclusion of behaviors as part of contextual factors that impact health. The original framework contained contextual factors that are known to contribute to poor health, such as inadequate housing, knowledge and access with respect to healthy foods, unemployment, quality of education and/or educational opportunities, and environment (Solar & Erwin, 2010). In the new framework I expand contextual factors to include psychosocial variables and behavior. While analyzing and reflecting upon the data, I realized, given the influence of historical experiences on behavior today, I needed to couch individual behaviors within larger structures. I also realized that although psychosocial factors such as coping and social support did not emerge in the interviews, such factors remain important risk and protective factors against diabetes and other health concerns (Solar & Irwin, 2010).

The last part of the framework is the reservation, which includes indigenous knowledge. Although I tried to assess the relationship between Indigenous knowledge and diabetes, it remains unclear. Nonetheless, indigenous knowledge remains an important determinant of American Indian health that warrants further study. As I conducted the interviews, spent time on the reservation, and then while revisiting the interview transcripts, it became clear that indigenous knowledge is a concept that is complex at same time it is abstract. Many interview respondents talked about indigenous knowledge with respect to the loss of a relationship with the land and its subsequent negative impacts (loss of Apache language and spirituality; lack of respect for land, self, and others), but connections between indigenous knowledge and diabetes remain unclear. However, Cajete (2000) states (on the displacement of Dine' on the Long Walk): "[Loss of land or place] led to a tremendous loss of meaning

Table 6.1

Contextual factors that contribute to health

Original	Revised
<ul style="list-style-type: none"> • Inadequate Housing • Access to or knowledge of healthy food • High unemployment • Quality of Education and/or educational opportunities • Varying levels of Internalized Racism • Environment (i.e., stray dogs, drug dealers, etc.) 	<ul style="list-style-type: none"> • Living and working conditions <ul style="list-style-type: none"> ○ Housing ○ Employment ○ Environment • Access/ability to buy quality/healthy food • Knowledge of quality/healthy food • Quality of education • Educational Opportunities • Psychosocial factors <ul style="list-style-type: none"> ○ Social support ○ Coping • Behavior <ul style="list-style-type: none"> ○ Nutrition (diet) ○ Physical Activity ○ Drug/alcohol use

and identity ... that can ultimately be healed only through re-establishing meaningful ties. Reconnecting with nature and its inherent meaning is an essential health and transformational process for Indian people” (p. 188).

Advancing Theory

In this study I examined the relationships between indigenous knowledge, land, local history, and diabetes on the White Mountain Apache Indian Reservation, using place as an anchoring concept. In carrying out this study, theory is advanced in several ways. First, a multidimensional conceptualization of place is created that is specific to American Indians living on reservations. My conceptualization of place for American Indians takes into account the “places” American Indians are located, including institutional structures that help shape place and contextual factors, as well as the reservation where indigenous knowledge is located.

Specifically, my conceptualization of place takes into account the “places” American Indians are located, including institutional structures that help shape place. I build on Bourdieu’s notion of social space and expand his theory of social space to include a larger unit of analysis, the reservation. Reservations, like individuals, are situated on the social hierarchy and experience marginalization including uneven development and institutional racism as a result.

My conceptualization of place expands theory beyond Gieryn’s (2000) features of place (geographic location, material form, and meaning and value) to include indigenous notions of place. Sociological research has not considered

the unique meaning AIs have of their places. For many AIs, place is central to identity, plays a key role in society (i.e. knowledge and respect), and has very specific histories. This research illustrates how concepts beyond location, material form, and meaning/value, impact health; specifically my research highlight the role of place-based history.

Popay, et al (1998 & 2003), discuss the importance of history on health. My research expands on Popay, et al's (1998) theory of health inequalities by illustrating the mechanisms by which historical experiences impact AI health. Diabetes on the White Mountain Apache Indian reservation is largely the result of history that changed people's relationship with the land, changed how people gathered and prepared food, and changed physical activity levels. Another way in which I advance theory is to highlight the prominent role of history and the meaning that place has in producing health for American Indians.

This research also advances sociology through this emphasis on history or historical experiences of place in health. Kemp (2011) encourages scholars to connect place and history in health disparities research, and Walters, *et al.* (2011) call "for work in the area of place and health, specifically examining how AI health outcomes can be contextualized and understood in light of historical losses tied to place or land" (p. 166). My research gives prominence to the premise that for a tribe residing in its ancestral homeland, disruptions and cultural losses do impact health. Whereas research on place and health has increased in the last few years, especially in the field of public health, much of this research

approaches place in a manner that does not take into account the consequence of place-based histories or the meaning of place.

Finally, I contribute to the theory of embodiment with respect to AIs. I advance this theory by demonstrating how history and place are embodied in AI experience and in the emergence of the diabetes epidemic. Krieger and Smith (2004) state that bodies exist in society, including social production and reproduction. Practices that fostered health existed in Apache society but historical events changed these practices, and such less healthful practices continue to reproduce. An example is the introduction of lard and flour whose effects continue today through the staple food of fried bread. In addition, I also demonstrate that the history of the Apaches is still very recent and keenly felt for many Apache people. History continues to be experienced and embodied through seeing Fort Apache and living on the reservation, through the foods people eat, and through learned sedentary behaviors.

Policy Implications

Findings from the interviews indicate macro-structures—specifically history and disruptions tied to place—are the most salient contributors to diabetes on the White Mountain Apache Indian Reservation. Disruptions tied to place changed Apache's relationship with the land, what they ate, how they prepared food, and their activity levels, the effects of which all remain today. Many people expressed the need to return to traditional Apache knowledge as a way to address not only diabetes but other issues as well. Since the White Mountain Apache tribe is a federally recognized tribe with tribal sovereignty, it

has the potential to create changes, which can revitalize or address Apache knowledge in order to combat diabetes and other health issues.

Although the White Mountain Apache cannot change their history, they can learn about and from it. The work of Paulo Freire (1970) underscores the idea of emancipatory education as a way for oppressed people to regain their humanity and reclaim their voice in society: “This pedagogy makes oppression and its causes objects of reflection by the oppressed, and from that reflection will come their necessary engagement in the struggle for their liberation” (p.48). In other words, Freire argues for examining the individual and/or collective forms of oppression as starting points, and from there individuals can move forward to combat and free themselves from oppression. Learning about White Mountain Apache history could potentially help Apache people understand conditions that could impact identity attitudes and actualization, which, in turn, could impact health.

More specifically, many people expressed a desire that the Apache language and history be taught in schools. Although this option of teaching language and history in the school does not specifically address issues such as diet or physical activity, it may indirectly affect health through increasing cultural buffers and indigenous knowledge.

Given the rich stories that resulted from the interviews, another potential intervention involves digital storytelling. Digital storytelling is the practice of using computer-based tools to tell stories that focus on a specific topic and contain a particular point of view. This approach revolves around the idea of combining the

art of telling stories with a variety of media, including graphics, audio, and video. Digital storytelling as an intervention has been used in several AI communities (Gray, Oré de Boehm, Farnsworth, and Wolf, 2010; Wexler, Eglinton, & Gubrium, 2012; Jernigan, Salvatore, Styne, & Winkleby, 2012; Iseke & Moore, 2011). Digital stories could be used in several ways, to tell stories about diabetes, to tell stories about the tribe's history, and to tell stories about healthy living. Many of these digital stories should be shown throughout the community including places such as the IHS Hospital, the Ndee Fitness Center, the grocery store, and in the schools, for example.

Currently, programs that target diabetes—including diabetes specific and nutrition specific programs—on the reservation are disjointed. Given the numerous providers on the reservation, one point of intervention would involve having various programs across the tribe, state, and Indian Health Services engage one another. For example, programs such as the Diabetes Prevention Project out of Indian Health Service, the Ndee Fitness Center, the Women, Infants, and Children program, and the Supplemental Nutrition and Assistance Program all have a nutrition education component; however, there is little or no cooperation or talk across these providers.

Another point of intervention involves food take-out options. In Whiteriver there are several food options that include “tailgate,” which involves people who sell food such as fried bread and beans or “Apache burgers” out of their cars. There is also “The Restaurant,” owned by the tribe, Falcon’s Nest, an independently owned café, and Burger King. Although it is unrealistic to

eliminate the tailgate cafes, since many people rely on them as a source of income, an option would be to create healthy alternatives. As the tribe owns The Restaurant and is in a position to partner with *Ndee Bikiyaa*, or "The People's Farm"—a farming project on the reservation aiming to help the tribe to create a sustainable food system (First Nations Development Institute, 2012)—a viable option might be to create a “new” restaurant that offers locally grown healthy take-out food. Additionally, the tribe could encourage and/or offer incentives for partnerships between “tailgate” operators and the farm.

Very few people are aware that several organizations on the reservation are trying to reintroduce gardening and traditional foods. For example, the Johns Hopkins Center for American Indian Health’s most recent initiative, “Feast for the Future,” has the goal of addressing food-related diseases, including obesity, diabetes, as well as poor nutrition. Specifically, the program aims to: 1) “prevent hunger and food insecurity”; 2) “support indigenous foods knowledge, growth, and re-introduction”; 3) “increase local food production, distribution, and access”; and 4) “promote healthy nutrition and fitness across the lifespan.” However, many of the interview respondents did not know about the Feast for the Future program. The organization could enhance its effectiveness through more outreach to the community, letting it know of the work it is undertaking.

The White Mountain Apache tribe, much like other American Indian tribes, experiences inequities with respect to health. Macro structures have the potential to impact contextual factors both negatively and positively. Housing is an issue across Indian country, not only because of financial considerations, but

because of flawed policies. According to a 2003 U.S. Commission on Civil Rights (USCCR) report on federal funding and unmet needs in Indian Country, housing is a major issue, which lacks adequate funding. There is a shortage of safe and sanitary housing, overcrowding is a problem, and existing structures are substandard. Further, American Indians on reservations have reduced access to home ownership resources because of limited access to credit, geographic isolation, and land ownership restrictions. (USCCR, 2003) Increased funding for housing programs on reservations is one avenue to improve living conditions.

While I was conducting my research, one of the most profound statements I heard was: "I didn't want to live on a reservation within a reservation." This statement was made with respect to housing policies on the reservation. Housing policies on the White Mountain Apache Indian Reservation force families to live in different communities in direct contrast to the traditional, matrilineal practice of residing with or near the wife's family. I suspect that this change negatively affects families and communities. The tribe could exercise its sovereignty to implement housing policies in a way that is culturally appropriate. Families, if they chose to, should be able to live near relatives. This policy would improve living conditions by making communities safer; and, indirectly, safer communities translate into those with less stress, a determinant of diabetes. A safer community would also encourage people to engage in physical activity, such as walking in their own neighborhoods.

Enhancing education is another point of intervention and could be accomplished by both improving the quality of schools and by increasing

educational opportunities. American Indian children in reservation schools (whether public, Bureau of Indian Affairs, or tribal schools) do not receive the same educational opportunities as other off-reservation students. Issues with schools include deteriorating facilities, underpaid teachers, culturally irrelevant curricula, and discriminatory treatment that results in achievement gaps.

American Indian children as a group have lower test scores in reading and math and are more likely to drop out (USCCR, 2003). Further, the U.S. Department of Education Office of Indian Education, which funds tribal and BIA schools, like so many other tribal programs, remains underfunded. However, in order to overcome some of the obstacles—short of increasing funding—tribes can exert their sovereignty at the public school level by requiring instruction in the Apache language, as well in Apache history and culture.

Future Research

One of the limitations of this research is that the study sample consists of only White Mountain Apaches who live on the White Mountain Apache Indian Reservation and who were asked about diabetes. As a result, the framework and findings do not generalize to White Mountain Apache who live off reservation, other Apache subgroups, or to other American Indians or other disease outcomes. The next step for this research is to test empirically the conceptual framework across different reservations to determine whether this framework holds for other American Indian communities and for other outcomes. For example, this framework of place should be tested across diverse American Indian groups, including urban Indians.

Findings from the interviews suggest that indigenous knowledge—particularly with respect to connection to land, respect for land, respect for self, and respect for others—is a protective factor against diabetes. Future research should therefore test risk and protective factors that have emerged from the interviews. Some of the potential protective factors include indigenous identity attitudes and actualization, enculturation, knowledge of history, and indigenous knowledge, such as that of language, values, and beliefs. I did not conduct enough interviews or ask sufficient questions to assess the extent to which these associations exist.

Another avenue of future research includes determining how housing policies are implemented and how reservation housing policies impact communities. In terms of my conceptual framework, future research should specifically examine how AI housing programs are funded and how this funding is disseminated at the federal level, how the programs are implemented at the reservation level, and, finally, how the implementation impacts families and their health.

The final recommendation for future research includes conceptualizing segregation for American Indian reservations. Segregation is “the physical separation of the races in residential contexts. It was imposed by legislation, supported by major economic institutions, enshrined in the housing policies of the federal government, enforced by the judicial system, and legitimized by the ideology of white supremacy that was advocated by churches and other cultural institutions” (Williams & Collins, 2001, p. 405). Williams and Collins (2001) state:

“Reservations are another prominent example of residential segregation that deserves careful examination in identifying the basic causes of health challenges faced by many American Indians and Alaskan Natives” (p. 116).

The effects of segregation on health are well documented and can adversely affect health directly and indirectly through social exclusion, economic opportunity, healthy choices, environmental hazards, housing, schools, crime, and incarceration (Kramer and Hogue, 2009; Lee and Ferraro, 2007; Polednak, 1996; Schulz *et. al.*, 2002; Williams & Collins, 2001), and the “poverty tax” (Fellows, 2006). However, in conceptualizing segregation for American Indians, given their unique status and distinct history, additional mechanisms that operate at the reservation level should be considered. For example, despite historically traumatic events, not all American Indians experience mental or physical health distress, and reservations can be viewed as a base for resilience, continuity, and revival of American Indian culture and traditions (Goodluck, 2002).

Concluding Statements

C. Wright Mills (1959) states: “Every social science—or better, every well considered social study—requires an historical scope of conception and full use of historical material” (p. 145). I think I accomplished what Mills advocates and, as a result, I have a better understanding of myself, of the Apache people, and of the conditions that exist on the White Mountain Apache Indian Reservation.

This work was very emotional for me. There were times during the course of this experience that I was overcome with sadness, with anger, and with joy. Sadness overwhelmed me after every interview, after seeing people suffering

from alcoholism, diabetes, and poverty, and after reflecting as an Apache person, even though I do not speak Apache (I understand it) and only have a superficial awareness of Apache knowledge. Although Apache was my initial language for the first few years of my life, at the age of four my parents made a conscious decision to adopt English. In the past few years I have been returning home more often for ceremonies and I am picking up more Apache and acquiring more Apache knowledge. Anger was another emotion I experienced, particularly after every suicide and senseless death that occurred during, before, and after data collection, as well as when viewing the dysfunctional nature of tribal government. I also experienced a lot of joy and happiness during this process, when I spent time with family and other Apaches.

This research experience was also a journey of learning and of healing. Prior to the study, I had very little knowledge about the history of my tribe or the pre-reservation nature of the Apache. As a result of learning my history, I have healed somewhat. I never understood some of the sadness that would sometimes consume me. I now recognize that the sadness I was feeling was the result of losses: loss of language, loss of culture, and loss of Apache knowledge. Recently, I have made a conscious effort to learn the Apache language and to speak with elders who are willing to share their knowledge. I know that there is strength in my Apache community, and that someday we will be a healthy people again.

Appendices

Appendix A. Place, A Core Determinant of AI Health

Appendix B. Interview Protocol

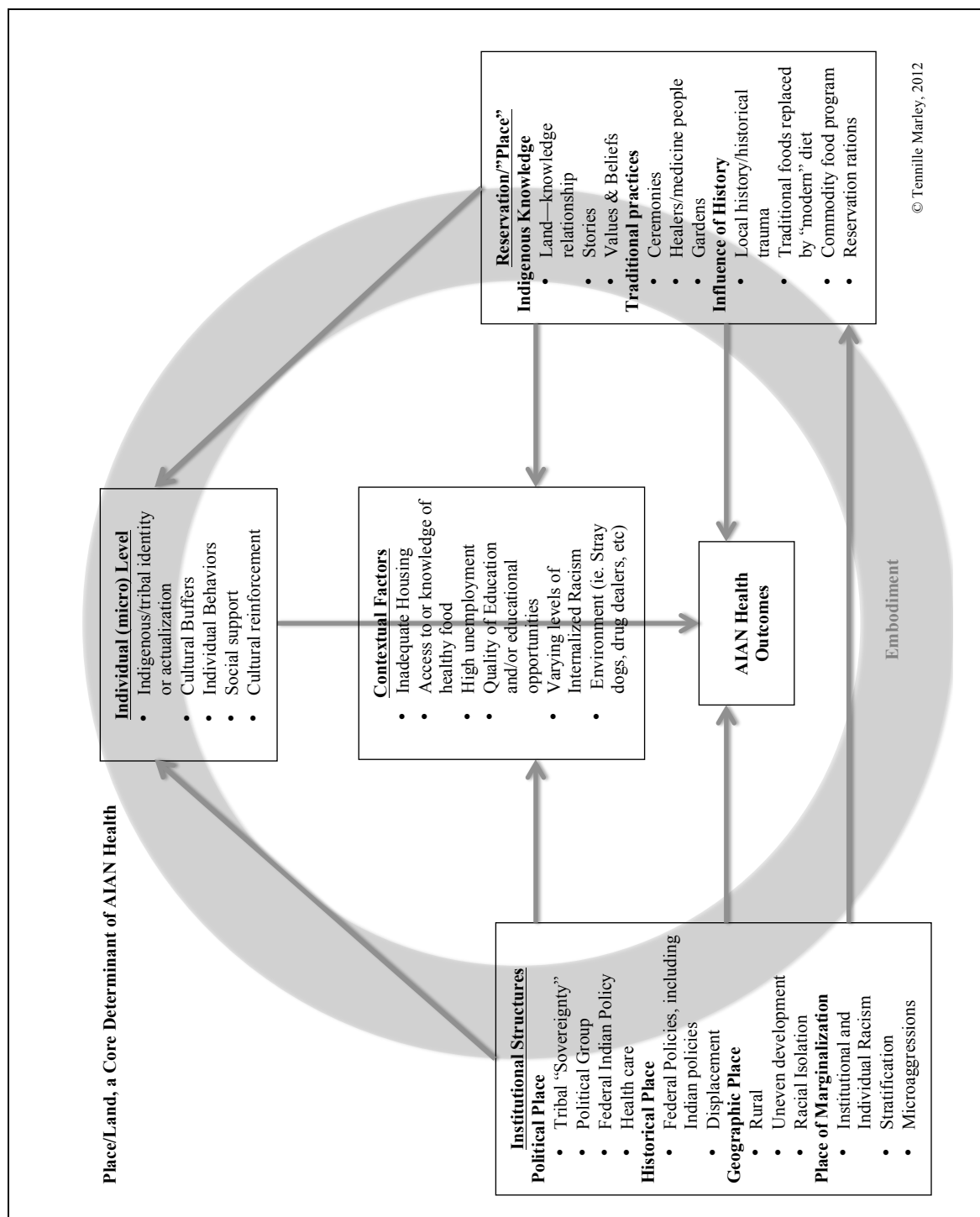
Appendix C. Type of Data and Sources

Appendix D. Coding—Potential Explanations for Diabetes

Appendix E. Interview Consent Form

Appendix F. Place, A Core Determinant of AI Health

Appendix A. Place, A Core Determinant of AI Health



Appendix B. Interview Protocol

PROJECT: Land, History, and Health: The Social Construction of Diabetes on the White Mountain Apache Indian Reservation

INSTRUMENT TITLE: Discussion Guide: Personal in-depth interviews

TOTAL PARTICIPANT TIME REQUIRED: 1 hour – 1 hour and 30 minutes

Interview Time: 1 hour – 1 hour and 30 minutes

Break Time: 0 minutes

OVERALL QUESTIONS TO ANSWER IN INTERVIEW DISCUSSIONS:

Below is a general guide for leading the interviews. This guide may be modified as needed based on pilot interviews.

- **Introduction and Informed Consent (10 minutes)**
 - **Welcome participant and introduce yourself (interviewer).**

Hello, Good Morning/Afternoon. My name is Tennille Marley. Thank you for coming.

- **Explain the general purpose of the discussion/interview.**

This interview is going to consist of two parts—a short survey that you will complete on paper so we know a little about you and an interview with some questions about diabetes on our reservation. The purpose is to see if there is a relationship between diabetes and our history as Apache people, the connection to our land, and Apache knowledge. There is no right or wrong answers. So, I would like you to feel comfortable with saying what you really think and how you really feel.

- **Explain that the interview will be recorded on tape.**

If it is okay with you, I will be tape-recording our conversation. The purpose of this is so that I can get all the details but at the same time be able to carry on an attentive conversation with you. I assure you that all your comments will remain confidential and any quotes we use from our interview will be published without your name or any other information that might identify you.

- **INFORMED CONSENT**

The first thing we are going to do is to review the Informed Consent for our study together.

- Give the participant a copy of the approved Informed Consent for Interview participants.

I am going to walk you through this process step by step. I'll begin by reading it page by page so I can answer any questions you might have about the form. Let me know if there's a word or a sentence that is unclear to you and I will do my best to explain it.

- You (Interviewer) will read the consent form, pausing at the end of each page to ask if participant has questions. If there are no questions, participant will be asked to initial the bottom of each page.
- After you have read the entire form, you will ask (again) if there are any questions regarding the informed consent.
- If participant would like to proceed with the interviewer, they are asked to sign the form in ink.
- Provide the Participant with a copy of the informed consent and emphasize the contact information should the participant have questions at a later time.

• **Demographic Survey (2-3 minutes)**

- Ask the participant to fill out the demographic survey. Remind them not to write their name on the survey.

• **Audio Recording (3-2 minutes)**

- Prepare the audio recorder for recording and discuss the process with the participant.

I am going to record our discussion today on the recorder so that I will not miss any important details from our conversation. And just to remind you, these audio recordings will be secured on my computer. After the recording has been transcribed/written down word-for-word, I will erase and destroy the recording so that no one else will have access to what we discuss here today. Do you have any questions about that?

- Begin recording. *Let's Begin!*
- Ask the participant to introduce themselves by giving only their first name.

• **Interview Discussion** (use prompts as necessary)

What do you think has caused so many Apaches to develop diabetes today?

A lot of things have happened to us historically as White Mountain Apaches. How have these experiences affected our health, specifically in developing diabetes?

The Apaches used to have a very close connection with our land. Do you think that is still true? Why/why not?

- How could this connection or loss of connection with the land affect whether people develop diabetes or not?

We, as Apache people, had our very own knowledge, Apache knowledge. Is that still true today? Why/why not?

- No: Is loss of Apache knowledge related to diabetes? If so, how?
- Yes: How does having Apache knowledge affect a person in developing or not developing diabetes?

Allow the participants some time to add more to the conversation with:

Is there anything else you want to add to this conversation that we didn't talk about already?

- **Closing (5 minutes)**

- Thank the participant.

- Closing Remarks.

Thank you again for helping me with this study! Your comments and suggestions will____. And I just want to remind you that everything you said here will be kept confidential. Do you have any questions about anything? Thank you.

- End Recording.

Appendix C. Type of Data and Sources

Type of Data and Sources	
Type of data	Source (data type)
Socio-demographic data General Demographic Characteristics <ul style="list-style-type: none"> • Total population • Sex • Age • Race Social Characteristics <ul style="list-style-type: none"> • Educational attainment • Marital status • Language spoken at home Economic Characteristics <ul style="list-style-type: none"> • Employment status • Income • Poverty status 	Census (quantitative)
Health data and trends, 1995-2009 <ul style="list-style-type: none"> • Risk profile of AI in AZ • Diabetes related deaths • Five leading causes of death 	Arizona Department of Health (quantitative & qualitative)
History and structure of tribe	White Mountain Apache Tribe website, Online databases (JSTOR, etc.) (qualitative)
Health care access—Types of services provided by the Whiteriver Service Unit	Indian Health Services website (qualitative)

Appendix D. Coding—Potential Explanations for Diabetes

Potential Major Themes	Potential Sub-themes
Losing “Apache” (indigenous) knowledge, including values, beliefs, and practices	Diminishing knowledge about symbolic meaning (land, clans, history, tradition) Changing relationship with the land Diminishing knowledge about Apache values, specifically those related to health Diminishing traditional Apache practices (i.e. cornfields are neglected; ceremonies, etc.) Diminishing use of traditional Apache stories that guided people how to live Moving away from a traditional Apache diet Loss of spirituality
Experiences of history	Historical trauma (i.e. Battle of Cibecue Creek, Apache scouts, history of Fort Apache, boarding school experiences, family stories, loss of land, etc.) Government rations (from the fort) Changed diet (i.e., introduction of cattle as a form of subsistence, replacing other proteins) Change from semi-nomadic lifestyle to more settled lifestyle Commodity food program
Other Explanations (outside original research questions)	
Structural	Food is expensive It’s not safe to exercise (stray dogs, drug dealers) Racism Internalized racism (i.e., only white people exercise, etc.)

Individual	Individual behaviors (i.e., not exercising, alcohol) Diet (i.e., too much soda, fried bread, etc.) Stress “It’s just the way it is.” (i.e., “Everybody has it,” “We’re predisposed to have it,” “It’s in our genes,” etc.)
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Appendix E. Interview Consent Form

The University of New Mexico Consent to Participate in Research

Indigenous Knowledge, Land, History, and Health: The Construction of Diabetes on an American Indian Reservation

12/15/2011

Introduction

You are being asked to participate in a research study that is being done by Tennille Larzelere Marley, who is a PhD student and the Principal Investigator and Howard Waitzkin, who is a faculty member, from the Department of Sociology. This research is studying the relationships among indigenous knowledge, land, local history, and diabetes on the White Mountain Apache Indian Reservation.


American Indians and Alaska Natives are at an increased risk of developing type 2 diabetes and are more likely than the general population to suffer from diabetes related complications. Many researchers argue that place and context matter for health and are necessary for deeper understanding of societal inequalities. This study will attempt to clarify the relationships among indigenous knowledge, land, local history, and diabetes.

You are being asked to participate in this study because you are at least 18 years, English-speaking, and a member of the White Mountain Apache Indian Tribe. Approximately 104 people will take part in this study at the University of New Mexico. About 40 people will participate in in-depth interviews.

This form will explain the research study, and will also explain the possible risks as well as the possible benefits to you. We encourage you to talk with your family and friends before you decide to take part in this research study. If you have any questions, please ask the study investigator.

What will happen if I decide to participate?

If you agree to participate, the following things will happen:

HRPO #: 11-548	Page 1 of 6	Version: 12/15/11
APPROVED: 01/05/12	OFFICIAL USE ONLY	EXPIRES: 01/04/13
 Human Research Protections Office		
The University of New Mexico Institutional Review Board (HRRC/MCIRB)		

- You will be asked to complete a short survey about your age, gender, race, education level, and occupation. You will participate in a 1.5 hours in-depth interview session with Tennille L. Marley.
- The interview will be held in your own home or an alternative convenient location in the surrounding community.
- The interview will be audio recorded in order to assure accuracy in capturing your responses and so that it can be transcribed later. Do you consent to having this interview recorded? ☐ Yes ☐ No. If you choose not to be audio recorded, you will not be able to continue with the study. If you do consent to audio recording, the interview will be recorded on a digital audio recorder. The audio recordings will be labeled with a number and kept in a password protected computer. Only the principal investigator will have access to the audio recordings. Once the audio recordings are transcribed, they will be destroyed.

The interviewer will ask you questions about Apache knowledge, land, local history, and diabetes. You will have the opportunity to respond and share your opinions. How long will I be in this study?

Participation in this study will take a total of 1.5 hours over a period of 1 day.

What are the risks or side effects of being in this study?


The potential risks associated with this study are minimal and include loss of confidentiality and possible discomfort in answering some questions. Feelings of discomfort are fairly likely to occur during the in-depth interviews, particularly for participants who may have family members with diabetes or who have traumatic "stories" from their family histories.

There are risks of stress, emotional distress, inconvenience and possible loss of privacy and confidentiality associated with participating in a research study.

For more information about risks and side effects, ask the investigator.

What are the benefits to being in this study?

There are no explicit direct benefits to participants. Some participants may find the interview process empowering as they get to present their own experiences.

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 UNM Human Research Protections Office		
The University of New Mexico Institutional Review Board (HRR/MCIRB)		

What other choices do I have if I do not want to be in this study?

Your only choice is not to participate in this study.

How will my information be kept confidential?

We will take measures to protect the security of all your personal information, but we cannot guarantee confidentiality of all study data.

Information contained in your study records is used by study staff and, in some cases it will be shared with the sponsor of the study. The University of New Mexico Human Research Review Committee (HRRC) that oversees human subject research, may be permitted to access your records. There may be times when we are required by law to share your information. However, your name will not be used in any published reports about this study. You will receive a copy of this consent form.


We will take measures to protect your privacy and the security of all your personal information, but we cannot guarantee confidentiality of all study data.

Information collected from the interview discussion is used by study staff and, in some cases it will be shared with the sponsor of the study. The University of New Mexico Health Sciences Center Human Research Review Committee (HRRC) oversees human subject research. There may be times when we are required by law to share your information. However, your name will not be used in any published reports about this study. You will receive a copy of this consent form.

The audio tapes from the interview discussion will be transcribed (typed out) later by the researcher. Your name will not be included in the transcript.

Information collected as part of the study will be labeled with a unique study number. This information (without your name) will be entered into a computer database and kept in a locked file cabinet in the researcher's office at the University of New Mexico. Tennille L. Marley will have access to your study information. Data will be stored for the duration of the project, and then destroyed.

We will take measures to protect your privacy and the security of all your personal information, but we cannot guarantee confidentiality of all study data.

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The University of New Mexico Institutional Review Board (HRRC/MCIRB)		

CONSENT

You are making a decision whether to participate in this study. Your signature below indicates that you read the information provided (or the information was read to you). By signing this consent form, you are not waiving any of your legal rights as a research subject.


I have had an opportunity to ask questions and all questions have been answered to my satisfaction. By signing this consent form, I agree to participate in this study. A copy of this consent form will be provided to you.

Name of Adult Subject (print)	Signature of Adult Subject	Date

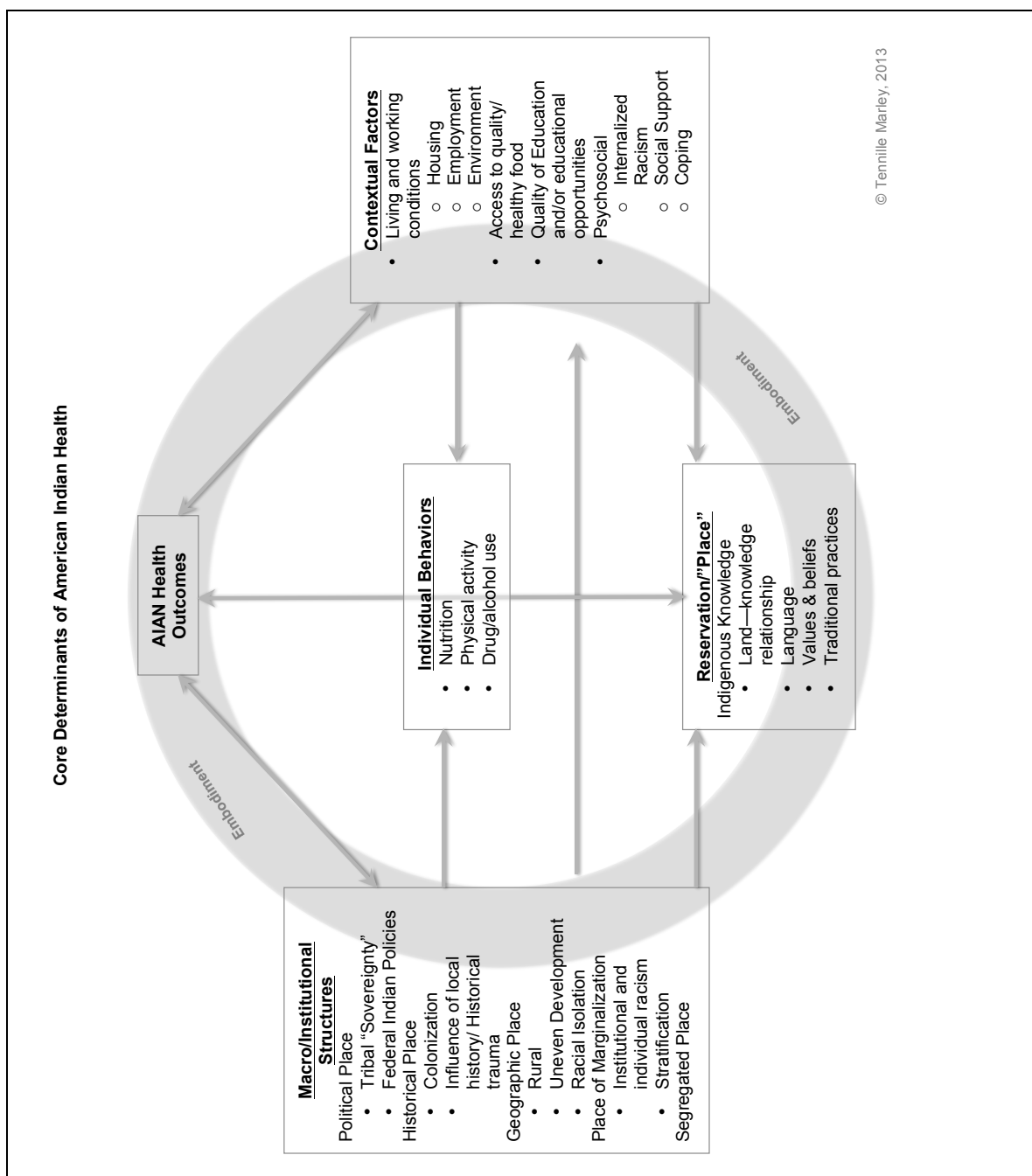
INVESTIGATOR SIGNATURE

I have explained the research to the subject and answered all of his/her questions. I believe that he/she understands the information described in this consent form and freely consents to participate.

Name of Investigator/ Research Team Member (type or print)	
(Signature of Investigator/ Research Team Member)	Date

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Appendix F. Revised Conceptual Framework



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