

Health Insights of Oglala Lakota Elders: From Wellness to Illness

by

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Dedication

For all the Indian people who have come before me and whose sacrifices made this possible

Acknowledgements

I humbly offer gratitude to the elders who generously shared their time, stories and wisdom. You have changed my life in deep and meaningful ways. I wanted to highlight the grace, beauty and life lessons. I hope the younger generations listen closely and carry your wisdom into the future. Additionally, I appreciate the family, friends and community of the elders who assisted in connecting me their loved ones and helped make this project possible.

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Chapter One

Introduction

The first seeds of this dissertation were sown when I was a second year Master of Social Work (MSW) student at the Washington University in St. Louis. Encouraged to apply to doctoral programs, I had assembled the applications and started thinking about the essay I needed to include as a part of my application. I agonized for weeks, often seeking counsel with my close friend Bobbie Jacobs, who is Lower Brule Lakota and at the time also fellow MSW student. After much deliberation, I decided to go for what had always been my 'dream project,' working with our elders. I had always been tailoring my social work education, through coursework and in writing papers, about Native elders. So I essentially wrote this project as my doctoral application essay: I wanted to immerse myself in the world of the elders, uncover the stories I had heard growing up, but more broadly, I yearned to work with many grandmothers, not just my own.

In the academic literature, the life histories and experiences of the generations of Native elders' living today are largely unknown. As Native students, we know that they survived many adversities, sacrificed a lot for their children and grandchildren to “succeed” in the educational system; we are also acutely aware that their wisdom fuels our ability to thrive today. Yet we are located in such a different environment. As students in the western educational system, the elders often describe us as living in two worlds – the 'Indian' world and the 'white' world. When these worlds intersect for Native people in the past, present and future, we have been irrevocably changed, yet we continue to survive and make strides moving forward. This intersection is the area that I was and still am most interested in – how did the elders manage to age into their late older adult years with negative traumatic forces acting upon them? How did they maintain their culture? How has this faltered in the face of modernity? How do we live our values in the modern context? What can we learn from them as we continue to evolve in the future? In seeking answers to these questions, I wanted to capture the wisdom of the elders before it was too late.

They are rapidly dying and the direct connections to the time before colonization are disappearing with them.

Once admitted into the doctoral program, I honed the details and initial research questions of my project through my interactions with elders on the Pine Ridge Indian reservation while visiting my friend Bobbie (and her family), who had lived, worked and raised her family there. Actually, during the course of my doctoral studies at the University of Michigan, they were my respite, allowing me to refuel my physical, mental and spiritual reserves as I made my way through the doctoral program. This study was developed in partnership with them, allowing me to learn about the generations of elders living at Pine Ridge that I would not have otherwise had the opportunity to meet. Indeed, the Lakota elders who participated in this study opened their lives to me, shared wisdom, jokes, hardships, and victories. They quickly showed me the inadequacy of western medicine, scholarship, and social programs; this was the case because of the very limited ability of western ways of approaching the world to fully serve their physical, mental and spiritual health needs.

When I was on the reservation and actively deciding on my sample population, I would often ask my peers, community members and elders I met, “with whom should I talk?” They all unanimously agreed that I had to first talk to Johnson Holy Rock. He was described as the *real* elder, who served as tribal chairman, tribal council representative, who was committed to upholding the treaty rights of his people, and who was also a voracious advocate of the Lakota language. There are many other accolades and descriptors of his service to and participation in the activities of his community. I was very fortunate to spend several hours getting to know him. Unfortunately, Johnson Holy Rock left this world on 21 January 2012 at the age of 93. Yet in my mind's eye, he will always be there as my audience, as the person to whom I want to tell my story and address all my research now and in the future. This is so because he shared many stories with me, stories that so eloquently illustrated the consciousness and experiences of Lakota people, and other Native people and their beliefs and abilities that are often misunderstood and overlooked by the western ways of thinking. For instance, once, when we had been talking about his family members and deaths he had experienced, this is what he told me:

Yep, they're all gone. I don't know why. And most of them, uh, heart problems in the family tree. My brother had an enlarged heart. Covered his whole left chest cavity [demonstrates moving his hand over his chest]. That's how big his heart was and it got growing and growing and before he died his heart was so big as, he couldn't breathe,

breathe. Filled his whole chest cavity there was no room for the heart to contract and, uh...his heart to pump, his heart. They finally had to, that was, this hospital¹ was still operating then. He was brought in here. I used to come from about 4 miles out, my place to visit him. And he had so many types of medicine that he had a little table by his bed he has to take so many different types of medicine and each one at a specified time [taps the table]. So he had one of these, uh, old time pocket watches on a chain. I said, "You mean you take all of these?"

"Yeah."

"And you know what each s'posed to do for you?"

"Not quite but... [we laugh] each one. I take this medicine and then I move the clock to the next one that's how I know to take each one at the certain specified time. Right by the clock."

And here, ooooh, he wanted to go home for, uh, Christmas. The doctor said, "No, no you stay here. I want you close by." It made him angry. Uh, he stepped out and the doctor said, "He doesn't have long to live."

"Why?"

"His heart can't pump anymore. There's no room for the heart to pump."

"Could you operate?"

"We'd have to take all the ribs out on the left side in order to let his heart function. I'm just telling you because by the end of this week I'll just, it's wasted [indiscernible] there's no more room. No more room. An operation would be foolish."

So I knew he was going to pass away. His doctor told me himself and here the next evening, next evening I went to visit him. Hey listen here, talking about just trying to keep our minds away from the inevitable. I think he knew. Finally, he was quiet for some time then he said, "I've been having a visitor."

"Who?"

"I don't know."

"Well, if you don't know then how do you know if - is it a he or she?"

"I don't know. But it's been coming eveevery night. Every night."

"And you don't know who it is?"

"No. there he's at the door again."

I looked toward the door and I didn't see nothing. The room was kind of oblong so the door was over there. [gestures to the right] I kept looking over there and I couldn't see anything.

"Comes every night."

"What does he do?"

"Just stand there and towards morning, it's gone."

"And you don't know who it is?"

Then I knew! He was just about ready to leave. Our next, I repeated my visits because knowing, and usually one like that leaves a message or wants things done a certain way. I was the only one coming to sit with him. The next evening I went back. Sitting there.

"There he is again."

¹ "This hospital" refers to the first hospital that was built at Pine Ridge, often referred to as "the old hospital."

“You keep saying he, is it a man?”

“No, I really don’t know but I just say he because I don’t know who it is or what it is. He has a hood over his head and when he looks in my direction it’s just a black spot in front of his hood. There he is again.”

I stood up and “He’s really there, huh? You see him move?”

“Yeah.”

I stood up and walked toward the door, “He still standing there?”

“Yeah, there. He disappeared.”

I got real close to the door but I didn’t see anything move.

“When you got close he disappeared.”

The next two nights, I forgot what we were doing and I didn’t go. I got a phone call from the police and said, “Your brother died last night. We were supposed to notify you but we didn’t know how to get a hold of you.” So he left with whoever that was. So that’s why when the church people say when you are dead, you are dead, you don’t resurrect. You are finished kaput. It makes me wonder. He was seeing something. He swore by it. I couldn’t see it. So I guess I’ll still be wondering when I leave. Then I’ll know. I’ll come back and tell you about it.

Me: I hope you do!

His narration that I quoted verbatim captures his skills in combining the concerns of the mind, body and the spirit as it pertained to the illness of his own brother. And he told it in a way that also revealed his great affection toward his siblings and family. I want to emphasize the spiritual since it is so lacking in western conceptions of health and illness. In an earlier story about his father’s experience with spirits, he shared the following which I have reduced to this excerpt:

...That’s when I first became aware of there were other things that are around that are invisible yet very essential as to the reason for the existence of that bible. Because there were other things in this world. Just like anything else. You either believe in it or you didn’t. If you didn’t, they would harass you. There was something to which you committed yourself. And they get it out of you sooner or later. If you flip your lid and get the screaming mimis, they get you... So there are things in this world that are invisible but if a person expounds on it more and more and more they look on him like he’s ready for the loony bin and uh, they shy away from him. “He’s crazy. He’s going nuts. One of these days he flipped his lid.” So these things I know. I keep it here [taps heart] I believe what I believe and it stays here [taps heart], it stays here. It stays within my spirit. I don’t tell that cause I might find myself in a straight jacket and sent to a loony bin. So there are

things that are to be handled very carefully. I know of things, I've seen things. [tap tap on the table] No one has ever seen but it stays with me. And it will stay with me when they put me six foot under. I'll take it with me. It's not to be generally become knowledgeable about those things because you get deeper and deeper into the subject matter and before you know if you subject yourself to adverse views and treatment just like an elder afraid to speak of being rebuffed if he or she asks for certain things to be checked for him.

The stories shared by this respected elder highlight and bring to the forefront the spiritual beliefs and experiences that are held by Native people. The intersection of western medicine and the silencing of the social, cultural and spiritual norms within Native people are an incredible loss. There are many lessons to learn from the elders and their life history narratives, these particularly display the power and control of western medicine, the quiet experiences shared between brothers, fathers and sons, and the inability to talk about these spiritual and cultural experiences for fear of being considered mentally ill. He also warns us that we must immerse ourselves and dedicate ourselves to knowing who we are and our spiritual practices because the elders know these ways and they are taking it with them when they leave this world. Also, when we interact with adverse conditions and treatment of traditional Native ways, it erodes the well-being of Native people. His example of an elder asking for things to be checked on, offers advice to Native people as well, we need to respect our teachings, our elders and each other or we contribute to eroding our own well-being as well. The boundaries of Native people's physical, mental and emotional well-being have not fully been defined. This dissertation research and the wisdom of the Lakota elders who shared their stories begin to fill this gap. With their insights, a more holistic method of healthcare can be provided to them that uplift and does not create an adverse experience which diminishes their ability to live fully.

Given that I have now articulated the main concern that led me to pen this dissertation, I now have to situate it within the larger framework of health care that is a significant social issue in the United States. Yet, it is of particular significance for Native American populations because of their particular historical experience. That is, unlike the rest of the American population, Native Americans have had access to health care much later than the rest. As a consequence, it is quite a miracle that so many elderly Native Americans have survived to old age. This dissertation studies the factors that enabled elderly Native Americans to survive in

spite of their much later access to health care; it is specifically interested in the combination of their access to health care facilities on the reservation with their own indigenous resources.

At the moment, existing research indicates that the unprecedented cohort of Native people who are aging rapidly and living longer have among them, according to recent research, a disproportionate number in poor health (Moulton et al., 2005; Barusch & TenBarge, 2003; Rousseau, 1995, Weibel-Orlando, 1988). Traditionally, native elderly people have been respected, sought after for their wisdom, experience and leadership; they have also been supported by the younger generations. Social and cultural mandates have thus required the care of Native American elderly people (Balderidge, 2001; Colomeda & Wenzel, 2000). Yet in the contemporary environment, the traditional roles of Native elderly people are being challenged and may be changing; the care of the elderly within the community has started to erode. Not only are they not respected, but sometimes neglected and even abused. The purpose of this dissertation is to address contributing factors to health, wellness and illness for Native elderly people.

Aims and Hypotheses

In formulating what I wanted to study in this dissertation, I specified three aims that in turn enabled me to formulate three hypotheses. These all focused on locating the health and well-being of Native elders in relation to the Western world, their community, and the available resources. As such, these three aims and hypotheses were as follows:

1. To determine whether or not the patterns of defining health, illness, and wellness mimic or differ from the Western world. Native elderly people struggle with chronic illness with limited resources. Learning more about their experiences, such as understanding what they consider health to comprise of, when they seek help, and how they go about doing so would demonstrate how Native elderly persons cope with health challenges. ***Hypothesis I: Native elderly persons' definitions of health, illness, wellness and coping patterns are a combination of the Western worldview and their Native insights.***

2. To identify the health resources available to Native older adults, such as social support networks, and the effects of these resources on their health. Like the rest of American society, Native Americans make up for their lack of health resources with social support networks that

may affect Native older adults' health. ***Hypothesis II: Health resources, such as social support networks of Native elderly people will have a positive effect on their health.***

3. To reveal the connection between the status of Native elderly people within the community and their health. Traditionally, communities have always respected and taken care of their elders. Yet over time this pattern of respect and care has started to decline, which may adversely affect elders' health condition. ***Hypothesis III: The health conditions of Native elderly persons declines as their social status in their community declines.***

Significance

In assessing the significance of this dissertation, it should be noted that understanding the worldview of Native elderly is essential to an investigation of their experience of health, wellness and illness because the boundaries of these concepts in the world of Natives are much broader than in the Western world. While in the Western world of medicine one is considered to have been 'treated' and therefore to have 'reached health' when one's body is cured. In the Native world, according to my preliminary field work, this is just a partial treatment because the conception of health comprises not only the health of the body, but of the whole of the mind, body and spirit. Hence, when Native American health is only studied within the Western conception of health, only a part of Native American 'wellness' or 'illness' is captured. This study is significant because it brings together the Western and Native American conceptions of wellness and illness.

This study is significant in particular because it integrates the Western and Native American conceptions of wellness and illness. These Native American conceptions have eroded over time especially due to lack of resources. Native Americans do not have access to their own social support networks or their communities as modern living and values penetrate their communities as well. In addition, health disparities for Native populations are among the highest (Harnack, Story, & Rock, 1999; Neff et al., 2007). As a consequence, this dissertation will be significant in identifying these patterns of change and increasing disparities, enabling sociologists and social workers to better understand the current health care needs of Native elderly people. Social work researchers and educators can benefit from these findings by gaining knowledge to develop interventions and planning for Native elderly patients. Through an understanding of the cultural and historical perspectives of Native health, researchers and

practitioners can determine the impact of life experiences within Native communities and thereby develop interventions to improve them in the future. Additionally, the dissertation will make significant contributions by providing useful insights into the tribe as well. As tribes understand the health challenges of Native elderly people, they can tailor resources to overcome some of the barriers. Additionally, the tribe can take the findings of this study to apply for funding for programs and services. Also, collecting life histories of tribal members is important in contributing to archival data as Native elderly people are a unique population that is disappearing rapidly.

Conceptual Definitions

It is important to rigorously define the main concepts this dissertation employs. The definition of *health* guiding this research is provided by the World Health Organization (WHO) that defines health as “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity” (1948). As such, the definition takes into account the mental and the social along the physical, an accompaniment that is similar to the Native conception where all three components are equally significant unlike the western world where the physical trumps and often dominates concerns over the mental and the social. Still, it should be stressed that Native American conception of health comprises the wellness of the entirety of mind, body and spirit; it thus considers the healing of only the body a partial recovery. Unlike the Western conception of health improvement, which is often limited to the body and is attained primarily by medication, *health insights* refer to how Native American elderly people improve the health of the totality of the mind, body and spirit with rituals, prayers, singing and natural herbs. So not only is medication merely an insignificant aspect of health attainment, it is accompanied by other healing practices such as engaging in rituals, prayers, singing on the one side and consuming natural herbs on the other. In addition, I should note that the term *Indian Country* refers to anywhere Native people live – urban or reservation around the U.S. And the term *Native* is employed to describe the Indigenous people who resided in North America, and specifically what is now the United States prior to the colonization of European nations. Native people and communities are recognized as Native Americans, Alaska Natives, and sometimes referred to as Indians.

Finally, the term Native elder and elderly person needs to be further articulated because not all elderly Natives are elders. *Native elders* have traditionally held positions of respect and have special roles in their communities and spiritual practices. A Native elder fulfills a role that is not predicated on age alone. There are Native older adults who are not revered in the role of elder. A Native elder is a person considered by other people as a leader in the community. As leaders, Native elders perform important spiritual, political, and tribal functions (Carson & Hand, 2001). They hold cultural and historical knowledge, which they pass on through the telling of stories, the teaching of songs and dances, and through leading spiritual ceremonies and practices (Carson & Hand, 2001; Cross, 2004). They are respected and utilized for their knowledge and wisdom about traditions and languages. Other roles include being keepers of knowledge of family, teachers, mediators, unifiers, counselors, healers and caregivers (Cross, 2004). In addition, Native elders are an important link between family, clan and the tribe. The family networks and kin relationships provide a source of stability and encouragement (Carson & Hand, 2001; Redhorse, 1980).

Some tribes determine elder status when a Native person becomes a grandparent. Becoming a grandparent entails having a major role in the care and passage of knowledge to the grandchild (Cross, 2004). Grandparents are held in a position of great respect. Respect for elders is ingrained in children through these types of kinship networks beginning at a very early age (Carson & Hand, 2001). They pass on the “physical, social, and spiritual worlds by communicating to their grandchildren tribal history, traditions, philosophies, myths, and stories or special events” (Carson & Hand, 2001, p. 171). Within this conceptual framework, it is time to next turn to identifying the characteristics of the Native American Population in the United States.

Characteristics of the Native American Population in the United States

According to the 2000 Census, an estimated 4.1 million people self-identify as Native American living in the United States, and 2.5 million identify solely as Native American (Census, 2000). Of these, 5.6% of the Native population is over 65 years old (Census, 2000). There are over 569 federally recognized tribes in 35 states, with the highest percentage (43%) living in the Western region of the United States. Thirty-one percent of Native Americans live in

the South, 17% live in the Midwest, and nine percent live in the Northeast (Census, 2000). The states reporting the highest population of Native people include: Alaska, Arizona, California, Michigan, New Mexico, New York, North Carolina, Oklahoma, Texas and Washington. In 2000, 24.9% of Native people lived on the reservation or trust lands, and 75.1% living in urban, suburban, or rural non-reservation communities (USDHHS, 2001)

Health Characteristics

It is very difficult to assess the health characteristics of Native American populations because records that have been kept have been and still are scarce, spotty and inaccurate. This inadequate record keeping inevitably reflects upon the analyses or generalizations one can make based on such information. The major source of data is through the IHS, Indian Health Services, which unfortunately was not formed until the 1950's and did not start collecting data systematically until the 1960's. Also, limited or no access to U.S. health care systems may be responsible for lack of health data.

Life Expectancy. According to the IHS division of statistics (1998), the overall life expectancy of Natives is 71.1 years. Since the life expectancy of an average American is 76.9 years, Natives have a much higher chance of dying young than the rest of the population. Indeed, according to McFall, Solomon, and Smith (2000), only 60% of Natives make it to their mature years, as opposed to 86% of the white population; hence Natives are disadvantaged once again. The interaction of life expectancy with chronic disease rates vary by region as such rates are probably related to both the climate as well as the available food supply: Life expectancy which is 76.3 years in the California Area IHS declines to 64.3 years in the Aberdeen Area (serving North and South Dakota, Nebraska and Iowa) (Moulton et al., 2005). Further investigation is required to determine the causes of these regional differences.

Prevalence of Chronic Disease. Since infectious diseases in the United States have been successfully treated in the last 50 years, the causes of mortality have now shifted, a phenomenon referred to in the literature as the epidemiological transition. This has also been the case for the Native American population where now the major determinants of mortality are related to behavioral and lifestyle factors. For instance, many of the recent health problems faced by Native people are now often attributed to high rates of obesity. Especially Natives living in Arizona, Oklahoma, North and South Dakota have a high prevalence of obesity among adults aged 45-75

years (Harnack, Story, & Rock, 1999). When compared to Black, Hispanic and Asian groups, Native men have also been found to have the highest hypertension and cholesterol levels (Neff et al., 2007). Obesity also leads to chronic diseases, the leading cause of death among Native Americans (Harnack, Story, & Rock, 1999; Neff et al., 2007). Cardiovascular disease, however, is the leading cause of mortality only among specific tribes or regions, which has led some scholars to conjecture that it is related to particular lifestyle factors. For instance, Southwestern Indians have lower rates of heart disease than other regions probably because they still live in their original habitat (Harnack, Story, & Rock, 1999; Howard et al., 1999). The escalated level of chronic disease prevalence among Natives in comparison to the rest of the American population probably derives from a number of factors. The most significant factor among them is the displacement the Native population underwent thereby removing them from their natural habitat. Also significant is their removal from their traditional way of life as well as their traditional sources of food. Their increased reliance on processed food as well as their being forced into a passive, urbanized, stationary life over an active, mobile one contributed to this outcome.

The prevalence of chronic disease varies by age and gender. While Johnson and Taylor (1991) found that Native elderly men over 65 years had the same prevalence of arthritis, emphysema, cardiovascular disease, cancer, and hypertension as the general population, Native elderly men reported higher rates of diabetes, gallbladder disease and rheumatism than the general population (John, 2004). This difference may be due to the living conditions as well as the lifestyle; Native elderly women differed from women in the general population of the same age in that they were 2.4 times more likely to report diabetes. This vast difference in diabetes diagnosis is noteworthy.

Comorbidity among Native Older Adults. Comorbidity is the occurrence of two or more health problems in the same individual. As such, it is seen with increasing frequency among older populations. In the case of Native American elderly persons, however, given their lack of access to healthcare during their life course, comorbidity is much higher than the rest of the American population. As there have been no studies that report the extent of comorbidity in Native populations, four methods have been developed; these are to count the number of diseases, to consider the severity of the number of comorbid conditions, to assess the population proportion with comorbid diseases, and to assess the relative association between diseases (John

et al., 2003). According to one study employing such a method, a third of the population on one reservation experienced arthritis and vision problems (John, et al., 2003). Other findings pointed out that the majority of the population (57%) reported three or more chronic conditions, indicating once again the high prevalence of comorbidity among Natives (John, et al., 2003). The largest cluster of comorbidity occurred in cardiopulmonary conditions, including stroke, heart disease, diabetes, tuberculosis, and high blood pressure (John, et al., 2003). According to another study, the Native elderly population reported a mean of 3.90 illnesses with 37.6% having five or more chronic illnesses, 30.2% having three or more, and 25.1% having two or more chronic conditions (Chapleski et al. 1997).

One particular health issue that needs specific mention in the discussion of comorbidity refers to mental illness. This is the most understudied and under-researched illness among Native American populations. Preliminary studies have revealed the prevalence of mental illness, especially of depression. A significant consequence of comorbidity is that in the case of older populations it can limit the mobility of the person. Indeed, in the only other study addressing comorbidity in Native older adults, both diabetes and vision problems as well and arthritis and obesity emerged as more prevalent among Native elderly than the general population. This study also analyzed how this comorbidity led to ADL impairment (eating, dressing, grooming, walking, getting in and out of bed, bathing, and going to the bathroom) Chapleski et al. (1997).

Functional status, the inability to perform one or more ADLs, is often the path from the onset of a chronic disease to disability (Moss et al., 2004). In a study of 90 Zuni elderly, Moss et al. (2004) found that there were high levels of ADL limitation, a finding consistent with Chapleski et al. (1997). These studies have shown that elders experienced chronic illnesses; 46% with diabetes, 51% with vision problems, 22% with arthritis and a disruption in their abilities to care for themselves. The Zuni elderly persons experienced an average of 1.8 limitations per elder. Not only did many Zuni elderly people fail to access the community resources available, but those who did most commonly chose meals-on-wheels and transportation (Moss et al., 2004). Services for the severely disabled, those with two or more limitations in ADLs, were limited. Long term care services are still not available to those living on the Zuni Pueblo (Moss et al., 2004).

Disability. Given the range and number of health issues that Native people struggle with during their life course primarily due to lack of resources and adverse circumstances, they end up

becoming disproportionately impacted by disability and at younger ages. In order to put things in perspective, it should be pointed out that, unlike the rest of the American population, Native Americans who are 20 years old can expect to live a quarter of their lives with a disability (Okoro, et al., 2007; John, 2004). Native elderly people have higher rates of disability than Whites and other ethnic groups (John, 2004; Goins et al., 2007; Okoro et al., 2007). Yet the information from the 2000 Census has revealed that Native older adults have lower disability rates than African Americans in all age groups, except in the 55 to 64 age group (Goins et al., 2007).

Within the disabled population, Natives have particular characteristics that differentiate them. These characteristics are: higher rates of smoking, heart disease and asthma; lower education (below high school); unemployment; fair/poor health condition, and low household income (John 2004; Okoro et al., 2007). These factors all point to the alienation of Native Americans from American society in more ways than one. As Native Americans resist and move away and have no alternate means to sustain themselves, they deteriorate in health as well.

There have also been studies of Native Americans within the context of larger American society. Studies show that disability among Natives is also correlated with lower educational attainment (Logue, 1990, Goins et al., 2007, Okoro et al., 2007), low household income (Logue, 1990, Goins et al., 2007), living without a spouse (Logue, 1990, Goins et al., 2007) and residing in an urban area (Goins, et al., 2007). While the correlations of the first three variables are well known, correlations of the fourth variable, that is, between urban residence and disability, is counter-intuitive and does not hold true for the rest of the U.S. population. This is the case because urban residence improves one's access to healthcare and therefore decreases disability. Yet the fact that urban residence works to the detriment of Natives points to a cultural factor and demonstrates how the forced removal and adaptation of an urban lifestyle has led to the deterioration of the health of the Native American older population.

According to the IHS, the leading causes of death among Native peoples are 1) heart disease, 2) cancer, 3) diabetes, and 4) accidents for those aged between 55 to 64 years (McFall, Solomon, & Smith, 2000). Put another way, for Native elderly persons who survive to age 65 and older, for the population this dissertation aims to focus on, the causes of death are heart disease, cancer, cerebrovascular disease and diabetes (McFall, Solomon, & Smith, 2000; John, 2004).

In summary then, health characteristics of Native American elderly people demonstrate the consequences of the lack of resources and care. Not only do Native elderly people suffer from higher rates of chronic disease, comorbidity and disability but they also have a much lower life expectancy than the rest of the American population. Additional research is warranted that addresses the factors that could alleviate these conditions. By studying Native American older adults' health insights this dissertation aims to fill in gaps in our understanding of Native American older adult health.

Literature Overview

I locate my population within the existing academic literature in two sections; the first section analyzes the intersections of culture, health, illness and wellness while the second section focuses on the community status and the availability of informal and formal resources. As such, the first section reviews the literature on the social construction of health while the second section focuses on the provision of healthcare.

I. Culture, Health, Illness, and Wellness

The two themes in this section comprise the cultural constructions of health, illness and wellness on the one side and the perceptions of disease on the other. As it will become evident, these constructions and perceptions are significantly different from the experiences of most of the white urban middle class population.

Cultural Constructions of Health, Illness and Wellness In a qualitative study of multicultural elders who were asked what healthy meant to them, five Native elderly persons living on a reservation responded with descriptions that described someone who could get around and do what they had to do without much difficulty (Hakim & Wegmann, 2002). Also, when asked about health maintenance behaviors, they referred to a nurse from the tribe who works at the clinic with whom they talked and listened to her advice (Hakim & Wegmann, 2002). She refers them to the use of Native traditional medicine, as the belief is that one should seek traditional medicine before Western medicine (Hakim & Wegmann, 2002). As with the definitions of illness and unwellness, understanding the vernacular concepts behind notions of what is healthy behavior can open doors of communication and better affect the pathways of disease.

Four studies investigated the cultural constructs of illness that attempt to describe Native beliefs and cultural pathways about health, moving beyond constructs and spaces that are known in the Western scientific thought. Locust (1985) makes an attempt to bring together the common themes among Native people regarding health and unwellness. First and foremost, a human is made up of body, mind and spirit. The body is the vessel for the spirit, and the mind links the body (or physical world) and the spirit (Weaver, 2002; Locust, 1985). Physical illness may be brought about by spiritual or emotional causes. When a Native person experiences illness, they may ask what they did to bring this on themselves. Treating the physical body is part of the process, but the spiritual aspect needs to be addressed as well.

For many Native people, traditional beliefs included harmony or balance between the body, mind and spirit (Locust 1985; Weaver, 2002). The path to harmony is individualized. Unwellness has been characterized as disharmony or unbalance of the whole body, mind and spirit (Locust, 1987; Lang, 1989; Weaver, 2002). Unwellness differs across the tribes. For Apaches in the study, alcoholism was unwellness, for others feelings of restlessness and disharmony in the home were attributed to unwellness (Locust 1985). Violating sacred objects or animals can cause unwellness. For certain tribes being near a certain animal can bring about illness, for others touching sacred objects.

Activities can bring about illness as well, for example, marrying within your clan, touching the dead and other rituals surrounding the dead, participating in activities during menstruation, not honoring vows made in religious or spiritual arenas, not attending ceremonies or other cultural events (Locust, 1985; Locust 1987; Lang, 1989). In a study of Navajos about the causes of cancer, they believed that lightning was a cause. Lightning is an important aspect of their spirituality and of the belief system of the spirits using lightning as a tool or weapon (Cosordas, 1989). Lightning can be metaphorical for other things that radiate such as nuclear radiation, sunlight, microwave ovens, and television. Unnatural causes of cancer were “witchcraft,” an English term that is most closely related to the concept in Native languages, and accidents, because they were viewed as being caused by spiritual forces (Locust 1987; Locust 1985). Navajos also cited “witchcraft”, exertion, old age, animal violation and ceremonial contamination as causes of cancer (Csordas, 1989). Essentially there is good “medicine” and bad “medicine”. When someone is operating or walking on the dark or bad side then they can do harm – illness – physically and emotionally, harassment or even death - to you through

“witchcraft.” A healer on the “good” side can rectify the situation as well as using various sacred objects and activities that will ward off the “witchcraft.” Overall, Natives are responsible for their own wellbeing. They must care for themselves in order to keep themselves in harmony for themselves *and* for the health of the tribe (Locust 1985).

Investigating cultural views of physical facial paralysis, Henderson and Adour (1981) examine the Comanche explanations of ghost sickness. One Native person came into contact with a ghost, the ghost hit him in the face and ran, the Native person fell down and woke up later and his face was paralyzed. He sought help with a traditional healer, or Indian doctor, who was able to fix it (Henderson & Adour, 1981). Others believe that someone puts themselves in the situation. Often a Native male will be living between the Native world and the White world. When moving between the worlds there often was rejection from both sides and an episode of ‘ghost sickness’ would occur (Henderson & Adour, 1981). The ghost sickness would be rectified through formal reintegration into the traditional group. In Kiowa-Apaches, ghost sickness can occur through fear and ambivalent relationships with parents (Henderson & Adour, 1981). These authors weave the scientific explanations throughout, showing that the integration of culture and western explanations allows for a fuller understanding of what may be occurring in Native illnesses.

Perceptions of Disease: The Case of Diabetes Native people have very high prevalence of diabetes and this disease impacts a disproportionate number of Native people. Given this far reaching experience in Indian Country, this disease makes for an excellent illustrative example of the meaning and experience of chronic disease among Native people.

In an ethnographic study among the Navajo, Huttlinger et al., (1992) shared the metaphorical language many of the Navajo used to describe their lived experiences with diabetes. They often used metaphors of war and that they were “doing battle” with diabetes. In describing the visits to the health clinic, they were battles in the war, and there was a sense that the war could not be won. Within this framework many felt, and described themselves, as prisoners to the disease and Western medicine (Huttlinger et al., 1992). Several Natives “described diabetes as an Anglo disease and that an Anglo Christian god was used as one of the weapons to fight diabetes” (Huttlinger et al., 1994, p. 709). Diabetes was also interpreted as a metaphor for the social changes that have occurred as the result of Western influence. Those with diabetes are not allowed to eat their cultural foods of mutton and fry bread. Thus, they tend to

view diabetes as another influence of the White man or even a White man's disease given to Navajos (Huttlinger et al, 1994). Similarly, the Dakota believe that diabetes is the result of living a lifestyle that is not in balance and not adhering to traditions. Diabetes is seen as another in a long line of destructive diseases given to them by the White man. Thus, diabetes is given through the food that is packaged and processed and not treatable by traditional medicine because it is a new disease.

The Yaqui also believe that diabetes is the result of the change in eating habits. Previously, the food was natural and pure and full of love. Food from the grocery store is not nourishing to the spirit and the body (Locust, 1985). Additionally, the secondary effects of diabetes, such as renal failure, amputation, and vision issues were not seen as connected to diabetes but to outside influences of "witchcraft" or consequences to breaking vows (Locust 1985). The older adults in the tribe who "clung" to old ways exhibited fewer health issues such as high blood pressure and renal problems and seem to have escaped most illnesses related to stress (Locust, 1985).

Lautenschlager and Smith (2006) examined the perceptions of diabetes of 40 urban Natives through focus groups in Minneapolis. Natives participating in the study discussed their personal knowledge of diabetes and its relation to the notion of Western medicine. They were unsure of the origins of the disease – possibly food related and lifestyle choices and genetics (Lautenschlager & Smith, 2006). Some participants were confused about how to change their conditions as the healthcare professionals did not provide adequate explanations of causes and treatment. Some participants did not attempt to eat differently as they did not see the changes in diet as effective treatment; they felt the blood sugar was uncontrollable regardless of the treatment. Access to affordable healthcare, treatment, and healthy foods was a major barrier affecting their ability to learn more about diabetes.

In conclusion then, information regarding the meaning of health, wellness and illness in Native communities is limited in scope and breadth. What is known demonstrates a more holistic view of these constructs and includes dimensions of the mind, body and spirit. Gaining insight into the local, cultural and societal construction of health, wellness and illness in Native communities is important for mapping interventions and services for influencing the health, wellness, and illness of Native older adults. Understanding more fully other factors that influence

the health, wellness and illness of Native older adults is important for creating a holistic view of the aspects that contribute to health, wellness and illness in Native communities.

II. Community Status and Formal and Informal Resources

The literature on community status intersects with formal and informal resources in two subsections. In terms of informal care and resources, the practice of traditional medicine is especially noteworthy; in relation to formal resources, long term care, community based services and in-home services provide the three components of healthcare provision.

a. Informal Care and Resources Informal support or care refers to the unpaid care provided by friends and family to Native elderly people living in the community, often a daughter in a family (Denton, 1997). In order to situate caregiving in the lives of Native older adults, it is necessary to take into account the cultural expectations that often dictate caregiving. Providing care to functionally dependent elderly persons has been viewed as an expression of identity for Native people, and highlights the importance of the family, and the values of the tribe, which is to care for the older adults in their community (John, 1999; Hennesy & John, 1995; Evans-Campbell et al., 2007). Family members provide the majority of caregiver services to Native elderly people living in the community (McDonald, 2004).

Often when considering informal caregiving for Native communities it is taken for granted that Native elderly persons have family to assist in providing support and caregiving in their communities. Although many Native older adults have siblings and children, one study revealed that 11% of the elderly persons did not have living siblings and 32% did not have a child or sibling who lived on or near the reservation (John 1991). Another study revealed that a range from 16% to 20% of reservation and urban Native elderly persons did not have adequate family or support networks (John, 1999). This information suggests that key family members may not be available to provide care for elderly people living in the community. Thereby suggesting that Native elderly people will draw on others to fill social support gaps with people beyond their family network. The inadequate family or social support network of Native elderly people raises concerns for not only their care but also of their overall decline of status in the community. Given inadequate literature, this dissertation seeks to contribute to the literature by connecting the community status of Native elderly people and their health.

Evans-Campbell et al. (2007) discuss the notion that caregiving is viewed differently in Native cultures than in Western culture. Caregiving roles are valued and proscribed for Natives as they age and reach elder status in their communities (Evans-Campbell, 2007). Caregiving as a role is not only defined by illness but through nurturing and passing on knowledge to others. Intergenerational caregiving is expected between grandparents caring for grandchildren, and I would argue vice-versa. Caregiving is an important contribution to Native older adults' health and wellness. There are few Native older adults who are able to access formal long-term care services or have access to caregiving services in their communities. Even for low income urban elders, they are unable to afford long-term care services. Also, Native older adults, like African American older adults, may prefer informal caregiving help over professional caregiving assistance. There are many reasons to distrust formal caregiving systems and Native older adults may feel more comfortable with their families and friends providing support over hired caregivers.

While not discussing caregiving specifically to Native older adults, Waller and Patterson (2002) report the Navajo view of helping one another is a way of life in their culture. To be Navajo is to fulfill one's responsibilities to relatives. This study investigates *25 natural helpers*, as defined by the community as individuals who have earned the reputation of being caring competent problem solvers (Waller & Patterson, 2002). Natural helpers mediate the effects of life stressors. Relationships between helpers and recipients were long standing and it was accepted that everyone will need help and therefore the social distance between people in this relationship was minimal. This differs from the mainstream context where asking for help is seen as having a negative connotation and the less fortunate being helped by others who have resources (Waller & Patterson, 2002). Natural helpers in this study often assisted in environmental problems (feeding ranch animals, assisting in illness, helping single mothers with their children, etc.) but also provided instrumental and emotional support when needed. This study also revealed that Navajos were more likely to seek help from a natural helper than from a professional. Therefore, social workers and others working with Native clients need to be aware of the informal natural helping system and collaborate with it in order to disseminate information and services.

Traditional Medicine. In using the term traditional medicine, Rhoades and Rhoades (2000), define it as "the healing practices and beliefs of the Indian population" (p. 402). Portman

and Garrett (2006) use the definition, “those which may involve traditional medicine practitioners, such as medicine men and women, herbalists, and shaman, to restore an individual to a healthy state using traditional medicines, such as healing and purification ceremonies, teas, herbs, special foods, and special activities such as songs, prayers, chants, dancing, and sand painting” (p. 455). These practices contrast dramatically with the Western practice of medicine, which is predicated on scientific principles brought forth by Euro-American cultures centered on the concept of disease (Rhoades & Rhoades, 2000).

Traditional medicine, casting broadly across tribal groups, has the main characteristic of including religion and the realm of spirituality with spirits who can heal or harm (Rhoades & Rhoades, 2000). Conceptually, Native healing traditions include four constructs of spirituality, community, environment, and self (Portman & Garrett, 2006). Other aspects of traditional medicine include time (Mehl-Madrona, 1999). Many hours of contact are required and with either side traveling long distances, the healer will work with one person at a time until the “job” is done. Healers may often concentrate their work over a number of days with multiple hours of work on each of those days (Mehl-Madrona, 1999). Also, the healing takes place within a relationship, the quality of the relationship will impact the ability to find wellness (Mehl-Madrona, 1999)

Rhoades and Rhoades (2000) delineate the differences between traditional medicine and biomedicine. First, traditional medicine operates on the definition of health as, “the ability to exist in a harmonious relationship with all other living things, but also with a number of spirits, including a great and all powerful spirit” (p. 404). This definition takes into account a more holistic view of a person in comparison to the absence of disease or the physiological explanations of Western medicine. Music is a central component of Indian medicine; singing and the beats of the drum are essential (Rhoades & Rhoades, 2000). Indian medicine is societally based rather than biologically based, and contributes to maintaining community integrity in ways that biomedicine does not. Traditional medicine includes holistic healing that uses ancient methods and techniques that have been passed down from one healer to another and addresses many aspects of an individual’s life through song, herbs, ceremony, and contacts with the spirit world (Murillo, 2004; Parrish, 2004). Traditional healing often focuses on the underlying causes and not the acute symptoms of illnesses.

Murillo (2004) brings forth other practices that may fall under the term, “traditional health practices”, defined as “the practice of medicine people, community ceremonies, and any other socio-cultural practices, beliefs, attitudes and behaviors related to health from an AI/AN (American Indian/Alaskan Native) perspective” (p. 109). Some of these practices include talking circles, storytelling, and sweat lodges (Murillo, 2008; Portman & Garrett, 2006). The author recommends more research in the areas of utilizing Native healers, herbal medicines, cultural diets, philosophy, healing ceremonies and traditional forms of living such as subsistence lifestyles involve hunting and fishing (Murillo, 2008). Other healthy traditional practices that may support health and well being include language, cultural games, Pow Wows or other dancing and celebrations, arts and crafts and acknowledging stages of life such as birth, death, adulthood, etc. (Murillo, 2008).

b. Formal Resources Formal support is defined as care provided by a service organization or independent contractor who is paid to provide or manage care for persons with illnesses or disabilities (Whitlatch & Noelker, 2007). The Indian Health Service (IHS) is the federal health care provider for Native people, mostly in reservation based hospitals and clinics with few urban clinics around the country. These services were negotiated in treaties in exchange for the land tribes had lost or given up to the U.S. government which some have referred to as the trust responsibility the government has towards Native people (Johnson & Rhoades, 2000). The IHS was created formally in 1955 when Indian health care was transferred from the Bureau of Indian Affairs to the Public Health Service (Johnson & Rhoades, 2000). At the time of the transfer, the conditions in the health clinics were marginal at best (Johnson & Rhoades, 2000). This transfer allowed for the consolidation of the preventative, curative, environmental and local management into one national program (Johnson & Rhoades, 2000). Tribal self-determination, passed in the early 1970s, allowed tribes to have control and direction of their local IHS services (Johnson & Rhoades, 2000). The IHS has developed many programs with the main goal of providing accessible care to each Indian individual, family and community. Eligibility for services is recognition as a member of the tribe, the non-Indian wife of a tribal member, or someone who is of Indian descent and has close social and economic ties to a federally recognized tribe (Johnson & Rhoades, 2000).

The IHS is managed through 12 area offices and more than 150 administrative units that deliver care in 35 states (Smyer & Stenvig, 2007; Johnson & Rhoades, 2000). The IHS and tribes

operate 49 hospitals, 77% have fewer than 50 beds, and 492 ambulatory facilities (majority clinics) across the country (Johnson and Rhoades, 2000). The IHS also purchases medical care and services from non-IHS providers. These services are reserved for the most urgent cases. Patients living within 90 miles of an IHS are required to visit an IHS service provider prior to seeking care from the contract services. IHS funds are often limited and Native people are limited in their access to these services. IHS medical professionals were surveyed in New Mexico and Montana and found that rural Indians had poorer access to specialty care because of financial constraints related to limited funds for contract services, and lack of insurance coverage (Baldwin et al., 2008). Those with insurance, 20.3% and 31.1%, respectively, reported restrictions in receiving specialty care and distance to travel to access specialists (51 to 143 miles) for care as obstacles to care (Baldwin et al., 2008).

The IHS has been criticized for the widening gap in healthcare expenditures, which is \$1,430, less than one half that of the general U.S. population (\$3,766) (Joe, 2002). Currently the spending is lower than Medicare (\$3,369); the Bureau of Prisons (\$3,489) and the Veteran's Administration (\$5,458) (Joe, 2002). Adjusting for inflation, the current per capita spending is less than it was in 1977 (Joe, 2002). The IHS services are able to accept Medicare and Medicaid. Of all racial groups, Native peoples underutilize Medicaid funds. Many barriers identified may explain this underutilization of Medicaid funds indicating lack of understanding of the application process, difficulty completing the application, and lack of awareness of availability of qualification (Joe, 2002) The IHS is a payment of last resort and often requires patients to apply for state and federal programs, or use private insurance before paying for services at IHS clinics and hospitals (ihs.gov, 2007).

Long-term Care. The IHS model of care is largely predicated on acute care. As reviewed previously, older Native Americans experience chronic diseases and debilities that require services over longer spans of time. Examples of services needed and services available are conceptualized within the continuum of care (Manson, 1989). The continuum of care is defined as "a series of initiating, continuing and concluding care events that result when the patient seeks providers in one or more environments within the health care system" (McBryde-Foster & Allen, 2003, p. 630). These services can be found in Indian Country, however, never all of them in one community (Manson, 1989). Acute care hospitals are one aspect reviewed in this section regarding the IHS. Skilled and intermediate care facilities are rare in Indian Country and often

Native elderly people are placed in non-Native care facilities that are often far away from their home communities and away from their families (Manson, 1989).

In 1989, Manson reported there were 10 reservation nursing homes with 435 residents, occupancy levels were high and waiting lists are common. In Native nursing homes, males outnumber females by a ratio of 2 to 1, quite different from the mainstream where women typically outnumber men by 3 to 1. In 2002, the National Indian Council on Aging (NICOA) found there were 12 nursing homes with 625 beds, 11 of these facilities were tribally owned and one leased by the tribe (Benson, 2002). Federally funded long-term care is non-existent in Indian Country and most of the facilities report receiving Medicare, Medicaid, and Veteran's Affairs (VA) benefit money or subsidized by the tribe (Benson, 2002). These findings are similar for all older adults in the United States and not only a challenge faced by Native people. However, nursing home facilities are expensive, difficult to fully occupy, and are often found to be a drain on tribal funds (Benson, 2002).

A few reservations have been able to provide elder housing including apartments or retirement villages, and private homes in their own subdivision or neighborhoods. These types of housing, that allow Native elderly persons to live independently, are rare and the need is greater than the availability. Assisted living, short-term rehabilitation facilities and intermediate nursing facilities are rare in Indian Country (Benson, 2002). The receptivity and cultural fit has yet to be determined among Native elderly people and the communities in which they live.

Community based services. Congregate meals and nutrition programs are funded through the Social Security Administration and the Older Americans Act (Manson, 1989). These programs include group meals, menu planning, nutrition education, recreational activities and exercise programs (Manson, 1989). Manson (1989) reported that virtually every Indian community has aging related activities and services targeted towards meeting their needs including providing social and cultural interactions, in addition to the health related activities. NICOA found that these services were the most commonly provided services to elders in their communities (Benson, 2002). Despite the pervasive availability of these services, Manson (1989) and NICOA are the only insights into these community based services. Further investigation as to the types of services, the magnitude of elderly people that receive the services, which agencies or organizations provide these services, and how effectively they work, are all important areas that need attention as they are a vital aspect of Native elderly people's lives.

In-home services. Manson (1989) reported that in-home services were desirable as they allow Native elderly persons to live independently in the home. In Nevada there once existed a Native organization providing in-home services, including assistance with ADLs, homemaker services, meals, meals-on-wheels, shopping, laundry, supervision with medications, nutritional counseling and transportation, but these services no longer exist (Manson, 1989). As previously stated, 90% of the services provided in Native elderly persons' homes is provided through informal support from family (Baldrige, Pecos & Docedos, 2001). More attention to the in-home services accessible to the Native elderly population is imperative. Disseminating the availability of these services to Native elderly across Indian Country is important for learning best practices and offering insights into the services that are possible for communities struggling to provide support for their Native elderly persons.

The IHS provides in-home services, and it hires tribal employees through the Community Health Representative (CHR) program. This program developed in the 1960s and remains an important aspect of training Indian people to work in their own communities (Johnson & Rhoades, 2000; Manson, 1989; Baldrige, 2004). CHRs can provide a range of health education, first aid, outreach, and referrals (Johnson & Rhoades, 2000; Manson, 1989; Baldrige, 2004). CHRs are the connection in the community to the acute care facility; they often provide transportation to those who otherwise would not have the means to get to the clinic or hospital (Baldrige, 2004). Similarly, Public Health Nurses working in IHS clinics provide in home medical care visits. Often public health nurses and CHRs collaborate to coordinate service availability. In conclusion, then, there is a great deal about the cultural and social resources of Native American elderly people in relation to their health that we do not understand. This dissertation will shed light onto the social resources utilized by Native elderly people and the formal resources available to those living on a reservation in South Dakota.

Outline of the Dissertation

The dissertation will adhere to the following format: *Chapter One* undertakes introducing the aims and hypotheses of the study, situating the Native elders in the broader context of health disparities in Indian Country, reviewing the literature on Native conceptions of health and illness and formal and informal resources available in Native communities. *Chapter Two* discusses

identifying the population, constructing the theory and developing the methodology by reviewing the social and physical context in which Lakota elders live on the Pine Ridge Indian Reservation. Three theoretical frameworks were employed in this study, 'Triple Consciousness,' Life Course Theory and the Social Construction of Illness. Indigenous methodologies were employed to build relationships with Lakota elders, respect their social and cultural position within the community, and acknowledge their agency in order to honor and respect their wisdom and knowledge shared. The following three chapters present the empirical chapters revealing Lakota elders' constructions of health wellness and illness. *Chapter Three* reveals the physical health and Lakota elders, mapping their health experiences across their lifetimes beginning with their families of origin and the patterns of work, food production and schooling. The chapter continues to explore the present challenges of Lakota elders' health and concludes with the challenges of healthcare across their life spans. *Chapter Four* focuses specifically on the life course of Lakota elders from the perspective of the mind across three generations; first the elders' own childhood experiences, then the experiences of their children, and finally the experiences of their grandchildren. *Chapter Five* defines the third component of health of Lakota elders: spiritual health. Spiritual health encompasses the lands and community as elements of Lakota health, informal support Lakota elders provide to each other, and the formal community services that are available, for example the Indian Health Service and elder meal sites. *Chapter Six* concludes the dissertation and provides a summary of the findings and implications for interventions and future research.

Conclusion

This chapter first introduces the characteristics of Native populations of the United States, situating Native elders within the broader health experiences of Native people by analyzing their life expectancy on the one side and the prevalence of chronic diseases, co-morbidity, and disabilities on the other. The chapter then delves into a review of the constructions of health, wellness and illness in order to contextualize the health experiences of the Lakota elders in later chapters. Native elders have largely lived without formal health care resources as the Indian Health Service was not developed until the 1950s. Hence initially, Native people had to rely exclusively on their own community and informal resources. The continuing scarcity of resources throughout Indian Country necessitates a more complete examination of the resources available to Lakota elders participating in this study since how they

meet health challenges vary from the rest of the U.S. population. In order to uncover the ways in which Lakota elders experience and define health, wellness and illness across their life span, it is next necessary to turn onto and articulate the theoretical framework and Indigenous methodologies. The following chapter will therefore provide the context in which Lakota elders live, the theoretical and methodological frameworks employed while partnering with the Lakota elders and their community.

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Chapter Two

Identifying the Population, Constructing the Theory and Developing the Methodology

This chapter first discusses the population studied to then articulate the theories and methodology employed. The setting of the study, namely the Pine Ridge Indian reservation, home of the Oglala Lakota, is significant in terms of its population composition, economic and housing conditions and transportation: in spite of being citizens of the most technologically advanced country in the world, the exact population count for the reservation is inaccurate at best; it has been economically the poorest county in the United State and the housing conditions are poor as well. In addition, it is necessary to travel for more than a hundred miles to get from one end of the reservation to the other.

In analyzing this challenging social, economic and cultural positioning of this population, three theoretical approaches proved useful. First, based on the life experiences of the Natives in the United States, I employed critical race theory, developing in the process the concept of 'Triple Consciousness' to capture their particular standpoint, and their construction of social meaning. Second, predicated on the manner in which their interactions with their environment transformed over time to impact their health, I employed life course theory to capture how their health and well-being changed over time. Third, focusing on the way in which they approached and defined health and well being, I used the social constructionist approach to articulate the manner in which the Natives defined health and wellbeing in terms not only of the physical body as Whites often do, but instead of the body, mind, and spirit. Indeed, the three empirical chapters are centered around these three components of health according to the Natives.

Articulating the methodological approach also proved challenging because the population itself was not and could still not be analyzed in accordance with the most advanced quantitative techniques and measurements for the simple fact that such information did not exist on the one side and any attempt to collect such information would have reflected the cognitive framework not of Native people but instead the Whites. I therefore employed snowball sampling and

Indigenous Methodologies predicated on demonstrating respect toward the agency of the Native people; I engaged in the conversational method whereby the Elders discussed, in relation to the topics and research questions I raised, what they wanted in terms of what they chose.

The major contributions of this dissertation derive from the analysis of a unique and understudied social group through the employment of innovative theories and methodologies: it reveals how and why the health and well-being of Native Americans have been so compromised over time.

Setting of the Study: Pine Ridge Indian Reservation

The Pine Ridge Indian Reservation, the home of the Oglala Lakota Indians, is located in the southwestern corner of South Dakota along the Nebraska border. The reservation consists of 3,468.86 square miles of land area, or 2.1 million acres with 1.7 million acres as tribally or individually owned land (Bureau of Indian Affairs). Pine Ridge is the eighth largest reservation in the United States. The reservation lands encompass the entire of Shannon County, but also include the southern portion of Jackson County, reaching into adjacent Bennett County. There are also trust lands extending into adjacent counties, including Sheridan County in Nebraska. (See Appendix D for map). Geographically the reservation is a large space that represents the reservation population in a spatially fragmented manner. The tribal government is not centrally located and struggles to represent each of these districts equally. Additionally, the reservation is encompassed by District 27 of the State Representatives. They elect two representatives in the South Dakota House of Representatives as well as a state senator. Politically, there is a tribal, state and federal level of political consideration.

The reservation is divided into nine political districts: Eagle Nest, La Creek, Medicine Root, Pass Creek, Pine Ridge, Porcupine, Wakpamni, White Clay, and Wounded Knee. These districts were originally established in order to distribute government rations, but currently have another function as smaller political communities with representatives serving on the tribal council, the governing body of the tribe. The major communities on the reservation include: Pine Ridge, Kyle, Wanblee, Martin, Allen, Porcupine, Manderson, Wounded Knee, Oglala, and Red Shirt. The lands consist of three geographic regions. Wide-open grasslands are found in the southern and eastern areas of the reservation. In the North, there are approximately 160,000 acres of Badlands. The Badlands provide a landscape of grass prairie eroded ridges, peaks,

mesas, and canyons. In the west central sections, the grassland merges with the eastern edge of the Black Hills. Further to the west the landscape reveals rolling pine covered hills and ridges, leading to the name Pine Ridge. The communities have a central town where there are resources like a small gas station, convenience store, community center and elder meal sites and often a housing area. There are also homes and individually owned lands with homes in the wider open spaces between the small towns. There is a network of rock and dirt roads that connect communities and the main roads. There are horses and cattle that are used in family ranches throughout the reservation. Pine Ridge is not an agricultural center with production centered around grains and hay for animal feed. Much of this fertile land is leased to farmers and ranchers with the tribe benefiting very little from this production. As a result, there is little food production on these lands, small family gardens are able to produce fresh vegetables and there are wild berries, chokecherries and plums that grow in and around the reservation. Most residents rely on federal food programs and have to travel great distances for quality fresh food and ultimately rely on processed, mass produced foods. The reservation is a geographically large area with complex social issues that are difficult to serve given the limited resources and large distances to travel.

Population. The population of the reservation is difficult to determine as sources vary in their estimates. The Oglala Sioux Tribe reports 41, 226 enrolled members (BIA, 2012), however not all members live on the reservation. According to the 2000 Census the population of the reservation is 15, 521; yet, Census figures are inaccurate on the reservation because the rural population containing many people are overlooked. The Federal Department of Housing and Urban Development accepted the results of a study by Colorado State University which determined the population to be 28, 787, although the Oglala Sioux Lakota Housing Executive director stated that the population is closer to 40,000 (Lakota Country Times, 7/27/05). Pine Ridge is unique in that Shannon County has the highest population rate of Native Americans and the lowest percentage of Caucasians (U.S. Census, 2010). There are many reasons for the inaccuracy as the population is transient with people moving between Rapid City and Denver or other off-reservation communities. Additionally, there are several family members living in one home, often the Census workers are unable to accurately identify the household sizes or do not locate all of the homes as many are unseen from the roads. The inaccurate numbers reduce the community's political power and limit the influence in representation and qualification for state

and federal resources. The inability to accurately estimate and track the population results in an inability to ascertain and provide resources for the reservation communities.

Economic and Housing Conditions. According to the 2000 U.S. Census, Shannon County is the second poorest county in the United States with unemployment on the reservation reaching nearly 80% -- 49% live below the federal poverty line, and 61% of children under the age of 18 live below the poverty line (Census, 2000). The median household income is \$20, 916. The per capita income for Shannon County is \$6, 286. The annual income for 26.7%, or the largest portion of households, is less than \$10,000 (Census, 2000).

There are only 3, 919 housing units on the Pine Ridge Indian reservation with 1,705 owner occupied homes, 1,795 rented housing units, 431 vacant housing units and 51 seasonal or occasional housing units. Of these, 2,644 are 1-unit detached homes and 1,053 mobile homes (Census, 2000). The largest percentage of these homes, 31.1% (1,218 homes) were built in 1970-1979. Mobile homes are considered old after twenty years and are often more expensive to maintain. Of the 3,919 homes, 11.6% lack complete plumbing facilities, and 8.1% lack complete kitchen facilities, and 23% do not have telephone service (Census, 2000). These data compared to the broader population of the U.S. are striking. Only .64% of Americans lack complete plumbing in their homes (WIN Report, 2006). According to a South Dakota State University report in 2003 more than half (59%) of the homes are substandard, with 33% lacking basic water and sewage and many homes lacking in adequate insulation and central heating. There is a severe problem of black mold, with 60% of the homes experiencing infestation which leads to health issues such as asthma and other respiratory infections (EPA, 2010)

The Oglala Sioux Tribal Housing Authority is constructing homes to address the substandard housing and provide homes for the families that do not have houses of their own (Oglala Sioux Tribe A Profile, 2001). Bureau of Indian Affairs (BIA) housing is often in disrepair and the waiting list for repairs is backlogged. Original construction in some of the BIA homes was substandard. Many families live in multi-generation homes and the exact conditions of tribal housing are not available from the BIA due to the Cobell Litigation (Chapman et al., 2003). There is a large homeless population on the reservation due to this housing shortage. American Indian culture has a value or tenet of caring for family, often family members will not turn away a family member, thus there are many two or three room homes with 3 to 4 families, upwards to thirty people living in them. The housing shortage and living conditions lead to dire

circumstances for families leading to exacerbated health concerns, hypothermia and even death. This social and economic concern has been on the agenda of the tribe and reported in the state and federal levels, however, very little is being done to adequately address this issue. It has been reported that four thousand homes need to be built in order to adequately address the housing shortage on the reservation (EPA, 2010). The inability for the tribe to meet these needs leads to further abuse and neglect of the tribal members that has been inflicted on them by the federal government.

Transportation. There are 197.85 miles of South Dakota highways on the reservation including 59.33 in Shannon county, 72.05 in Bennet County and 66.27 in Jackson County. South Dakota Highway 18 is the major artery from east to northwest, others include SD 87, 29, and 75 (Chapman et al., 2003). There are 426.3 miles of BIA roads, including BIA 2, 27, 28, 40, and 41; and 352 miles of country roads criss-crossing through all three of the counties (Chapman et al., 2003). Many of these roads are impassable during blizzards or heavy rains. Isolated homes and communities are served by gravel and dirt roads. Traveling to the elders' homes and to the elder meal sites and activities around the reservation was arduous as many elders live in homes that have a dirt road or lane leading to their homes. During times of heavy rain, some roads and driveways are impassible by car. Often, it was necessary to wait until the dirt roads were firm enough to drive on. Traveling from Pine Ridge to Wanblee, colloquially referred to as the "tail end" of the reservation was nearly one hundred miles and I always took the main roads that moved through the small villages, such as Porcupine and Kyle. The reservation roads are often rough and have less maintenance than the other roads that serve the rest of the state. The paved roads are repaired but many of the dirt roads and older paved roads are rutted or only partially paved. There are often jurisdictional issues between the state, federal and tribal government in regard to the maintenance of the roads with the tribe recently contracting the service for a stretch of road that experienced many fatal car accidents (Rapid City Journal, 11/19/2012).

There is a large Lakota population which is difficult to estimate as a direct result of the housing and road conditions. The housing is substandard and there is a great shortage leaving many families occupying a single family home. The transportation, road conditions and large geographical distances compounded by extreme winter weather result in difficult physical and economic conditions that exacerbate social and health conditions for the Lakota people living on the Pine Ridge Indian Reservation. The Lakota population residing on these lands have

experienced historical, social and cultural conditions unlike other populations in the United States and therefore, three theoretical constructs are necessary in examining this unique and important population of American Indians.

Theoretical Framework: Three Perspectives

The health of Native American older people can be approached from three theoretical perspectives. The theoretical frameworks are necessary in understanding more fully the complex social, cultural and historical position of Lakota elders both in their lives on the reservation and their position within the broader United States. Lakota elders have lived through incredible assimilation tactics, sparse physical and social conditions yet they have persevered into their older adult years. In order to fully understand the many facets of the Lakota experience across their lifespan, their health and their cultural consciousness three theoretical frameworks are necessary and include: Triple Consciousness of American Indians, Life Course Perspective and Social Construction of Illness.

American Indians have often been approached theoretically as a minority population with information collected and knowledge constructed through surveys. Such an approach assumes universality of human experience and therefore overlooks the unique characteristics of the population: it treats populations as objects that provide data, and by so doing disregards or silences meaning creation in such population. Yet one cannot understand the social reality of such populations without accessing their meaning creation process. In addition, this is also crucial in restoring agency to the Lakota people; including meaning creation restores their agency. As such, of the three theoretical perspectives, the second and third ones are based on the assumption of universality of the human experience, collecting data that enable you to collect information that you can compare with other populations elsewhere. This is the case with the life course; the explanatory illness captures, in addition, how they construct illness: in so far as these two theoretical approaches provide space for the Lakota population's perspective, they recover the agency of the locals. Yet the first approach is the one that truly collects information that is not already structured, as in the case of the preconceived framework of the 'life course' or 'illness.' As you see, what I undertake here is a comparative analysis of the three theoretical frameworks before starting with each one.

The first theoretical perspective, "Triple Consciousness of Native Americans," originates from American Indians' own life experiences and assumes that their health is ontologically determined by their social reality, which is distinctively different from the rest of the American population. The second theoretical insight is based on the "life course perspective," which takes into account the transformations the health of Native elderly people over their lifetime, like the rest of the American population. The third and last theoretical insight is based on the "explanatory illness perspective model" that provides insight into the ways in which Native elderly people shape their perceptions of health, illness and wellness.

I. Triple Consciousness of Native Americans

This theoretical approach is predicated on two premises: that the ontological construction of social reality needs to be analyzed in order to understand the meaning-making process of a social group, and that such an analysis will restore the agency of the social group in narrating their meanings as they see fit rather than as it is imposed on them by others. In the case of Native Americans, it is also assumed that the experiences of Native Americans in this society are ontologically different from the rest of Americans. Unlike the rest of Americans, Native Americans are not immigrants; they are actually indigenous to these lands. As such, they predate all the immigrant groups that start to steadily arrive on the continent from the seventeenth century onward. Yet, Native Americans are often marginalized and excluded as if they were immigrants, living under conditions they not only could not and still can not control, but were and still are adversely affected by them. This differentiates the Native Americans from all other social groups currently living in the United States: they have to live on their own lands, constantly aware of the lands they once had and have now lost irretrievably. In addition, they have to constantly negotiate with a society and culture that continuously perpetrated violence against them, reducing, or taking their land base and sustenance away from them.

Currently, there are no existing studies that have aided the development of an adequate theoretical framework within which to address such collective violence and the subsequent negotiation of loss, especially in terms of the adverse impact it undoubtedly must have on the health of Native Americans in general. Still, the review of the theoretical literature reveals a starting point, one based on the theoretical insights provided in the case of another group, African Americans, who arrived in this country to experience and live under similarly adverse

conditions. W.E.B. Dubois (2003) developed the theory of the '*double-consciousness*' of Black Americans to refer to the process of their identity formation in American society, where a person always feels the duality, or two-ness, of being "an American, a Negro; two souls, two thoughts, two reconciled strivings; two warring ideals in one dark body, whose dogged strength alone keeps it from being torn asunder" (Dubois, 2003, p. 9). Hence double consciousness refers to how Black Americans see and value themselves "only through the eyes of white Americans;" how they "measure their intelligence, beauty, and sense of self-worth by standards set by others" (Griffin, 2003, p. xvi). While they have one identity as Africans, this was socially erased over time especially through the violent practice of slavery; African Americans were torn from their native lands and had limited choice of return, thereby having to leave the one identity they were born with behind, and being forced to recognize the identity imposed upon them by the White American world. Building upon the experiences of Black Americans and the transformation from Africans into slaves has been developed further by Orlando Patterson (1982) in *Slavery and Social Death*.

Sociologist Orland Patterson (1982) refers to this as a slave's "natal alienation" whereby the African person was converted to slave, recruited as a 'socially dead' person. The slave was "isolated from all 'rights' or claims of birth, he ceased to belong to his own right to any legitimate social order (p. 5). Hence, what occurred was the forced, violent stripping of the African identity, producing not physical death but instead a social one: what existed and gave meaning to the Africans before their capture and arrival as slaves was destroyed. Hence they were forced to lose their world of meaning, what made sense to them, turning them into socially dead people whose identity now relied totally on what their white masters were willing to bestow upon them. As such, all the slaves experienced, at the very least, a 'secular excommunication" (p. 5). This excommunication also severed their connection with their history, with their ancestors, isolating them from the latter. Not only did the slaves lack a social consciousness that integrated the teachings and experiences of their ancestors, but they were not able to "anchor the living present in any conscious community of memory" either (Patterson, 1982, p. 5). In addition, this lack of a sense of identity, this social death also impacted the future: the slaves were not able to pass onto their children a sense of identity other than what their white masters chose to give them. The slave was introduced to the community of the master as a 'nonbeing' (Patterson, 1982, p. 38) Slaves were recruited in two categories, intrusive, or locally and internally recruited,

a permanent enemy on the inside could never belong to the dominant community because “he was a product of hostile, alien culture” or extrusive representative of an insider “who had fallen, one who ceased to belong and had been expelled from normal participation in the community”(p. 39).

Indeed, even the name 'Black American' captures this duality where not only the adjective American but also that of Black symbolizes the value system within which the forcibly removed African migrants had to refer to themselves. And in the process, that one adjective that had given their lives meaning for the entire time before they were captured, namely 'African' was stripped away from them. They were forced not to remember the past: if they did, they were severely punished. They could not practice their religion either and were forcibly Christianized. And this violent socialization into White American society did not lead to social inclusion as they were constantly treated as the other. Still, while the forcibly imposed identity dominated and defined them within American society, the Black American was always aware of his other, original one the s/he had been born into. The ensuing duality of always being on the margins, never belonging, and always feeling close to an other that they could not draw upon created a double consciousness. Unlike other white Americans whose identity was normalized as the dominant one, the Black American had to constantly negotiate everyday life through two separate lenses, one as s/he viewed him/herself and the other as the dominant White Americans viewed them. This liminal state ensured that they were never socially adept, never able to build an identity with which to challenge their liminality. With the emergence of critical race theory, however, the inequities emerging from the intersections of power with particular identities has been fully articulated. Now, both for Black Americans as well as for all others living on these soils, the struggle is for everyone to be equally comfortable with all of their identities. And it is from this vantage point that we can theoretically move onto the case of the Native Americans.

In the case of Native Americans, identity formation acquires an additional layer in that unlike African Americans, they have not been torn away from their native lands: these *are* their native lands. Yet, on their very own lands, they have been systematically ravaged by Western European colonizers through violence and disease. And they have also been forcefully removed from their ancestral lands into barren regions where they have been made to live on reservations or federal trust lands. Some tribes are living on reservation on or near their traditional territory,

but now reduced to a tiny portion of land bounded by the reservation. The collective violence Native Americans have experienced has been referred to by some scholars as genocide.¹ And the current tragedy is that Native Americans not only have to live together with the perpetrators of the collective violence against them, but they have to do so under conditions and in a state and society dominated by their perpetrators. There are parallel experiences between the Black American experience and liminal state of existence. Native people were not considered a full human being, they were considered savages and the assimilation strategies strived to “kill the Indian and save the man” (Pratt, 1892). The boarding school movement was one of the main methods of removing Indian culture, they cut the children’s hair, removed their traditional clothing and replaced it with western clothing, and Native people were required to speak English and were given new names in English. Patterson described these activities as “a sign of castration of manliness and freedom” (Patterson, 1982). These strategies also encompassed removing Native spiritual practices through punishment and making them illegal. Native people experienced a similar process of being forced to practice Christianity. The main difference is that Native people experienced this while residing in their homelands. Some tribes were removed from the Eastern United States and relocated to the Western United States, many in Oklahoma. This alienation of the traditional practices, ways of dressing and removal from their ancestral lands parallels the experiences of Black Americans in the process of becoming slaves. In addition, those same perpetrators complain about and constantly limit the resources they make available to the Native Americans.

The major difference between the African Americans and Native Americans is thus a spatial one: while African Americans have been forcefully removed from their ancestral lands and taken across the ocean as slaves against their will, Native Americans still occupy their ancestral lands, but have just as forcefully been transformed into a much lesser version of what their identities had been before the arrival of the White Men. Due to this spatial difference embedded in the past, through the eyes of Native Americans, Dubois’s double-consciousness acquires a *third layer*: when a Native elder gazes upon a White man, not only does he see himself through the eyes of the White man, and through his own eyes as a Native elder, but he also has another stronger image in his mind's eye: of what life could have been for him had

¹ For further exploration of genocide, see the works of Vine Deloria, Jr., Andrea Smith, Philip Deloria, and Maria Yellow Horse Brave Heart to name a few.

White men not arrived here on his land, and had there not been so much ensuing destruction and decimation through the last six centuries. I draw upon this third layer to generate a new term, that of "triple consciousness".

The three layers of consciousness comprise the following: (i) How a Native American sees himself through the eyes of the White Man; (ii) How a Native American regards himself as an elder of his community at present situated within a hegemonic White society that has stifled, marginalized and impoverished him; and (iii) How a Native American views himself as an elder of his community at present, imagining what life for him and his community would have been like had the past before the arrival of the White Man continued uninterrupted. What if life had continued like it had been before the White Men arrived? This is the layer that is special, unique to Native Americans alone, differentiating their ethnicity from other communities in the United States. This unique layer is especially significant in terms of its health consequences. Since the Native American conception of health is predicated upon the unity and well-being of the body, mind and spirit, the third layer challenges the well-being of the mind of each Native American on the one side and also the spirit of the community on the other. In addition, this third layer interacts with the other two: the first layer dominated by the White Man and the second layer capturing the present state of the Native American adversely impact not only the mind and the spirit, but also the body. Native Americans face severe health challenges to their bodies because of the change forced upon them by the White men in relation to their diets: removed from their own fertile lands and the agricultural activities they once engaged in to lead a healthy living, they now live on barren lands and survive by purchasing food with the money the state hands out to them. As a consequence, they have very high rates of diabetes and heart disease among other illnesses. In addition, their marginalized, excluded and impoverished life condition escalates incidents of alcoholism, domestic abuse and violence.

This articulation of the Native American triple consciousness, if handled properly in a constructive manner, might help heal them, however. It would do so by enabling them to identify and improve upon the roots of their discontent in and through terms they themselves would define. Yet if it is not handled properly, if they do not have agency in determining the future course of action, it might lead to the permanent death of their culture, their way of life and their identity as Native Americans. This new theoretical perspective is predicated on the health

insight the elder thus has in approaching the world around him in trying to heal: it is a truism that the body-mind-spirit connection of the Natives has been permanently disrupted. However much the White medicine may think it is healing the body, it certainly has failed to heal Natives because it has not addressed the problems of the mind and the spirit. Unless the health conception of the Natives is not acknowledged and unless the Natives are given agency in working their body-mind-spirit well-being, the health of Natives would wither away. This dissertation attempts not only to articulate the health well-being of Native Americans, but then turns to them first to understand how they identify and diagnose their problems, and second to provide new solutions in relation to how to deal with illness of Native people.

This theoretical framework is important for working with Native elders particularly because they represent a cultural and historical community that has thrived on these lands for centuries and therefore a theoretical framework must be constructed through their consciousness and worldview. A framework constructed by non-Indigenous White scholars reflects a limited vantage point. Using ‘Triple Consciousness’ is a change in vantage point that takes the innate power away from the White man, thus freeing the life stories and experiences of the Lakota elders from the weight of the non-Indigenous theoretical intervention.

II. Life Course Perspective

The life course perspective focuses on how explanations of “time, period, and cohort shape the aging process for individuals, as well as for social groups” (Bengtson et al., 1997, p. S79). Elder (1994) employs the life course perspective in order to emphasize the significance of historical time and place in a person’s life, asserting the “[t]he life course of individuals is embedded in and shaped by the historical times and places they experience over their lifetimes” (p. 202). The developmental impact on an individual’s life is contingent on when certain events and in this case, health challenges occur within their lives. These experiences are shared through social relationships of cohorts of people experiencing these events at the same time and the negotiations and subsequent impact resonating through their social networks. Additionally, individuals construct their life course through the choices they make and the actions they take at particular junctures, creating social transitions and marking a time and space in terms of the interpretations of their environment individuals come up with at these particular junctures. Thus,

the life course perspective can offer explanations of the effects of history on the behaviors of cohorts of individuals (Bengtson et al., 1997).

In the case of Native elderly people, their lives are marked by assimilation tactics that altered the lives of Native people living on the reservation. These experiences wind through Native elderly peoples' lives leading to a cohort of people with similar experiences. The decisions individual Native people made as a result allow for insight into the meaning making of their lives and health, wellness and illness. For instance, the health challenges Natives faced as children, as young adults, as adults and then as elders vary. As children, the elders in this study faced disease largely without formalized western health care, so when serious illness was wrought upon a family or children it often resulted in death. A flu epidemic took the lives of many adults and children on the reservation in the early 1920s. Other serious illnesses were addressed by traveling in a horse and buggy to a clinic with one physician serving the reservation community. For serious illnesses requiring further treatment or surgery the children were sent to Rapid City, South Dakota. For minor health issues and prevention, the children were often treated by their grandmothers with traditional plant based medicine. As adults, the elders gave birth at home with midwives, or female family members. They experienced the shift from traditional medicine to western medicine, the shift away from traditional foods and more self-sufficient homesteads growing vegetables, raising farm animals, and gathering fruits to a dependence on federal food programs that provided foods that are highly processed have resulted in the development of diabetes, heart disease, and obesity, challenges to health not faced by Native people previously. In their older adult years, they are faced with chronic diseases in resource poor environments, a social environment that leaves families living separated around the reservation and struggling to balance their western medical treatments with the limited options for healthy foods. Many Lakota elders are raising grandchildren and thus the stresses of the environment are compounded by the pressures to provide and raise small children.

As this analysis indicates, the life course analysis generates an awareness of the passage of time across generations on the one side and within a cohort in terms of the life cycle on the other. And such an analysis also provides insight into the vast and violent transformations Native cohorts went through their lives and across generations, resulting in debilitated health all along. There are significant limitations to the life course perspective however. In this particular case, it

is difficult to empirically incorporate the many contextual variables of the social aging process (Bengtson et al., 1997). Additionally, it is a framework or perspective and has not yet developed into a theory explaining aging. The life course perspective provides insights into the Lakota elders' lives and individual and family cohorts of shared experiences. It does not, however, provide any explanations of the power differentials that result from colonization. An additional force acting on the lives of Lakota elders was the assimilation strategies and federal policies that shaped the social context of the lives of Lakota elders. For example, the spiritual practices of Native people were not legal until 1978 and therefore the ceremonies and rituals that have long been practiced were silenced in the public space. Lakota elders throughout their lives were forced to subvert the oppressive forces of the federal government. The life course perspective acknowledges the shared cultural experience but is limited in explaining the power differences experienced by Lakota elders as an Indigenous population living under the pressures of their colonizers. The life course perspective offers a framework for studying the lifespan development, experiences of Lakota elders throughout their lives and can bring to life the shared experiences, the life choices that shaped their trajectories and can complement the other frameworks used in this study.

III. Social Construction of Illness

Illness is socially and culturally constructed as different social groups explain and define illness in disparate ways. These differences include illness definition, symptom recognition as well as the interpretation of the experience of illness. Based on social constructions, perceptions of overall health, illness, wellness, and disease in turn shape help-seeking behavior, reception of formalized healthcare and other health related interventions, such as care-giving and adhering to healthy lifestyle choices. (Silverman, Smola, & Musa, 2000).

Given the complexity of the social construction of illness, scholars have developed many models with the intent to articulate, understand and acknowledge these social and cultural differences. Western medicine, a biomedical model, is one method of defining and treating illness; it includes the employment of particular tools for assessing health such as rating scales. Yet these rating scales are culturally based on the dominant social group in the United States, namely those belonging to the urban white middle class. As such, the model limits the practitioners' knowledge about their patients' views on their health. Such measures also bound

patients' ability to communicate lay meanings around health and wellness. Ultimately, what the practitioner measures is not what the Native, for instance, identifies as problematic, but rather imposes upon the Native the urban white middle class conception of health, well-being or illness.

In contrast, Kleinman (1989) uses another explanatory model, one that privileges how patients explain the causes and courses of disease on the one side, and how such explanations are shaped by the larger social and cultural context in which they live their lives on the other. One way to elicit everyday understanding of these explanatory meanings of illness is through narratives. The elements of "the illness narratives are drawn from cultural and personal models for arranging experiences in meaningful ways and for effectively communicating those meanings" (Kleinman, 1988, p.49). Such use of narratives to document the experiences of health, illness and wellness may offer insight into the cultural, social and environmental context in which Native older adults live. Native elderly people sharing illness narratives will allow for a greater understanding of the attributes of the experience of chronic illness in their social contexts, therefore allowing their social networks and health providers to understand their views for more effective treatment and limitation.

In summary then, in this dissertation I employ three theoretical perspectives to capture the agency of Native Americans: the triple consciousness allows access to their social meaning production, the life course enables the analysis of their timelines within and across generations, and social construction of illness captures how these relate to the experience of health, wellbeing and illness. This complex theoretical approach highlights the care with which one needs to approach especially marginalized social groups whose agency has been repressed through history. Within this theoretical framework, the next section focuses on the methodology.

Research Design

This study was designed to better understand the health and well being of Lakota elders living on the Pine Ridge Indian Reservation in South Dakota. The research questions were designed to uncover their unique lived experiences and how these shape their health, wellness and illness, what resources are available to them and how their cultural norms enhance or detract from their health status. The Lakota elders who participated in this research shared their life histories, stories and experiences through Indigenous methodologies, more specifically

conversational interviews. The interviews were transcribed and relevant themes were identified and both the university and tribal review boards approved this study.

Research Questions

The main observation that initiated this research project is the severely poor Native health at present in spite of the Natives' years of access to Western medicine. Given that it is now evident that the existing model does not work, the dissertation aims to develop an alternate model of health and aging within the Native community around three specific research questions:

- 1) How do Native American older adults construct health, wellness, and illness over time and space?
 - a. How do they account for health and illness?
 - b. What are their particular definitions and interpretations of these constructs?

- 2) What social and cultural resources do Native older adults employ for their health and wellness over time and space? Specifically,
 - a. What informal and formal support services are utilized?
 - b. Who are key members of these informal and formal support networks?
 - c. What resources in the community do they have access to?
 - d. What are the challenges and barriers they face in accessing resources?
 - e. What needed resources are not available to them?
 - f. What are their particular attitudes toward service use?
 - g. What are the expectations for younger generations in caring for Native older adults?

- 3) How does the social and cultural location within the community and American society of Native older adults affect their health, wellness and illness over time and space? Specifically,
 - a. What is the social and cultural status of Native older adults on this reservation?
 - b. What is the relationship between cultural status and health, wellness, and illness?
 - c. What are Native older adults' understandings of these phenomena?

- d. To what extent does this understanding shape their health practices?
- e. Do such factors vary with social status?
- f. How does contact with the dominant American culture influence these factors?

Native people experience high rates of chronic diseases in limited resource environments. Very little is known how the elders experience these diseases, and their own definitions and explanations of these chronic diseases. Building upon the few studies that have uncovered cultural constructions of disease (Hakim & Wegmann, 2002; Locust, 1985; Lang, 1989) I designed these research questions to investigate more holistically the experiences of Lakota elders in a particular place – the Pine Ridge Indian Reservation and how they experience health, wellness and illness across the life span, without focusing on a particular disease. I wanted to capture the experiences of health, wellness, and illness and how these were shaped by their resources, however, very little is known about their early years prior to the formation of the Indian Health Service, and what informal resources they rely upon to support their wellness.

Sampling and Recruitment

The following sections describe the sampling and recruitment procedures I employed in engaging the Lakota elders. They are a unique population and adhering to their cultural and social norms is imperative, therefore I utilized Indigenous Methodologies and developed relationships with the Lakota elders living on the Pine Ridge Indian reservation.

Sampling In order to answer these questions, I participated with 25 Native elders in carrying out in-depth, semi-structured interviews or conversations. Lakota elderly people who met the criteria of a) age of 55 years and older; b) enrolled in the Oglala Sioux Tribe; c) living on the Pine Ridge Indian Reservation in South Dakota; and d) are English speaking, were all eligible for participation in this endeavor. I chose the age of 55 years because the Indian Health Service (IHS) employs this age as the criterion of defining an elder or older adult. Even though my primary target group thus comprised of adults aged 55 years and older, I was particularly interested in elders over the age of 70 years. Lakota adults over the age of 70 will have lived longer and may be able to draw upon a more breadth and depth of memories. Also, the 70+

population has been under-researched and their life experiences are virtually unknown; they therefore capture a Native American experience that is unique to this cohort. Primarily, the younger older adults (55-70) provided insights into the onset of the aging process as well as cultural insights into becoming an elder and transitioning from middle age to older adult status in their communities. The older adults (70+) uniquely captured what this particular life-stage meant for them, for their immediate families as well as their community at large. In the end, the Lakota older adults who participated in this research ranged in age from 55 to 98; seven were men and eighteen were women; and all of them experienced at least one chronic disease including diabetes, heart disease, or arthritis.

There are more women than men participating in this study largely due to the fact that Lakota elder women were more easily accessible to me as a female researcher working within Lakota cultural norms among the elders. All of the elders are enrolled members of Oglala Lakota tribe, with exception of one elder who is enrolled in the Rosebud Sioux Tribe, but married an Oglala man and raised their children, worked and lived at Pine Ridge her entire adult life; all of the elders speak English, with the oldest elder relying on another elder as a translator to communicate with me, as Lakota is her first and most salient language with all but five elders able to speak Lakota, with most of them communicating in Lakota to each other on a regular basis. All of the elders were born on the reservation and attended school in their community day schools or the boarding school. At the time of the study, most of the elders reside on the reservation with exception of three, two elder women live in Rapid City, one had recently moved there in order to provide a better educational opportunity for the grandson she is raising, the other resides in a long term care facility but had lived on or near the reservation prior to moving to the nursing home. A third elder lives and works on a neighboring reservation but was born and raised on the Pine Ridge Indian reservation. He had left the reservation for most of his adult life to work and after retirement returned to South Dakota.

Recruitment In order to conduct a study with Lakota elders, the methodology and research design must be respectful of their cultural and social position. Therefore, this study employed what is referred to in the literature as "Indigenous Research Methodologies," that is, the theory and methods of conducting research from the standpoint of an Indigenous epistemology (Kovach, 2009). Indigenous methodologies have a different history and approach

than Western research methods. Western research methodologies were formulated during the 18th century Western European Enlightenment; they privileged reason over belief and public facts over private experiences. In contrast, indigenous research methodologies are born out of Indigenous relationships – to each other, to their ancestors and families, to their environment, their spirituality, ideas, wisdom, and traditions that have supported the living on this land for centuries (Wilson, 2007).

The two methodologies have points of intersection as well as difference. Western qualitative research and Indigenous research both value the importance of relationships people form with each other. In addition, both must document process and content (Kovach, 2009). Unlike western qualitative research that often assumes the universality of such interactions, however, Indigenous research specifically articulates what is meaningful and logical for Indigenous people and the ways they interact in the world. Because of the overlap between these methodologies and the development of terminology in regard to *Indigenous methodologies*, the constructs used in describing my research activities include both western and Indigenous methodologies and descriptions

Building relationships and trust is an important tenant of Indigenous Methodologies. As Kovach (2009) states, “simply because a researcher is Indigenous (or following an Indigenous framework) does not automatically translate into community trust” (p. 147). Indeed, the fact that I am Native or follow this framework was not sufficient. Community trust building is a long process that takes years. And it is for this reason that most of the researchers who employ Western methodologies fail in accessing these communities; they often formulate their research questions without contacting the communities and then show up expecting them to answer their questions. In my case, the community trust building process began and developed over the years as I was visiting with my friend and her family who belonged to the tribe. Indeed, my friend's family later became my *hunka*, or adopted family for several years on the reservation. In addition to my *hunka* family, there were other families, individuals and elders that I visited with over the years; this study was developed through these interactions over the years during which I learned the proper ways of approaching Lakota elders and eventually began partnering with them in a research capacity. Following community protocol was thus especially significant in establishing trust.

I employed convenience sampling by networking the contacts I had made over the years of tribal members; they in turn generated a pool of Lakota older adults by referring me to their friends, family, and acquaintances (Weiss, 1994). For this study, I visited the Pine Ridge Indian Reservation for several years, participated in many community events, and developed relationships with several families currently living there. Specifically, employing the family and friends I visited there as a starting point, a year prior to conducting the research, I began to talk to tribal members of all ages about accessing the Lakota older adult population. These conversations enabled me to determine the feasibility of my study. Unlike the experiences of scholars employing Western methodologies, many people were receptive, assuring me that the Lakota older adults would participate and discussed the research project with their older relatives. I then compiled a list of older adults and discussed the project with the Lakota older adults with whom I had visited regularly -- they often identified other older adults in their personal networks to participate in an interview. Hence I employed a combination of convenience and snowball sampling for the study.

After receiving approval from both the University of Michigan and the Oglala Sioux Tribal Research Review Board, I employed additional recruitment strategies. Given that there are a multitude of reasons for Native people to be leery of academic research, recruitment can be challenging. For example, several elders shared with me of a researcher who had visited the reservation and borrowed photographs, collected interviews and then left the reservation, never having returned the photographs nor sharing with the community the results of her work. Not all of the elders were receptive to my presence in the elder meal sites; I was openly questioned as to what my motives were and what the final result would be. Having experienced other researchers taking from them and not honoring the relationship, one elder woman announced to the meal site that I was there as a college student looking to advance my own interests. The elders with whom I have a relationship buffered this interaction and we discussed why there are hard feelings towards outsiders conducting research. Also, a few elders are visited by researchers who conduct surveys with the elders, they are unclear as to why they are visited and what the purpose of the research is, thus revealing that the relationships are not formed and trust only partially built.

First, I asked the Lakota elderly person to be a 'participant' in my research rather than a research subject. A research subject is someone who does not have an active role in shaping the

direction of the study. They are asked questions, they answer the questions and the researcher leaves and interprets the data collected in the interviews. A participant indicates that the elders are active agents in the research process, they are able to direct their stories towards the question, tell stories they deem important, are welcome to ask me questions and the power differential between an elder and a younger person is acknowledged, are committed to a process of creating understanding between the researcher and elder around topics related to their lives. The elders were able to guide the interactions through their wisdom and desire to teach the younger generations. In order for this to succeed, the process required spending time with each person to begin learning about each other and begin the process of building trust and understanding about the research process. Meeting and speaking with potential participants in person was imperative. I frequently visited with the Lakota older adults at senior center congregate meal sites, during community events such as Pow Wows as well as events designed specifically to honor elders. I approached the elders, informing them about the research project without inviting them to participate. Often, they would volunteer to participate or recommend someone from their community who would be appropriate. Second, I networked with the younger age groups about the research project and they spoke with their older adult relative - parent, grandparent or aunt - and the older adult could decide to participate in the research project without feeling any direct pressure from me. The family member would contact me after speaking to their relative, or I would follow up with the family member after a week or two had passed to discover if the elder had consented and then the contact information for the elder would be passed on. I would then contact the older adult to arrange the interview place and time, sometimes the family member would schedule the meeting. For example, I was visiting an elder meal site and a younger tribal member noticed I had been talking to the elders, she asked about my research project and said that her mother would want to participate. I gave her my contact information and a few days later the daughter of the elder called me and told me that her mother wanted to participate and gave me the elder's phone number and informed me the elder was awaiting my call. I then phoned the elder and introduced myself and my research project. We concluded with scheduling a time for me to visit the home or a mutually agreeable meeting place.

When discussing the research project with Lakota older adults, they would often interview me before consenting to or declining participation. After identifying myself and how I know their relative, the ensuing conversation was typically as follows:

She asked, "Where are you calling from?"
I responded, "Pine Ridge."
"Where do you work?"
"I don't work on the reservation."
"You don't work?"
"I am a student."
"Oh, you are a student. At OLC?"
"No, I'm from the University of Michigan."
"Are you Indian?"
"I am. I am Athabaskan, my family is from Alaska."
"Oh, from Alaska, Ok, well sure you can come and visit. Where do you live?"
"Old hospital housing"
"Oh, up on the hill. Yes. Well, I live at [address]."
I asked if I could come around 9 or 10am and she said that she would be there and it would be fine. (Fieldnotes 6/2/09)

When I met with the elders, they often asked me these questions again and I provided them with more elaboration concerning the project, following with information regarding where I live on the reservation and when I am not on the reservation, where I am from originally, what tribe I belong to, what families I am connected to on the reservation, why I am doing the project at Pine Ridge, what I will be doing with the results of the project. These answers are found in the short conversation above; however, I did provide insights to them on why I chose Pine Ridge and the answer usually included that I had visited my friend and her family for several years and they had become family while I was working toward my doctorate. When it was time to plan my research project which is required for graduating, it seemed logical to combine my professional life and my private life by building on my connections here and being able to have a large block of time with the family.

In regard to what I am doing with the results of the project, I was honest that first and foremost it would be used to write my dissertation and beyond that I hoped that I would be able to share their experiences in a way that would impact their lives in a positive way. They often expressed hope that it would do something as well especially in regard to the Indian Health Service, or access to resources. They often asked who else I have met with or talked to, and often suggested other prominent elders on the reservation. Often, the elders refer to each other as a population as "elderlies" and individually they often called another woman, "Grandma [Last Name], or when they refer to someone older than they are they might call them Mrs. [Name], generally they just refer to individuals in their age cohorts or younger by their first and last

names. The elders are connected through their school experiences, for those who went to boarding school in Pine Ridge, they were bonded positively or negatively through that experience, in their older adult years it is through their current communities and who they see at community events or the elder meal sites. They are also connected through their community of origin and through their families. Often the elders were born into large families that grew through marriage and children who expanded their familial network. For the elders who practice Christianity, there is a church community network where the elders participate in church services and funerals.

During the interviews, they would often pause and ask me questions about my siblings, whether or not I have children, if I'm married, which social and cultural gatherings I have attended on the Pine Ridge reservation and in which districts, for example during the summer there are more than twenty Sun Dance Ceremonies throughout the reservation and the elders would be curious which I had attended and informed me of the upcoming Sun Dances. Also, they were very curious about Alaska as well as about my mother who grew up there and our family who continues to live there. For instance, I met one older adult at the Veterans Day Pow Wow in Pine Ridge in early June 2009. I was discussing the project with his brother when he joined his family where they were seated. The man I was speaking to offered his brother for the interview. At first, the brother did not seem interested, but at the end of the Pow Wow, as we were all packing up our chairs, he approached me, offering to talk to me over coffee. So we went to a concession stand, ordered coffee and talked about the project and its various details. We talked for more than an hour after which he consented to participate in the study. We agreed to meet the next day and chatted for several hours. But I have to note that this was not the formal interview. These were common situations where I realized that rapport building was necessary; it required an investment of time and usually coffee and a meal in order to build enough trust and understanding.

In terms of gender, Lakota men were more difficult to recruit than women. My gender probably played a part in this outcome, but one male elder was explicit in his distrust of other former researchers who had come to the reservation, taken all the information they wanted, and had not given anything back. Interestingly, it was through this elder that I was able to gain access to other older Lakota men. At events and at the congregate meal sites, often the men and the women sit apart unless they are married. So when I visited the senior centers or events, I sat

with the women gaining access to Lakota men more difficult. Likewise, as a young woman, it was easier and more appropriate for me to approach and visit with the women than with the men, when I did not know any of the family members of the Lakota older adult men. Additionally, in my peer network, several people gave me access to their grandmothers or aunts because their grandfathers and uncles had passed away and there were not as many older adult men to be referred to. There are many male elders on the reservation but my access to them was limited by a number of factors. Also, there were male elders who were referred to me by their family members but a significant event in their lives may have happened recently such as a health issue or a death in the family and they were not emotionally or spiritually able to participate in a recorded interview.

In terms of the use of space, the elders often did not have transportation, so I would pick them up and take them to the home where I was staying, or my friend's home, which was amenable to them because, unlike their own residences would have been, there were no interruptions. Always, I would offer something to eat and drink. Most memorably, one 94 year old elder woman who lives at a nursing home looked forward to going with me on an outing. She was in a wheelchair and I was not aware of that fact before going to pick her up. We managed the wheelchair as well as transferring her to and from the car. We conducted the interview at my friend's house, near where the elder lives as well. And we shared *wakalapi*, or coffee, since she said it is hard for her to get a good cup of coffee. Lakota is her first language and she liked using Lakota words and teaching me these words. Each visit we had after the recorded conversation she would have me review the words she taught me. She also wanted to have lunch at a restaurant before returning to the nursing home. It had to be a place that served buffalo burger so we determined an appropriate place and together had lunch there after the interview. In general, regardless of whether I took them out for lunch or prepared a home meal, the visiting after the interview was the time I cherished the most. It was a cultural space for getting to know one another better; they continued to tell me stories, but the tone was lighter, more informal and intimate. These meal times were not recorded and I intentionally considered them to be "off the record."

Doing research in a non-western, rural setting presents a variety of challenges. The trust building that occurs as a consequence of these interactions with the elders is often a slow, gradual process spread over time, and sometimes over several meetings. I would travel from Pine

Ridge, where I stayed, to Kyle, approximately 50 miles one way, to visit the senior center; I would visit with the elders during their congregate meal, which lasted one hour. Sometimes these visits resulted in recorded sessions and at other times they did not which was determined by the elder's schedule or desire to participate, by my schedule, or a lack of a private place to record our conversations. Some of the elder women did not want to be recorded until later in the summer, never sharing with me the exact reason why that was the case. Regardless, I complied with their wishes. In all, I drove 7, 800 miles on and around the reservation, visiting and building relationships with the Lakota elders, those who did and also those who did not participate in the study. I should note that in working with Lakota elders, it was imperative to maintain these relationships after the completion of the formal interviews because the interviews were only a part of the relationship we built. They would often ask when I would see them again, or when I would visit them again. And I would often visit with the elders who participated in my study when I ran into them in the community. For example, with a friend, I attended a Fourth of July Pow Wow at Wakpamni Lake, also referred to as Batesland, a community on the reservation. After finding our seats and settling in among family and friends, I looked around the shaded area and the area that surrounds the circle where the dancing occurs. Most of the elders I had recorded in my project were sprinkled around the circle. Seated right in front of me were two elder women from Oglala with whom I had visited. So we visited there as well, which involved me kneeling next to them or sitting on the ground and chatting with them. There are give-aways at the Pow Wow, and the elders often leave with gifts. I helped them carry their chairs and newly acquired goods to the car. That afternoon, I made my way around the circle visiting the elders from Oglala and Kyle, meeting their families and friends, often listening to stories and explanations of the dances and honorings² and the meaning of the naming ceremonies³ that were

² At Pow Wows there is usually someone who is honored because he/she has passed away, someone has been recognized for their accomplishments (graduation) or dedication to the community, etc. When someone is celebrating an accomplishment, receiving their Lakota name, or being honored in some way, they offer gifts to the community often called a "give-away" So family members move throughout the crowd distributing gifts and often sharing a meal at the event to give back to the community. At this particular pow wow there was a family who had lost a family member, that family member was honored and those attending were able to walk up to the family, shake hands, offer words of condolence and support, tell the family what the death of the family member means to the community, etc. As a visitor to the community, the elders filled in the context of the family, the death of the family member and what was appropriate behavior for me during the honoring of the family member.

³ The naming ceremony is one of the Seven Sacred ceremonies, or rights in the Lakota culture. At one event a young woman was given her name in Lakota, sometimes referred to as her spirit name. At these events, the family provides a give-away and meal, an elder, or spiritual person explains the name and why the person is being given this name.

taking place, laughing and teasing each other⁴ Often, I scheduled future visits with these elders and was often able to secure new connections with their friends as a consequence. My time on the reservation quickly became a delicate balancing act of maintaining respectful relationships by honoring the generosity and time that the elders gave me on the one side and creating new relationships and scheduling interviews and visits on the other.

I did not offer incentives, or gift cards in exchange for the interviews. Instead, throughout the summer, I tried to honor their time and knowledge through the more traditional method of providing services to them whenever I could. There were several social events throughout the summer, where I visited the elder women, carried chairs, gave them rides home, delivered their meals to them, picked up and delivered their commodities, and packaged their leftovers. At the reservation, there are several fruit and vegetable seasons. One, for instance, is *canpa*, or chokecherry season, when the chokecherries ripen and can be picked from a variety of locations around and near the reservation. The elders enjoy the chokecherries very much, and taking them to pick or bringing them chokecherries was a most welcome activity for many of the elders. I also arranged for deliveries of vegetables from the gardens of my friends to the elders since they were unable to get fresh affordable produce. Turnips, potatoes, onions, tomatoes, and corn fresh from the garden were highly sought after.

Conducting research at this time and place was often difficult, however. Life on the reservation can be very stressful since challenges often arise spontaneously and frequently. There were several instances involving ethical issues, stumbling moments, and emotional upheavals. The first and most prominent of these concerned an 84 year old elder whom I had been visiting for several years. He was first on my list to be formally interviewed because he was so knowledgeable. I visited him as frequently as a few times each week. He and I anxiously awaited the final approval from the tribal review board and the university so that we could start the interviews. Upon receiving the final approval the day after visiting him, I immediately went over to his house but he was not home. For two weeks, I tried to reach him, also asking around to find out if he was alright. He is a regular at the hospital in Pine Ridge, where he frequently visits a mutual friend, but he had not seen him either. Finally, I located him at the hospital in Rapid City and visited him there, and then at another hospital in a nearby border town where he had been

⁴ These activities may appear as ethnographic, however, much like the time spent with the elders after the interviews were completed, over meals and in cultural events around the reservation, these moments were “off the record” and I did not write field notes or use these moments in the formal information that I gathered while conducting this study.

transferred. He had multiple medical interventions over the summer and was recuperating at a small hospital. I was able to visit him at these facilities regularly, but I was not able to formally include him in this research project. He was lively and alert throughout his treatment and recovery, but we both did not consider the hospital an appropriate setting for recording his stories. Still, he continued to tell me stories and I began learning Lakota; often we would practice and he would teach me new words and phrases.

Another instance took place near the start of the research project. I had contacted an elder's granddaughter who was a member of my friend's network; they had told her about the study and she had already spoken to her grandfather who had stated that he would visit with me. She called her grandfather to let him know that I would be calling, and also offered to drive with me to his house. I thought I could find the house on my own so she gave me directions to his house. I told her that I would call her grandfather the next day to set up an appointment. When I called, he was distressed. The following is an excerpt from my field notes explaining what happened next:

I introduced myself and explained my connection to his granddaughter and the interview. He asked if we could talk at another time because he had fallen down. I asked if he was ok and he said he was in "bad shape." I asked if there was anything I could do to help him and he said no, that he needed to go to the hospital. We ended the call just after he graciously offered to meet with me at a later date. I offered to check in with him after he was well. He said he looked forward to it. I called [his granddaughter] to let her know that he had fallen, I left a voicemail, and then she called me back and said that she is headed out to help him and that she appreciated the call. She said to try back in a few days, she is going to take him to the doctor but assured me he would be up and around again soon (Field notes 5/12/09).

I waited for two weeks before checking back in order to give the elder plenty of time to recover. I called his granddaughter and left a voicemail. She called back to inform me that the elder had passed away. He had broken bones in his neck and had been in the hospital. She said he was not someone who would have wanted to live in a nursing home so he passed away. As I offered my condolences, she lamented the fact that I was not able to talk to him. She said that at the hospital, he had tubes in his throat so he was not able to talk. The loss of this elder was felt by the entire reservation community and I was very sad that I was unable to get to know him for he was a

prominent elder in the community who had been recommended to me by many others. Indeed, conducting research with the elderly teaches one how precious and fleeting time and life is.

Yet I should also note that I had positive emotional experiences as well. In one instance, one elder woman had taken a quilt to the governor's office located in the capital building in Pierre, South Dakota. Upon arriving there, she noted that there was a painting hanging prominently on the wall that was racist against Indians. She mounted the star quilt on poles and covered the painting with it. She then instructed me to go visit the star quilt at the capital. The painting was permanently covered as a consequence of her protests. I went to the capital and after much inquiry located the quilt in the archives associated with the cultural museum in Pierre. I had to make an appointment to visit the quilt at a later date, and eventually managed to see the quilt and learn more about where it was stored. While I was at the museum, the curator allowed me to visit the Native sections parts of the museum where I was able to view two Ghost Shirts⁵ that have been preserved from the Wounded Knee Massacre. I was able to report back to the elder woman that I had seen the quilt; I then shared with her my own story of visiting the quilt and learning more about The Wounded Knee Massacre. I also conveyed the spiritual experience I had of being with the Ghost Shirts, of feeling closer to her as a consequence, and of feeling proud that she had advocated on behalf of Native people by taking actions against the painting.

The cultural symbolism of the Wounded Knee Massacre for Lakota people needs further explanation especially since it also captures my own subjectivity in the field. In order to get to the communities of Porcupine, Kyle, and Wanblee central to my study from Pine Ridge, I would always drive past the Wounded Knee Massacre site. The site marks the Wounded Knee Massacre of 1890; there is a memorial placed at the mass grave where the United States Cavalry buried many Indians who perished during that attack. The United States Cavalry attacked unarmed Lakota men, women, and children who were participating in The Ghost Dance.⁶ At least 150 Indians were murdered and 50 were wounded. The Cavalry then left the wounded to freeze to death during the three day blizzard that followed the attack. The mass grave and the land are marked with a historical marker as well as an explanatory text. This site is particularly important because many of the elders in the study consider themselves Wounded Knee

⁵ Ghost Shirts were worn by the Ghost Dancers at Wounded Kneed in 1890. The shirts were believed to hold spiritual powers. After Wounded Knee, many of the sacred objects, clothing, and the like were considered artifacts, collected by the state and displayed in the museum.

⁶ The Ghost Dance was a spiritual dance believed to unify the spirits and aid in bringing peace to the Lakota people. While Lakota people were performing this dance, the cavalry attacked them.

Survivors; they narrated to me the stories of their relatives who either managed to escape or perished in the attack.⁷ Also, this site was a constant symbolic reminder to the Lakota people of the destructive policies of the United States government against Native people. At the same time, the site also symbolized the strength and determination of Lakota people. After all, the Lakota who had no weapons were able to fight against the fully armed Cavalry, taking down 30 soldiers with their bare hands in the process.

What I discuss above captures just a few of the emotional upheavals that are often experienced, but rarely discussed in the training one receives in research methodology. Yet I would contend that such instances reveal the process of meaning making in communities, often highlighting the agency of the community in the process I personally found these human dimensions of research to be just as significant as the knowledge generated during the research process. It was often difficult for me to negotiate such instances with the western approaches that emphasize objectivity at the cost of such emotional engagements on the one side and the subjectivity of the researcher on the other. I was often unable to reconcile the personal with the professional and the objective. The emotional and spiritual connections I made with many of these elders, I would contend, taught me much more about the community within which they lived, the feelings and emotions with which they created meaning around them than what I would have learned if I had solely assumed the distant, objective role of a western researcher.

Data collection techniques

I personally conducted all the communication in the study, including setting up the interviews and visits as well as the recording of the elders' stories. I sometimes refer to the recording of the elders' stories as 'interviews.' Yet this term does not accurately capture either the dynamics of the interaction I had with the elders or what I ended up learning from them. Indeed, the elders often described our time together as "visits." I prefer to employ this term they employed to describe and define the knowledge production process. Indeed, such 'visits' included a combination of storytelling, reflection and dialogue (Kovach, 2009). Kovach (2009) aptly states that in her research framework, "participating in the participants' stories – their experiences with culture and methodologies – was a primary method of [her] research" (p. 51).

⁷ See Appendix for photos of the hill where the mass grave and the historical marker of the massacre are located.

I scheduled the recorded sessions with the elders at a mutually convenient time, in a comfortable setting decided upon by both parties, a setting that was private and also ensured confidentiality. Each session lasted between 3 to 9 hours. I very rarely conducted formal recorded follow-up sessions; when I did, they often continued on the themes covered in the first interview. I scheduled follow-up sessions if the participant agreed that he/she might need or would like more time to share information on these topics. In addition, since I visited the senior centers regularly, I was able to have numerous conversations with the older adults after the interview during which they sometimes clarified some of the earlier points they had made or offered more details on them. I did not record these ensuing interactions, but I included them in my field notes.

In my visits, I employed a conversational method that Indigenous scholars describe as "storytelling," "talk story" (Kahakalua, 2004) or 'yarning' (Besarab & N'gandu, 2010). This method provides a "culturally organic means to gather knowledge within research" (Kovach, 2010, p. 42). It should be noted that stories, storytelling, oral histories, and narrative are also employed by western methodologies; yet such methodologies elicit stories merely as a method of obtaining knowledge related to a particular research question. Kovach (2010) delineates the ways in which Indigenous conversational methods differ from western methodologies as follows:

- a) it is linked to a particular tribal epistemology (or knowledge) and situated within an Indigenous paradigm;
- b) it is relational;
- c) it is purposeful (most often involving a decolonizing aim);
- d) it involves particular protocol as determined by the epistemology and/or place;
- e) it involves an informality and flexibility;
- f) it is collaborative and dialogic; and
- g) it is reflexive. (p. 43).

These Indigenous research methods created for the Native elders the space within which they could share their stories on their own terms; it enabled them to recapture the agency interviewees often lose in relation to the interviewer who is omnipotent in defining the entire knowledge production process. Indeed, as a research tool, "storytelling is a useful and culturally appropriate way of representing the 'diversities of truth' within which the story teller rather than the researcher retains control" (Russell Bishop in Smith, 1999, p. 145). Hence the research method itself ultimately contains within it the element of power. In western methodologies, the researcher alone possesses such power in its entirety at the expense of the subject. As a consequence, the subject loses her agency, and gets reduced to an information resource that is

exploited by the scholar. Yet the employment instead of the Conversational Method offered the Lakota elders greater control over what they wished to share with respect to the research questions; hence the method acknowledged, incorporated and operated within the parameters of their cultural norms (Kovach, 2009). Since the Lakota elders are accustomed to sharing knowledge through stories and through “visiting” with their families, friends and community, this research approach was much more familiar to them. Indeed the conversational visits honored their cultural practices as the Elders shared stories, both directly and indirectly in relation to a question, including all the pertinent contextual information.

This relational approach to research treats the interviewer and the interviewed as equal partners, ensuring that both parties understand and agree upon the information shared and the knowledge created as a consequence. The process is a mutual one benefiting both parties instead of the researcher alone at the expense of the subject. In this case, we were both comfortable with the fluidity of the story; I did not at all interrupt or redirect the Elders since I wanted them to generate meaning and interpret things as they saw fit. Throughout the recorded sessions, the elders would often pause during their own storytelling and start to solicit stories from me about my family, what I have learned, what my opinions on a particular topic are, where I have visited; they would often ask for assurance that I learned something from talking to them. Thus, the interviews, or conversations with the elders were often a reciprocal give and take, as we questioned each other to gradually create a mutual interpretation on a topic or an idea. Kovach (2010) notes that this give and take deepens the shared insights, builds richer relationships, and causes the researcher to become an active listener. She adds that “in all cases, participants shared stories from their lives resulting in a highly contextualized, powerful source of knowledge. In receiving the gift of story, I was ever mindful of the responsibility inherent in research and the reciprocity it entails” (p. 46). The weight of the responsibility assumed by the researcher includes the responsibility that the story shared will be treated with the respect it deserves and the context in which it was shared (Kovach, 2009). Such knowledge creation was also powerful in my case, enabling me to capture the social reality of meaning making much more rigorously than I would have had I employed western methodologies.

Additionally, my goal in conducting the interviews was not to uncover the minute details of historical information, but instead to explore how historical, cultural and social events influenced Lakota older adults’ meaning of health, illness, wellness, their roles and identity

(Evans-Campbell, 2008). Indigenous Methodologies are a burgeoning intellectual area among Indigenous scholars in Canada, New Zealand, Australia and the United States. Evans-Campbell is a social work scholar who utilized these methods in caregiving of two spirit American Indians. It is important to utilize these methods and build upon the scholarship and culturally appropriate methods when working in our American Indian communities. I should note that in designing this study, the university and western methodological approaches required me to develop an interview protocol before entering the reservation to conduct research; this protocol was to guide the semi-structured interviews that I planned to conduct with the elders. I carried this protocol with me to each session yet I rarely utilized it in any formal way (see Appendix A for interview schedule).

In addition to the recorded conversations with individuals, I also conducted a community assessment to identify the resources that are available to Lakota older adults. This involved speaking with the Lakota elders receiving services, the representatives in the tribal government and tribal programs, the Indian Health Service (IHS), and community organizations that provided congregate meals and other services. (See Appendix B for the community assessment questionnaire). These were not recorded and notes were taken during these conversations.

Data analysis

The interviews were digitally recorded, transcribed verbatim, and then manually reviewed for reporting patterns, or themes (Braun & Clarke, 2006). Thematic analysis can be either essentialist or realist method, which “reports experiences, meanings and the reality of participants, or it can be constructionist method, which examines the ways in which events, realities, meanings, experiences and so on are the effects of a range of discourses operating within society” (Braun & Clarke, 2006, p. 9). The analysis for this study employed the essentialist method of thematic analysis. The themes capture a patterned response within the Lakota elders’ narratives. The themes are identified when a topic appeared both across the narratives, for example experiences of illness in childhood, or attending school; and also for a more nuanced and detailed account of a particular theme or event, for example the removal of families from the area known as the Bombing Range. Two elders provided in depth accounts of this important experience of more than a hundred families in the early 1940s. In order to identify

the themes, the narratives were coded inductively, which is “a process of coding data without trying to fit it into a pre-existing coding frame, or the researcher’s analytic preconceptions” (p. 12). Thematic analysis involves six phases of analysis of the Lakota elders’ narratives as defined by Braun and Clarke (2006). Phase 1) *Familiarizing Yourself with the Data*. I participated in the interviews, transcribed them myself, checked for accuracy against the recorded narratives and once printed re-read them thus becoming very familiar and close to the data. Phase 2) *Generating Initial Codes*. The initial production of codes is organizing the narratives into meaningful groups. In reading the narratives of the elders I identified interesting, repeated patterns across the data set. Initially, their birth experience, their families of origin, their experiences with childhood illness, food production and daily life, experience with illness as an adult, and so forth. Phase 3) *Searching for Themes*. After coding the data, there is a long list of different codes. The codes are analyzed to consider how different codes combine to form a theme. Some themes remained as the main theme with others as a subtheme for example, Physical Health was developed as a main theme with subthemes of Home Births, Western Medical Care and Chronic Diseases with subthemes of Diabetes, Heart Disease, etc. Phase 4) *Reviewing Themes*. The candidate themes are evaluated and refined. The final stage of this phase is evaluating the theme across the Lakota elders’ narratives to assure accurate representation Phase 5) *Defining and naming themes*. For each theme, I wrote a detailed analysis by identifying the “story” that each theme told and how this fit into the overall “story” that the Lakota elders shared. The themes were analyzed in relation to each other. For example, Mental well-being was addressed through their school experiences, deaths in their immediate families, raising grandchildren and how these fit into the overall experiences across their lifespan in relation to physical, mental and spiritual health. Deaths in the family were often related to physical disease but was refined into the mental well-being theme as the weight of the loss has affected them since they lost their family members. Phase 6) *Producing the Report*. The chapters were written based on the themes with compelling illustrations selected from the elders’ narratives.

I analyzed the Community Assessment data by scanning the community assessment forms. These data enabled me to identify the health resources available to Native older adults. I first analyzed the health resources independently of the interview data in order to gain an understanding of the resources available; I then merged the data with the themes that emerged

from the interview data, such as experiences at the elder meal sites. The elder meal sites were identified as an important resource for many of the elder women, providing an important meal and social interaction. I discussed the elder meal sites and the challenges of providing the meals on the reservation with one of the elder meal site managers. These two sources of information were merged into the final narrative about elder meal sites as a resource. After all, community resources supplement the resources that the elderly people are aware of and use. Through adopting such a process, I was able to incorporate the elder perspective alongside the provider perspectives.

Research and feasibility

This study was feasible because of my scholarly, research, and professional competencies. I established relationships with members of the tribal community, which included Native elderly people as well as with health care professionals. I have worked closely with tribal members to ensure that recruitment of the elderly persons is conducted in a way that honored local and cultural norms. I obtained formal written permission and Institutional Review Board (IRB) approval from the University of Michigan as well as from the Oglala Sioux Tribe Research Review Board (OSTRRB) to conduct research at this site. As a student in the Joint Degree Program in Social Work and Sociology, I have received rigorous interdisciplinary training in social science theory, methods and its practical applications. Fellowship funding from the National Institute of Aging (NIA) and the John A. Hartford Foundation have allowed me to concentrate more fully on gerontology and exploring topics in aging.

Human subjects

Approval from the University of Michigan IRB and the OSTRRB was completed before the research commenced in order to ensure ethical research practices. Maintaining the confidentiality of data collected during interviews was a very high priority. I did not gather and keep the research participants' names or any information that could identify them. I stored all information collected for this project, including the notes and digital files saved on CDs from interviews, in a securely locked file cabinet and identified only by a code number that was not

linked to the participants' names or any other identifying information. The digital files, CDs, and notes will be archived in a locked file cabinet for an indefinite period of time.

Prior to the interview, potential participants read, or had me read to them an informed consent form. I provided a consent form with larger text font, if needed, to facilitate easier reading. The consent form explained the voluntary nature of their participation, the purpose of the project, what will happen during the interview, potential risks and benefits, confidentiality, and any possible future use of data. Also, Native older adults were assured of their right to refuse answering a question, ending the interview at any time, and could refuse participation at any point of the process. The form also included contact information for the researcher, primary faculty advisor from the university, and the IRB, should participants have any comments, questions, or concerns they would like to discuss after the interview.

Conclusion

This chapter introduces the context of this study, namely, the Pine Ridge Indian Reservation, home of the Oglala Lakota Indians. The reservation is a challenging environment in that, for many years it was the poorest county in the United States. The formal resources are scarce, the distances between communities are great and as a result the community experiences challenges of substandard housing, rutted roads and limited economic and job opportunities. Despite these challenges, Oglala Lakota elders have managed to live, work and raise their families. Three theoretical frameworks proved useful in analyzing this unique context and population. I employed critical race theory to develop 'Triple Consciousness,' life course theory to capture how their social interactions capture their health and well-being over time, and the social construction of illness to determine how Lakota elders defined health and well-being.

In order to capture the experiences of Lakota elders respectful relationships are necessary to develop as a foundation for entering a Native community and in working with their elders. These relationships take a great deal of time and patience and began a year or more in advance of conducting the recorded conversations. Indigenous Methodologies were employed in order to more fully capture the elders' experiences, world view and life stories and conducted in a manner that honored their social and cultural position on the reservation and their agency in the research interactions. The Conversational Method allows for a give and take between the elder and researcher, therefore developing a deeper understanding of the meaning and context of the

elders' lives. These methodologies differ from Western methodologies in that my own subjectivity, emotional and spiritual ties with the elders and the community can be more fully acknowledged and reported on, thus giving a more complete understanding of conducting research with an incredibly important and rapidly disappearing population of Native elders.

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Chapter Three

Physical Health and Lakota Elders: From the Past to the Present

Before we can talk about the details of the elders' health insights, it is necessary to know who they are and where they come from since their current physical health is predicated on their life course. And this is what this chapter endeavors. In this chapter, I intend to provide insights in the lived experiences of the Lakota elders beginning with the context in which they and their families lived. I demonstrate that lived experiences from the Lakota perspective capture the various dimensions of what comprises their physical health over their life course. The Lakota elders remember their childhoods fondly, filled with the families working together for subsistence. The elders had very limited access to formal health care; for some their grandmothers were often present in their lives, providing them with traditional Lakota medicine to remedy illnesses. For some families, their children were forced by the government to attend boarding school, fragmenting the families, and negatively impacting the Lakota families for generations. The culmination of these experiences, coupled with the living conditions on the reservation has contributed to the elders' current state of health.

I further contend that unlike mainstream American definitions of health, health for the Lakota people does not solely comprise the physical body; it instead includes the combined health of the physical body, mind and the spirit. The three empirical chapters of this dissertation thereby articulate each of these three components that comprise the health of Lakota elders. This chapter specifically focuses on their physical health in three parts: 1) Childhood, 2) Present Struggles in Older Adulthood, and 3) Challenges of Physical Healthcare Across the Life Span.

Part I. Childhood: Family, Work, Food and Education

Family and the Communal Lifestyle. In general, the elders grew up similarly, regardless of where they grew up on the reservation. They lived in 2 or 3 room log cabins, with neighbors in sight but often located remotely, “out in the country.” The log cabins typically had

one big bedroom, kitchen and living room, without indoor plumbing or electricity. There were various formations for sleeping which included the children huddling together in beds for warmth, putting a mattress in the kitchen near the wooden stove used for preparing meals, and in the heat of the summer time they would set up tents in the yard for sleeping in the more comfortable cool nights.

The days began with the entire family helping with chores. First, by tending to the horses and other farm animals, milking cows and collecting eggs. Mothers, or grandmothers made bread and prepared meals. With the milk, the mothers also made other dairy products like butter, cheese, cottage cheese, and sour cream.

We made our own. The way we used to do, my mom used to put it in a flour sack she'd boil it first – the cheese, I mean the sour cream and then she'd boil it and then it'd get hard and then she'd take it and then she'd rinse it and then she would [put] it in a gunny sack and hang out it on the clothes line so it would shake out. That was good. (Elder 1, 85)

In the summertime the children would harvest vegetables for and with their mothers. Each family had a big garden where they grew onions, potatoes, squash, pumpkins, tomatoes, corn, radishes, beans, etc. Horses were used to plow the gardens. The adult women canned every part of the harvest they could and one elder related,

We would pick fruit with my grandma. It was like the grandmas picked the fruit. They had cherries and plums and apples and they called these little berries - buffalo berries (Elder 3).

Often the children were enlisted to help with the harvesting of fruits that were growing away from their homesteads. A grandmother enlisted the help of her grandchildren to:

We'd have to pick all the berries and get jiggers and itch to death. We'd go and when we'd go down to the creek and toward the Bombing Area when you are coming up this way, remember? From the Rocky Ford way, down that hill, all on this side there were all kinds of yellow cherries, sand cherries, and we'd go and pick all the cherries. She'd never let us break a branch if you did she would switch you with it. They would put down canvas around the tents, I mean around the tree and she'd get a hard, uh, a real hard, uh, tree branch I guess you'd call it, about that big and she'd hit the limbs of the tree and they would just rain down. We had little buckets and big buckets and everything they could they'd fill up. Big old plums. Oh I used to love those sand cherries. Just yellow and we even found yellow cherries down there. Buffalo berries. (Elder 4)

Mothers also performed an array of services for the family including sewing clothes and blankets, washing the clothes at the creek and indoors in the wintertime. Many of the female elders have fond memories of learning to sew and sewing alongside their mothers, aunties, and grandmothers. The oldest elders shared that their grandmothers also made moccasins for the children to wear in the winter¹.

Fathers performed a wide range of labor for their families, including caring for animals, planting gardens, caring for the land, building fences and the like. One elder shared that her father made a rocking chair and couch for her mother (Elder 4). Fathers would dig cellars and add shelves, or straw bales for storage of the food supplies over the winter. The cellars could also use straw to help insulate and the doorways were covered in canvas to protect it from the elements. In addition, some fathers were employed away from their homes, leaving these tasks for before and after they returned from work.

The homes were without indoor plumbing so they hauled water from a nearby dam, or creek, which was described as:

The water was real clean and the weeds weren't in there and the water was really nice and it was deep and you could see down to the bottom and in the winter time then the water would freeze they used to go to the school and ice skate (Elder 1, 75).

The water was stored in a big wooden barrel behind the house and they had a wagon especially for the barrel, their father or older sibling would pull it to the creek, fill it up, return it to the cabin, and cover with canvas. Otherwise, they would make several trips between the creek and their cabins with buckets transporting water.

The creek was an important location that provided fresh water, firewood, and recreation. The families would work together and go down by the creek to collect fire wood. They would picnic and prepare meals down there.

When my dad go down at the creek, she [her mother] takes the coffee pot and coffee and sugar and then she was going to take potatoes and eggs and gonna boil eggs and potatoes together for dinner. We chopped wood and chopped wood and piles a wagon was going to haul it out for us to the house...we were doing ok (Elder 11, 79).

¹ An elder shared that her grandmother also helped in the making of clothes by resourcefully using flour sacks and repurposing others' clothes. She shares, "She made all our own stuff. She'd get real pretty sacks of [flour] – they were real pretty and all colors or they were like all purple and just different colors and she'd make our little dresses and panties out of it. She'd go to these churches like our Lady of Lourdes or the Mission and they'd give them big boxes of pants or stuff and what they could use and we'd have to rip out the overalls and this part right here [she gestures] she would make little boys pants." (Elder 4)

The creek was also a site for picnicking while traveling. Decorating the grave sites of loved ones was an important gathering time for family.

Our great uncle and aunt were right along, were right along the creek there when we went to decorate we would stop and visit and have picnics and sometimes we took kids, see they traveled in wagons. I'm talking about the days when they didn't have cars. They took their tents and along with the tents, their bedding and they made little campfires and soup and made coffee, that's how we were used to living [long silence] you had to stake [the horses] out on a long rope and camp you know. Tried to camp near water so the horses could get up there. My grandma is buried up where we are going to decorate. (Elder 6, 94).

As the elders have shared, they and their families were always busy working for their families but also for the community not only with food but with material goods. One elder shared that the mothers and grandmothers shared their skills with others,

She was head of a sewing [group] and she made mattresses and she made curtains for people. They'd get all kinds of crocheting for people like that. With that extra she cut from the mattresses [she made things for others]...(Elder 4).

The communal nature of helping one another remained an important element of living and surviving as an elder from Oglala shared,

We dig up some cellars. Some people come and help themselves. We have a big community garden, right along the river. So has a machine that pumps water and the community and help to put it away and every year they come and every week they pick up whatever they want – if they need potatoes, then they take some and they don't get greedy they just take enough to last two or three days and then they come back. That's how they all grew up together. So the cellars are still there. (Elder 9, 77)

If one family was in need, another family would share whatever they could in order to help. The men came together and helped with branding of calves and any other help with animals that was needed.

Lakota families had survived the shift away from the traditional lifestyle of hunting game and moving with the seasons to gather vegetation to the reservation period of history where their land was bounded and plots were allotted. Breaking away from the traditional ways of living, the elders families had adapted to log cabins and plots of land where they survived through self-sufficiency as much as they could. In this situation, the communal ways of providing foods remained but adapted to the new environments of the reservation. Additionally, when an animal was slaughtered they continued to use all of it that they could.

My mom lived close to the slaughter house and my mom would always get the guts and cook the whole thing and then dry them during the fall. And dry them about 4 or 5 cow guts and then they bring them back. We'd eat them during winter time, put them in the cellar [laughs]. Cook already, dry already. Even the lungs! You make *bapa*², you know? Dried meat. Like the lungs and make it like dried meat and dry those and in the wintertime mom would make those and we'd eat it. The wintertime. (Elder 7, 75)

Another elder related that the lungs would be dried on the clothes line and then the gaps in the lungs would be filled with meat. This would be roasted when it was time to eat and sliced like meatloaf. She said it was, "Mmm good." (Elder 4)

Simple treats were made at home. Many of the elders reminisce about those treats with smiles on their faces, relishing the memories of the homemade treats.

Yeah, [home]made butter and cottage cheese. The cottage cheese was so good because it was *real* cream it was swimming in *reeeaaal* cream [chuckles] (Elder 6, 94)

Also, in each community there were some elderly women who would make baked goods, "Gee they could bake some good pies, oh cakes and anything, cause we never could go to the store to buy anything." (Elder 6, 94) Another elder and her brother would run over to their grandma's house and ask for sandwiches made of cream, cinnamon, and sugar as a treat (Elder 1, 85).

The fathers, and sometimes the mothers, of the elders would go to "town" which was often Gordon, Chadron or Rushville, in Nebraska, white border towns near the reservation, with their team of two horses and wagon, where they would get supplies that their homesteads could not produce, like flour, sugar, farm implements and clothing. The children often declined going to town with their fathers, or parents because they'd rather stay at home and play, as the ride was long and boring. Occasionally, they would go for a treat where they were able to eat ice cream or get candy.

...but in those years, oh the hard candies and the walnuts they are in barrels, in little barrels about this big around [makes a big circle with her arms], they sit not behind the counter but in front, all different candies (Elder, 6, 94)

It is apparent to see the foods start to change with the incorporation of the non-Native foods like candy and ice cream, although limited to occasional treats.

² *Bapa* is Lakota for dried meat

Modes of Recreation. When they were children, recreational activities included swimming in the creek, riding horses, or playing with their siblings and cousins. Often the elders made their own games and toys, bone horses were popular among them. One elder explains,

We'd play or we'd just do you know race or any kind of sack race. I used to like to sack race. (We laugh.) "You do because you can win," they'd say. I'd play marbles with my brothers and I'd beat them and they'd get mad. I had a big shoebox just full of marbles that I would win from them. We'd always play bone horse. You know these match boxes and my brother [would] take those and spools cut off the little - the end then those were the wheels he'd put throw and take match sticks for the tongue and he'd make this little wire men. And we used these pigs, different parts of the bones of the pig and the bigger ones were the horses or cows and we'd make little corrals. I was always outside on the ground with the boys. Eee, they'd get mad. (Elder 4)

Another elder related a story of the cousins coming over to play. There were a lot of boys in the family and if she was going to play then she had to play with them.

The funniest thing for recreation - my aunt had boys, a lot of boys. On Sunday they would drive over, then they had cars, and they would drive over and my dad had a, he got a, bought a pair of boxing gloves, a set of boxing gloves so he used to have me to box with my brothers. Then they when my cousins would come over and they'd make a ring like that and you know and I'd have to box with my cousins.

I³: Did you win?

E⁴: (laughs) I used to really make them, I would win! It was two rough ones too. One was older than me but I don't know! I made them laugh and they'd laugh when I hit them and they'd just laugh and I guess they thought I couldn't do anything. (Elder 1)

The elders related these stories of their play time which often focused on their outdoor activities and they did not mention their indoor playtime activities. They did share that at Christmas time they were gifted with dolls, mostly handmade, but as one Elder shares, on trips to Rapid City with her Aunt:

The women in those days made dolls and they made our Christmas presents. They made little dresses and dolls, they made things. So we never knew what it was to have all boughten Christmas things, you know? (pause) And there was no country stores on the reservation we had to go to town - they had to go to town, we used to go to town my aunt - my great aunt, she just had one boy and she would come by in her little buggy and I'd go with her to Scenic. That's still there. We'd get on the train and go to Rapid City and stay all night over there and we didn't have - I didn't have enough money. Just to look in the stores, "Oh those pretty things." Our stores were just grocery stores - country stores. We used to go to Rapid on the passenger train and stay all night - \$2 to stay all night. Boy, the only thing - you never had plumbing in your room. It was a big long room like that all those people stay and all those people shared this room and this was the seats and

³ I is Interviewer

⁴ E is the elder being interviewed.

it was two dollars to sleep there. And it was about like that to ride the train from Scenic and got on the train to Rapid City. I got to go to Rapid a lot with my Great Aunt. She didn't have no girls, you know. She'd take me along with her to have someone to visit with her she didn't want to go alone. But she'd buy me maybe a little doll in the dime store and Ooooh I just thought it was great. The little doll would have a little like a basket, just little bitty just like that (uses her fingers to show size). Probably about 10 cents. Probably one thing that's what I liked was a little doll (Elder 6, 94).

The elders appreciated the small things that were gifted to them and the treats that family members shared with them. They described these outdoor activities and small trips. They cherished the times with their Aunts and grandmothers who taught them to sew, cook, and make things for example, beadwork.

Modes of Work. The families were supported through self-sufficiency, or as the elders say, their fathers were ranchers, where they would raise their cattle, livestock, horses and feed. If they were unable to do so, they were often hired as ranch hands by white ranchers who leased land on the reservation or off the reservation. One father was a jockey, so he would travel away from the reservation to earn a living for his family. Other fathers were employed by the Bureau of Indian Affairs (BIA) or the railroad.

...My dad, the years got bad, real bad there was no work, they didn't pay anything at all so my dad had to look for outside work but he went to a cattle ranch. That's where he worked at and then they moved him to Red Cloud where he could take care of the dairy cows.

I: When he was working with the wagon who was he working with?

E: They called it uh...it was BIA they had to go around building dams and whatnot, fixing roads and stuff like that. Now just think they did that in a wagon in a team. (Elder 1)

The fathers, and sometimes entire families being forced to leave their family homes and the reservation. Thus, deepening the fracture between traditional communal ways of providing and the individual family focused ways of survival. Depending on the steady work of the jobs, the families were often strained in trying to care for all of the children. Sometimes the children being sent away to boarding school helped the families survive in lean times.

Then when my dad would look for work and we would have real nice houses – water and all that. Lights and everything, heat. They had, the government had nice houses for their workers. We didn't live in that too long. Like me now, living at the Mission and my brothers as we went to school then if we didn't come back until Christmas then it was, there was no, they would manage better for the smaller ones, you know. So that's how we managed. (Elder 1)

Mostly, the mothers worked in the home raising children and taking care of cooking, cleaning, sewing, gardening, laundry and the like. There were women who worked outside the home, Aunts or other women in the family who owned little country stores, midwives who traveled around their communities, and workers at the boarding schools. In some cases, the parents as a team would go into Nebraska, Colorado, or Wyoming to work in the fields as a farm laborer, during the summers and after the children stopped attending school, the family would go together to work and earn money.

I: And so after you finished school what did you do?

E: We went to Nebraska working. We sewed beads and cleaned gardens. So many long strips, said Mom, "We should go home and [plant a] garden over the hill like this." The boss told me some more tribes coming in but they are going to give you numbers and to pick green stuff, like green beans and stuff like that. And you carried that number and they already counted how many sacks they gave to one worker, if anybody steals your sack then they would know it...we cleaned the garden, we cleaned the garden, and uh pulling the weeds, pulling the weeds with long gloves... (Elder 11)

The children working in the fields as migrant workers were a tremendous help to their families. Alternatively, when the children went to school there were fewer hands to help support the chores and the home. When the elders were children, some went to school willingly and others resisted until the government flushed them out of their homes.

Educational Experiences. The elders attended school in their districts⁵, for some it was a one room school house or a day school with multiple grade levels. There were two schools that served the entire reservation and taught all grade levels: the Holy Rosary Mission, a Catholic school which was later named Red Cloud Indian School and Oglala Community School (OCS), the boarding school. After the children completed the 8th grade in their district schools, for high school they could attend OCS in Pine Ridge. Depending on their age and where they lived on the reservation, some elders were rooted out by the federal government to attend school. One of the most respected elders on the reservation shared this story of how he was forced into going to school:

...before that I lived way out in the boonies. I was born out there I lived out there up 'til the time I was 8 years old and then my mom kept me home because I was kinda weak and sickly and ugly and she kept me home but they were sweating my father. The educational people say, "This your boy?"
My father would nod.
"Is he in school?"

⁵ The reservation is divided into 9 political districts, used for organizing resources and communities.

He'd say, "No" then my mother would intervene, "He's sickly and he's not well."
"Well you still have to send him to school, that's the law."

I guess I was kind of headstrong from the beginning. They had to figure how to get me to school, what excuse they would use because they knew I was going to resist. One day they said, "We're going to Pine Ridge to the agency. How would you like to go and see your sisters up at the school?"

Yeah that would be kind of nice so I said, "ok OK" so I went with them.

We traveled in a wagon - there were no cars then. I wanted to go horseback but no, they wanted me to go with them in the wagon. So I came to rode in the wagon from north, 8 miles northwest of Manderson. So we came early one morning and we made it to Pine Ridge, they went and pitched their tent up at the school. So I stayed at the tent that night. The next day I visited my sisters - they were going to school then, they were all much older than I was. I was happy to see them. I enjoyed seeing them but I was ready to go home. That was the red letter day. Finally they said, "Uh, well, we're going to go home."
"Ok!"

I ran and jumped in the wagon and here some tall boys, they must have been 16, 17 year old, they grabbed me and pulled me off the wagon. That's when I knew something was wrong. (taps the table) It's pure unadulterated kidnapping. And I let the world know about it. The whole school vibrated with my screaming. I locked my legs in between the spokes of the wagon and they had to pry me off there. I screamed and hollered and wept and cried and kicked. They held me fast - they were big boys. I saw my father and mother get in the wagon and drive off. They heard me. They said they heard me scream all the way home. I thought they were the meanest people in the world. Oh I was angry. That was the only way they were going to get me to stay in to school. That's how we were supposed to be educated. We were not supposed to know how to talk Indian. We were to speak the English tongue. If anyone heard us talk Indian we got punished. So that's the way it all started, oh I was angry at my father and mother. Almost never forgave them. Then when I was in the 8th grade, then I knew why they, I used to believe that they felt bad too. Maybe they were happy to get rid of me. (laughs) I believe they got enough of me. It made them sad when they had to leave me. It was the law. They had to put me in school. The federal government said so. So that [his name] grew up at the boarding school at, that's the high school now and part of it is the elementary. Then I realized...as I said, I believe they felt because I felt bad but they knew I'd be living here today somehow. So they had to sacrifice and push me out of their house to get educated. In a way I forgave him. They had to the law said so but they also knew that I was I was going to be living (taps table) that I was going to be living alone in this world when they were gone. So they wanted to prepare me. Of course, they had my best interest at heart. I was never so angry (laughs).

That's the way it all started, I was 8 years old when I was supposed to be sent to school when I was 6 or 5 but...my mom wanted to keep me at home as long as she could, so they kept me at home until I was 8. Then they had to threaten my dad if he didn't put me in school. So that's how I was sacrificed to get an education (we laugh). Anyway, I'm glad they did. I forgave them (Elder 2, 90s).

This story is extremely important because it comes from a very respected elder and he guides the younger generations to learn many lessons through the details in the story. His boarding school experience was nearly 80 years prior to the telling of the story, he has analyzed and shares the ways in which he experienced his childhood. He was close to his mother and she resisted sending him as long as she could and the ways in which the government forced his parents to take him to school, how heartbreaking and divisive these actions were, leaving all them carrying anger, sadness, confusion and loss at the fragmentation of their family. These experiences were traumatic and forever imprinted their lives. He has come to terms with these feelings and gained insights and is able to forgive his parents and used the schooling to support his later endeavors. He recognizes the sacrifices he and his family made and that by surviving the experience he was strong and able to carry on to nearly 100 years old.

For another elder in the same age cohort, she was not discovered by the education officials until she was 13.

I was cripple from when I was a child and they didn't take care of me right among my people. They don't care. So I got worse and I couldn't hardly walk sometimes so it just healed kind of funny so - but it was alright. I can walk on it. Just the best way I can do it. And they make me work so hard. And so I work, work, work all the time and then I went to school. A woman came along and she made me clothes - for me. Dresses and underclothes, that woman did. She was a white woman. She sewed them. And she said that I have to go to school and so that people don't say nothing. My people. So she took me and sent me to boarding school. So I was 13 years old and I was in the first grade (she laughs). (Inaudible because of laughter] whole bunch of them. But I was always telling them things to make them laugh, the kids you know. So gee, I got along with them so good. And then I just went as far as 4th grade. And then I was old enough to work now. Real hard, you know. So I even chopped wood and go after water, you know, even though I was kind of crippled a little bit. But then I work hard so Grandma made me stay home and take care of the little ones. My mother had a whole bunch of them now (Elder 5, 94)

It was imperative for her to go to school, however, her health and physical well-being seemed to be a low priority for school and for the white woman helping her with clothing. Also evident is that she sacrificed her own education for the greater good of her family, despite her physical limitations worked hard physically for her family. The feelings of abandonment by the tribe and the adults around her in regard to her physical health are palpable, so many years later.

For others, the start to school was less dramatic and more uneventful. They would walk or ride their horses to school.

We had to go about a mile and half down out here in the country. And then, I guess it was about two miles. And then my, I was the oldest one. So my dad used to take me to school every day on a horse. Sometimes it would almost hit, he would throw me behind him and I would really hang on. Sometimes that horse would be, wanted to buck and everything. Oh sometimes, sometimes I got a little bucks sitting in the back there. He would reach back and hang on to me and then uh, the next summer, I mean year, yeah the next year my brother started so then we got, he got us our horses so we rode horseback. Ooooh, it would used to be so cold on your legs right here (points to thighs) riding horseback. He had his horse and I had mine. That's how we used to go to school. There's Catholic school up here from the 1st grade to the 8th grade and my dad thought it was pretty cold for me. So he sent me up to Catholic school [Holy Rosary Mission].

I: How was that?

E: It was...I liked it. It was, we had our own dorm, we had a dormitory, we ate and all that. I went up there until I graduated there 8th grade. And in the mean time we stayed up there all week and on the weekends my dad would go after me (Elder 1, 85)

The elders who attended school in their district school or at the Mission school, they related a fairly uneventful experience. Few stories emerged about their younger educational years.

Challenges appeared in the form of disagreements with other children, lack of money to go on to high school, no motivation to attend school, moving away with family, getting married at a young age, loss of a parent or sibling, and grief.

Younger elders experienced boarding school in both similar and different ways than the older elders. They highlight how the divisiveness has permeated the ways in which the children interacted with one another and the violence that ensued.

I: Who is [name]?

E: That's my brother. He lives in Kyle. He's kind of extroverted in a lot of ways and he had a speech impediment. We called it tongue tied back then. He was a bed wetter and he got beat for that. It was a lot of abuse in the boarding schools.

I: The kids abused each other too right?

E: Well we learned how. Yeah, the pecking order. The gangs in school too. I worked through a lot of issues as I got older. I probably started about 25 years ago, through therapy and stuff. A lot of people have not worked though they're still carrying around. (Elder 21)

Working through the feelings and traumatic experiences of boarding school is something that is desperately needed, healing is an important aspect of becoming healthy. At another point in our conversation he mentioned the dynamics that arose between the Lakota speakers and the non-Lakota speaking children at boarding school. For the children that stayed in school and did not quit they bonded and supported each other.

...When [Elder 12] went to school he didn't speak English. I met a few of those guys, [Family name], [Family name], and [Family name] and when they came to school they didn't speak English. I sat with them and communicate with them. I became real close to them and they got made fun of but you know we survived (Elder 21, 63).

The oldest elders seemed to take work ethic and the discipline as a positive element of attending boarding school and the notion of any physical or sexual abuse was baffling.

They might have whipped them or spanked but I never did hear that that was going on in the schools at OCS and they couldn't be in the Catholic schools because the nuns never leave you. You don't dare do anything wrong or they spank you. I and I've had cousins that have gone to OCS up here until they graduated and I never did hear that. I know they gave them whippings and spankings and punishments like that to do something like that I never did hear that and if they did something like that they would have said something. And that that must have happened before our time, maybe. Cause they were more rebellious. I think the full bloods the Indians that they had to put in the school. They probably wouldn't mind - won't do nothing, and that's why they did that. I never did hear. In my time I never did hear that. I kind of don't know, best about six, cause you know how kids get to talking we would have heard it from some of them, never did hear that.

I: That's good to know.

E: I really don't think it. Maybe isolated case but I doubt it. Cause I've had a lot of relatives go to OCS and graduated from there and I'm around them all the time and I never did hear it. I never did.

I: That's good to know.

E: I'm sure somebody that I knew and was close to that it would have come out and I never, never did. I know they didn't like their matrons for spanking them but not like that. (Elder 6)

The experiences and resulting trauma of the boarding school experience is widely documented by many scholars, however, it was important to situate the elders in their own life experiences and views on their education and experiences in the schools. The impact of the boarding and regular schools in the district varies by age cohort and the personal toll of these situations will be discussed further in later chapters.

One elder in particular had an unusual upbringing compared to the rest of the elders in this study, in that she was raised in a tuberculosis sanitarium for many years, where her family did not visit her. Her story is of particular importance because of the high prevalence of tuberculosis in Native people. Also, her story shows how the pressures on the families and the effects of poverty and strain of having a child more than a hundred miles away and trying to provide for their other children at home. Also, the traumatic affects on Lakota culture and families begin to show in the elders' families. Despite this she was connected to her aunt and

uncle and learned some traditional ways and culture, showing how the extended family helps to raise the children. As a result, she did not attend formal schooling like many of the other children her age. She is not connected to her siblings in the same ways, thus showing how sickness, treatment methods, and far away location of treatment further fragmented families. She was born at home, birthed by her mother and grandmother because their family home was so remote that this was the only alternative. Her family moved to Pine Ridge and she opted not to move, she explains,

E: I came and moved out here with my uncle. I didn't like them.

I: How was that?

E: Good 'cause I learned a lot from his wife. She taught me how to make moccasins, to do quillwork, and all that stuff, to make *bapa* and all that stuff when I was 5, 5 years old. She taught me *allll* of that. We used to laugh. We used to sit outside and she taught me all of that stuff. That's how I learned.

I: How long did you live with them?

E: Geez until I was...when I was 5. I didn't know I had tuberculosis and I grew up in the Sioux San⁶ until I was 20. I didn't even come back. So, I think when I was 4, I think I had that but they didn't find out until I was 5 and I was really sick then. I knew I had fevers and I was cold and I sleep a lot.

I: What is Sioux San?

E: It's a hospital.

I: You grew up in a hospital?

E: They didn't even come back.

I: And then you left when you were 20?

E: I came back when I was 20 years old.

I: Did you see your family?

E: Huh uh. They never even came up. That's why I don't hardly know them. I don't know my sisters or brothers. I just know their names.

I: How many are there?

E: There's 13.

I: 13 kids and you are the oldest?

E: Second to the oldest. So yeah, there are 13 and out of there I am the only one that got sick. I was born at home and they said maybe in those days I might have caught it from my grandma, that's how my grandma died after she raised me. I've been around her and she died with that in 1949. She died of tuberculosis. No other problems except that. They said she was healthy but then she I think she had that that time. So I caught it.

I: So in 49 you were 6, she pry struggled with it like you did, huh? So you speak Lakota, so there were other Indians in Sioux San?

E: Just a few nurses

I: So they spoke Lakota with you?

E: Yep

⁶ Sioux San is a shortened and often used term for Sioux Sanitarium in Rapid City, South Dakota, currently an IHS hospital/health clinic.

I: Were they good to you?

E: Yeah! Mm mhmm.

I: I can't imagine this! This is the most unusual story I've heard. So you grew up in a hospital?

E: With tuberculosis.

I: Did you go to school?

E: Nope, I didn't go to school. I learned how to just read through pictures and I learned how to sew from one of the nurses. A couple of the nurses they taught me how to sew the pillow cases and the pillows and make little blankets and stuff like that. There was no school in those days. No school. Not in that hospital anyway.

I: So you were really sick and you just laid in bed.

E: Mm hmm. Take medicine and take shots.

I: And you grew from birth to 5 you spoke Lakota at home and then continued until you went up there.

E: it was mixed, I didn't know what they were saying though the nurse, one of the nurses I think she's still alive. [Nurse's name]. I think she's still alive I think she might be 80 or 90 years old. She was the one that helped me with everything. She brought books and taught me through books. (Elder 16, 66)

This elder may not be the only elder who has a unique upbringing, this was a very interesting life story from the others that were shared in this study. She grew up to have her own children and family and the amazing kindness shared by the nurse to teach her to read impacted her in positive ways. On one visit with this elder, she received a letter from the hospital related to some tests she had – she was unable to decipher the medical jargon and understand what the letter was trying to tell her, frustrating her but in light of the way in which she learned to read, she has overcome many challenges.

Part II. Actual Present: Struggles in Adulthood

Many of the elders receive support from the food assistance program, operated by the federal Food and Nutrition Service under the Department of Agriculture, widely known on the reservation as 'commodities,' or 'commods' where individuals and families meet a certain criteria and then are able to pick up food from the commodity sites located in Pine Ridge and Wanblee. Some manipulation to meet the criteria is often essential to survival and maximizing the benefits.

I: Do you get commods?

E: Yeah but commods, I just got them yesterday but um...my grandson and he used to stay here and he stays with her auntie in rapid but he's still under me so we count as two and we get two packages of hamburger.

I: Cheese?

E: The gold. Its good the warehouse is in Wanblee. We used to have to go all the way to Pine Ridge. I'm diabetic so I can't really eat what they give out. (Elder 22)

Later she shared seeing another elder frequently at the commodity warehouse where they commiserate about the quality of the food

... I see her with her daughter when I went to get my commods they were both sitting there. She said, 'I'm diabetic and they don't give us nothing.' (Elder 22)

Some elders struggle with chronic diseases and limited income creating some tension with the dependency on and dissatisfaction with the commodities. They compare the food to the abundance of good vegetables they were able to eat when they could maintain a garden of their own, or how they ate when they were children. The lack of these vegetables and the large amounts of processed foods given in the commods leaves them at a loss for managing their illnesses in a resource poor environment. The invasion of the government food which differs dramatically from traditional Lakota foods has contributed to unhealthy diets and exacerbates chronic diseases, especially diabetes and heart disease.

In addition, they struggle with meeting other needs like rent, electrical and heating bills and food is often last on the list.

I: How do you survive on \$150/month?

E: I don't. I want to have a roof over my head, I want to be warm and I want to eat. Whatever so I have to put propane in there. That's how I ended up with no food. That's how I ended up dependent on commods and the doctor told me, he said, "You are not eating well. You aren't eating well because you are losing weight and all your chemical tested - protein is low" and my sugar is very low. Because he said, "You aren't eating." I said, "I know my lights were shut off and my food spoiled and I didn't get my commods."

And he said, "that commods ain't going to do you any good because that's just like generic and maybe old stuff that they might be giving you but they just change the label." So he said, "I want you to eat a lot of meat."

And I said, "they don't give us that much." I wished they did. (E16)

There are conflicting feelings and perceptions about the commodities and what they provide and what they should include.

I: Do you eat a lot of vegetables?

E: No, not really. I used to when I lived out in the country but I don't because they are too high here, the store here. I don't, I eat a lot of canned vegetables but not the fresh. I don't get to eat the fresh vegetables very much. I get to eat canned vegetables. Cause, see we get commodities and they give us canned vegetables.

I: You get commods?

E: Yeah

I: Do you like the food?

E: Oh yeah. It's good.

I: I heard the meat is sometimes just ok.

E: Well we don't get much meat. We might just get a little bitty roast or we used to get frozen chicken but they don't give that to us anymore or we get like...not so much beef just a little bitty beef maybe like 2,3 pounds of fresh beef but we use that up right away. We get a lot of ham. Yeah. Ham, you know. Yeah that's about all. Ham and chicken and beef.

I: Do you get fruit in the summer?

E: Not fresh fruit.

I: Oh.

E: Well we get apples and oranges!

I: And pears? I saw someone with pears.

E: You know if there is just one in your family then they won't give us fresh vegetables. They'll have corn and cucumbers and if there is only one in your family then they ain't going to give us that. They give us potatoes and onions...that's all we get and we get apples and oranges and we don't get all that sweet corn in the summer they don't give it to us because there is only one of you. I argue with them but I don't get [those] commodities. But they won't give us those nice fresh vegetables that they give the others get when there's a lot in the family.

I: Awww, well do you like all kinds of vegetables?

E: Yes I'd rather have corn, sweet corn because nobody - its so high down here that we can't buy it down here. Cabbage - [the program] gets all kinds of nice fresh vegetables and they won't give it to us - just the potatoes and onions and a little bag with two carrots, two turnips and two onions. That's all the fresh vegetables we don't get all the good vegetables. (silence) (Elder 6)

A general narrative around the reservation is dissatisfaction with the food given in the commodities, while they may voice their dissatisfaction they also learn how to adapt and make the best of the food that is provided.

I get commods but a lot of them quit giving a lot of stuff out but I think it's the way they cook it. The way they handle it. Because a lot of that the canned meat isn't any good and I think it's the best because you rinse that fat out of it. If you take beef and can that beef - that's what we used to do over at Grandpa John's. He canned his beef and that's what helps keep it preserved and it has salt in there. You rinse it off with water put it in a colander and rinse it off, chop it up and whatever you are going to make - potpie or beef stew or if you are going to put some pork in the beans you just rinse it off. I don't really think it hurts anyone it's the way they take care of - they prepare their meal, I think. (Elder 10)

In order to obtain the commodities there are barriers, including transportation and they have to manage the pests that are carried in the boxes. These fears of pests impact the desire to get commodities for some elders.

I didn't know they came with commodities. I guess our commodity house at Pine Ridge is full of cockroaches so when you bring that stuff back they're all over it. I went and brought back some commodities - some lady was there. It's ok to take them to the hospital [in her role as a CHR⁷] and she said, "I need some commodities" and I said, "ok." I didn't even think about it. They got it from the warehouse and they should clean – do something with it but they just let it go. So, some are that big (shows with her fingers). I brought it back and it had cockroaches and I forgot all about it. I said, but they keep telling me if you get commodities keep it outside and don't bring it into your house. But I never did it before, I forgot all about it. Right away I had some. I had a hard time getting rid of them. (Elder 9)

Later in the conversation she shared,

I: So you don't have to get commods, right?

E: ...But I don't like the commodities. I like it but I'm scared of it. It's too much work there. They don't have cockroaches on them I'll take them but too much cockroaches and we have to fight with that all the time. Its hard to get rid of.

I: Do you feel like the food is good?

E: Some of them are, I really like those, uh, those powdered eggs. They're really good but I'm scared of it. On the count of those cockroaches. [Elder 7] had a whole bunch of them I wonder if she still has them. She always wants me to eat with her and I'm scared of those cockroaches, they climb all over you. They're not even scared of you they just start climbing all over you. That's what I don't like about it. (Elder 9)

Limited transportation is a great barrier for elders to obtain their commodities as they have to be picked up at certain times of the month from the sites. For two elders in Kyle who did not have cars and they suffer when they are unable to pick up their commodities as seen by the interaction with the doctor above. I picked up the commodities from Pine Ridge for one elder and it was physically arduous and the elders need help packing the food into the car and into their homes. The workers at the facility are helpful and I witnessed them helping some elders and other people struggling with the process.

I filled out the paperwork and called her so I could relay the selections she wanted on what kind of meat, what kind of cereal, etc. I grabbed a flat bed cart and went down the assembly line and picked up the goods, which they pack into boxes, pushed the cart to the car, loaded them, returned the cart and then drove to the elder's home, with a few trips carried the several heavy boxes of canned goods, canned meat, boxes of spaghetti and cereal into her house. (Fieldnotes)

⁷ Community Health Representative, shortened to CHR, a tribal paraprofessional working in the community.

For the other elder living in Kyle, she needed a new tribal identification card and wanted to pick up her commodities in Pine Ridge. She was nervous about taking the bus from Kyle to Pine Ridge.

I: If you go to Pine Ridge, how do you get there?

E: I hire somebody. But now there's a bus traveling. A transit bus and they could pay \$5 a ride, the white buses. I might ride in one of those buses. I have to get papers down there around tribal i.d. card and phone number. I may have to go down to pick up the phone numbers and the [commodities] and I don't know how things go. I'll try that tomorrow. I might, if I have money, I might ride the bus. (Elder 11)

She had never done it before and was worried once she was dropped off that she would get lost and was very unsure of the whole process. She had to get up very early to meet the bus at the pick-up site. I had spoken to her in the week leading up to the day she was going to try doing so.

I happened to be in Kyle visiting with [Elder 16] and we decided to visit with [Elder 11], so we headed over to her house. As we approached we saw the white bus in her driveway with the bus driver helping to carry her boxes. I ran over and intervened as [the elder] was attempting to lift a box of canned vegetables. She was happy to see us and I carried the boxes in and we thanked the bus driver for bringing her to her front door. After the boxes were secured on the kitchen table, the elders and I sat in the living room and visited. [Elder 11] shared the adventure of going on the bus. She was proud of herself and felt accomplished for negotiating all of the aspects that she had feared. She was happy that the bus drivers were helpful and accommodated her with the commodities. She said many times, "He's a nice man." (Fieldnotes)

The elders use different methods for accessing food resources. Some are unhappy with the commodities, others accept the commodities for what they are and they did not express any opinion in any direction regarding them. Some of the elders are able to maintain a garden, as aforementioned, one elder is struggling with arthritis, but her son helps her plow the garden. Other children share their resources with their mothers, stretching public assistance and commodities further to make sure the elders are eating and able to spend their money more wisely on affordable groceries and not just the local gas station/convenience store.

I: Where do you get food?

E: I always get it from Angels⁸ or if I have a ride, if I don't I have to catch a ride down to there. Angels is really high and so is the other one and that's why my son says to "Save your money and I'll take you to Rapid. Take you to Rapid and then you could buy your stuff there. Bread is on sale and the eggs and the hamburger- the meat." See my son gets food stamps over there too, him and his wife so whenever they could they bring me something. They bring me boiling meat or eggs, potatoes. She gets a lot of potatoes in

⁸ Angels is a gas station and small convenience store

commodities and she brings them and at least I have something to eat where sometimes I make a yeast bread and sell it. Like I make loaves out of them or something. (Elder 16)

The elders are their own greatest resource as often there are elders who are hubs of resources for their community or district. For the elders on the most limited income, others are aware of their struggles and are sure to share what they have; in this case an older elder helps a younger member of her community.

But [Elder 19, age 89] really helps me out she gives me food – beef stew and potatoes and onions. What she eats she sends me...yeah so that's what she does and she sends up she always asks me in Indian about my grandkids who are out here. I say, "yeah there are two out here "and she'll send down chips and soda for them (Elder 22)

Making bread is an important part of the meal and for living for the elders. Before [Elder 5] moved to the nursing home in Rapid City, she lived in Pine Ridge where she lamented leaving because in spite of health issues that threatened her ability to live alone, she argued that she works and that it gives her exercise.

E: I'm determined. Want to bake bread all the time. I used to bake bread all the time. And then I put them in paper sacks and then I take it to people down the hall. We live in an apartment in Pine Ridge...And then I tear a hole and then I hang it on the doorknobs, so early in the morning they have fresh bread to eat. They like it that way.

I:What kind of bread?

E: Yeast bread...Yeah. I had to get up early in the morning to do the, you know, fix it. [indiscernible] and then I make a sponge. And then real early in the morning, well then I put them in pans. I baked them. So it comes out just fresh. Nice and smell good in the house.

All of the elder women referenced bread and making bread, making sure that it is understood how important it is to make it at home and from scratch and that they carry these skills from their mothers and grandmothers.

Part III. The Challenges of Physical Health Care Across the Life Span

Home Births. Generally, for most people, the first interaction with a healthcare professional occurs at the time of birth. For many of the elders, they were birthed at home, by either a couple of ladies who were known midwives in their communities, or by their grandmothers, some, because they lived close to the hospital were born in what is now known as

“the old hospital” in Pine Ridge. Curious, about how the midwives traveled in the wintery weather, one elder in her 90s shared,

I: And when you were born they had midwives, didn't they?

E: Yeah. I remember there was one lady named Leona Winters. She goes all over.⁹ Delivered babies down in the countryside where she lives and she said there was one time, that it blizzard and still she had to deliver babies. You know cover over her, now she hold a blanket over like this [demonstrates over her head and shoulders] and then they have to - her and her daughter, then went to this lady's place. Follow each other. She said that was *really* the hardest walk she ever did. The snow was so deep.

I: She didn't have a horse?

E: No. Just walk. (Elder 5)

One elder shared a story of her sibling being born, while she was telling me about her youngest child's birth. The midwives of the elders' time were able to use techniques that have changed in the advent of hospitals and professionalization of child birth.

E: She [her mother] was born in the Bombing Range before they moved them out. Most of them were born at home.

I: Yeah with midwives.

E: my Aunt Louise was really good at that. How come you couldn't get a chair so a person could sit up? They have you strapped to the bed and then they give you these things and when you are straight its like the babies get caught.

Aunt Louise would come outside when she was done and she'd get after us. We wanted to see. She'd cover the window but we could about that far [shows a gap] and we'd all pile up on the bench and try to peek in. She made them scrub the floor with lye and she'd take a real clean blanket she had in paper sacks – like and she'd put a real thick one on the floor and she'd have all her basins ready if she had to go or something. She'd turn the chair over and she'd have her hang on to the back legs and squat and that seems easier. (Elder 4)

This story is particularly compelling because it reflects not only the past but the present methods of child birth and the Indigenous knowledge that resulted in home births has been debased and undermined.

Western Medical Care. Johnson Holy Rock, one of the most respected elders on the reservation, offered insights for understanding the administration of health care on the reservation in the early years before the current Indian Health Service (IHS) hospital was built.

When I went to school this was bare hills, no buildings here, the only building was a little square, that little square big building at the end of, way at the west end of the old hospital, way over here, little square big building. That was the first hospital, the first

⁹ It should be noted that the Lakota elders often use the present tense when they are talking about situations in the past.

hospital. That didn't happen until oh..the 30s, the 20s and 30s something like that. They built that hospital, little square building - really it was just a clinic. People came from out in the country to be examined physically for different sickness but there was no place to have a hospital so they gave them medicine and sent them home – some survived many died. Following WWI, during the time I was born, there was terrible. It was the first time they were aware of something called the flu, flu, they died by the hundreds, thousand they died so fast that the, uh, they had to call for the lumber to be shipped in so they could make pine boxes, there were no caskets, people died too fast. (taps). That hill above where the high school is, there's a high point there, that hill was full of graves, just caskets upon caskets. They dug trenches on that hill and lined up the pine boxes as the people died. There was only one doctor for 4 counties. *ONE* doctor. And there was no place, no hospital. They were sick it was inevitable they died. *One doctor* would die trying to serve all the people – several thousand Indians. They died too fast for one doctor to try to keep them alive. When I was 7th or 8th grade we used to play up on that hill. I grew up in the boarding school and we found those pine boxes. So out of curiosity we took an iron bar and pried them open. There were skeletons in there. That whole hill was full of skeletons. They were people that died. That was when I first found out about that epidemic following WWI. Hundreds upon thousands died. *One doctor*. He probably died too. It's a terrible way to live. But we survived. I'm still here. Pushing the century mark – not going over it.

I had my share of sickness. I say there was only one doctor that served 4 counties – Shannon, Jackson, Sheridan, and Bennett, four counties.

I: Who paid for the doctor?

E: Only one doctor, one physician

I: Who paid him?

E: Bureau of Indian Affairs and that was required by treaty. In our treaty they promised us healthcare. One physician. So it didn't, it didn't go from place to place. People had to come in. Most of them didn't have competition so he had it made. They were just [indiscernible] if there was surgery there was none. (Elder 2, 90s)

The Oglala Lakota tribe has a treaty with the United States government that stipulates that the healthcare of the people would be provided. There were efforts in that there was a small clinic and only one doctor. As shown, there were great efforts to root out the children and enforce them going to school, yet the health and health care was not a priority. Obviously, enforcing the children's attendance to schools was one of the major assimilation strategies of the 20th century.

Chronic Diseases. When asked about chronic diseases, the elders shared their current conditions they experience while emphasizing the fact that the treatment regimens, the ability to get to the clinic to see a physician, to understand what the medical professionals prescribe are more arduous than living with the disease. Their reaction is significant because it reveals how one learns to be a patient which differs greatly from the ways traditional Lakota medicine healed.

Living with chronic disease often requires medicine and often assistance from others in order to fully adhere to the treatment regime. As one elder related:

Oh I am diabetic for two months now. They gave me some pills and I went like this [gestures] and was hollering around and [her son who lives with her] came and helped me out and I was alright and I went to clinic and they told me not to get the pills so they gave three little small pills but those others ones made me, I'm scared of those pills and I told them I'm not going to get it. But I'm alright. (Elder 7)

The confusing regimen is often combined with poor treatment decisions. One elder was struggling to follow the treatments but the side effects created life altering consequences. Fortunately, she had access to a health care professional who could eliminate the mismanagement of her treatments.

E: I'm diabetic so I can't really eat what they give out. [commodities]

I: Do you have anything else?

E: Heart – high blood pressure.

I: Pills?

E: Yeah, last year I was getting 14 pills a day and I was on insulin. This doctor who comes from Denver said he read the chart and he was really upset and said maybe that's what made me this way the way I am. I lose my appetite. He was really - so so he took the insulin out and here I feel a lot better and here I was getting all those pills, the insulin and about this time of day I'd be sleeping and then I'd get up and really lonesome and then I'd have a hard time sleeping in the bed. He took me off of it and its better. Yeah. (Elder 22)

The physicians at the IHS hospital change often and are usually non-Native people and the motivation for practicing is for loan reimbursement. After they serve their time, they leave. There are other physicians like this one who visit and consult at various intervals, leaving the elders to interact without continuity and are unable to build a relationship with one physician over time.

Transportation is a major issue for the elders, especially those with chronic diseases and limited familial support. Frustration and fear of worsening the conditions is felt by both the health care providers and the elders themselves. The community health representatives (CHRs) and the public health nurses often make house calls but as this elder attests, they may not always show up when they are supposed to, leaving the elders without care.

...Screws to keep my leg that's why I have this problem. The doctor thinks that might go in the bones. He said, you are bone on bone now and its dangerous and you might have to lose your leg but he said that we'll try to fix it. We'll try I don't know if we'll be able to or not. But we'll try. That's why its important that I got this years ago. That's why with

no help I had to keep postponing and canceling that and he's really angry. Dr. Morris. "You need to get that done or else you aren't going to be able to walk and then you will be in a wheelchair" but he told me its going to my hip now. It's in my hip. Yep.

Sometimes when I do things it hurts me and I have to lay down and take my pill right away and lay down and lay down oh it just really pains. It really hurts. That's why I ask for all this help through the state because the tribe can't even come out here and the CHR doesn't even come up here. She's supposed to be coming up here every 2 week to take my blood pressure and report it and she doesn't even do that. So when I go down and then they ask me. Dr. Morris asks me if she came up there and take your blood pressure? Do you have your paper? I said, "No she didn't. she's supposed to come up early in the morning and before she gets off work about 3 o'clock and she knows and she don't want to do it. And maybe she reports that she's coming up here and doing all this for me and getting paid and not doing it – anything."

So, now like, like when the lights went off I had to catch a ride to use my nebulizer. Yep. Because I use that 4 times a day and I use that [points], its underneath the table and when I didn't have that oh geez! That was hard. My throat started to get what do you call it? I was getting dizzy and light headed and I didn't have any oxygen in my brain. Yep, so I caught a ride down there and I called my cousin and she said, "I'm not doing anything I'll take you right away" cause I called an ambulance and it didn't even come. Didn't even come! So she came and took me and she got really mad down there. She said, "She called the ambulance and nobody came and picked her up! She's having a hard time breathing!" So they put me on the nebulizer for awhile then they gave me a spray and that spray don't really, I don't think its really working for me.

I: So you got out when you were 20 went swimming and got polio and then what happened?

E: Up to that I developed a spinal meningitis because of the polio I almost died I got in the spine really bad and I couldn't open my eyes because it was going up to my head.
(Elder 6)

Often these illnesses accumulate over their life course, often having experienced them when they were much younger and with formal health resources more limited than they are currently. All of the elders experience at least one chronic disease and several of them manage more than chronic disease. It is easy to see with this elder how the resources are close to where she lives but so far away for her to access easily. The ambulance, the CHR and other home services are not delivered to a vulnerable elder is left to her own devices as she relies on family members to help her reach health interventions. The conditions are easily exacerbated by the intertwining of the lack of good nutrition, transportation, limited income and isolation from the health professionals.

Diabetes. It is widely known that diabetes is experienced by a disproportionate number of Native people. So much so, one elder uses diabetes as her yard stick for measuring health.

I guess I'm always thankful because on the reservation there are so many diabetics you know and I'm not a diabetic so I'm thankful for that.

Later she mentioned it again,

I: Well it seems like your health has been good.

E: Yeah I, I would think that I'm healthy because I'm not a diabetic [chuckles] So, I would hate to be a diabetic. Pry if I did I wouldn't live this long (Elder 6, 94).

All of the elders have been impacted by diabetes, whether in their own health experiences or through their family members. As evidenced earlier, many of the elders have strong opinions about diabetes. It does seem to evoke strong feelings. Sometimes, I would hear, "it is not just an Indian disease" or "We're not the only ones that have it" when I was in the senior centers around the reservation. Some elders who have been diagnosed with diabetes, they resist the notion that it is a disease.

See I didn't believe in diabetes. I didn't know what it was and then all of a sudden I had it. Even the way I grew up not eating junk food and all that stuff. They said it comes from there but no it don't. It's a disease that will kill. Nobody knows where it came from. Too much worries start costing us diabetes. It's a little sack in here and it fills up and it explodes in your body – that's where it comes from that's where cancer comes from. It's not the food. It's not. They're not eating right. You could eat all you want. Don't tell them we don't have to do that. We eat soup and we're healthy. (Elder 16)

For others, it is not something they worry about, they manage it and take it as a fact of life.

E: I don't eat too much anymore. I don't hardly eat meat. At my age just soft food. Diabetic so I really watch myself.

I: You are a diabetic?

E: Mmm hmmm

I: How long have you been a diabetic?

E: Since uh...let's see 2000, no 1999 or 1998 or something like that. I was alright when I was working as a CHR. Never was sick but after I retired about three days- years later I got sick and here I had high blood pressure. But sometimes my sugar goes down to 9- or 80 and then it really makes me sick. If I can keep it up over 100 but that's hard to do. (Elder 9)

For another elder, she had a hard time accepting the lifestyle change after being diagnosed with diabetes.

And then I had this diabetes next, of all things. And I kept fainting and I fell down 2 times, and I hurt my arms. So doctor said that, "You shouldn't live alone. You're doing things alone, that's why you keep overworked and that you keep falling down." Well I said, "Yeah, but then I can't do that you know. I can work and that gives me exercise." I'm determined. Want to bake bread all the time. I used to bake bread all the time. And

then I put them in paper sacks and then I take it to people down the hall. We live in an apartment in Pine Ridge. (Elder 5, 90s)

Many of the elders experienced diabetes and the others were very aware of the possibility of being diagnosed with it. For some, there was little they could do to impact their eating as they are presented with foods that negatively impact their health like in the commodities, but also in the feasts and other events where the elders are served food, there are often sugary beverages and always cake with frosting. This combined with their beliefs about diabetes and how it affects their lives makes living with diabetes very difficult.

Parkinsons. One elder in her 90s had recently had eye surgery for glaucoma, but otherwise she did not grapple with chronic disease, but recently had started to develop Parkinson's disease.

I didn't have arthritis at all a year ago. I fractured my hip and I was in Rapid in rehab and in hospital rehab but it didn't bother me. It didn't bother me. I don't know, no, I don't have diabetes she says my blood pressure is normal and my heart is good. I don't have anything else wrong with me. Every now and then I get a pain in my knee or leg kinda hurts sometimes.

I: Is it scary to think you might have Parkinsons?

E: That I'm getting it? Yeah, I am. It worries me 'cause we had about not so much as me but my nephew is a Jesuit priest in [a town in SD] that's what he got, that's what he got. He had to quit saying mass and he couldn't say mass and he couldn't stand up he can't stand up so his brothers they manufactured – they figured out some kind of lift that lifts him up because it's his legs and that's what going to get bad on me is my legs. It lifts him up so if he can get stood up cause you got no strength in your legs and you can stand up then it moves him. So that's the only one that I heard about that it affected his legs so he couldn't say mass no more so he lives, the last time my nephew goes over there – he lives in Rapid too, he goes and visits him every week with food he can fix quickly. I know of him that his legs gave out on him and that's what's going to give out on me, is my legs. So...and I find myself with that you know, I can't write some things, some days. I can't sign my name some days.

I: My friend's dad has it and he shakes like this [I demonstrate with my arms].

E: Mine do too. And sometimes I'm worse and I try to pick up a cup of coffee and they just flop around and some days I'm not so bad. So that's the only worse thing that happening to me.

The elders are very resilient and as they face these chronic diseases they always insist that they were "alright." They do have fears about how these diseases impact their independence.

Arthritis. Broadly, arthritis affects Native American people at higher rates. Many of the elders in this study have arthritis and suffer with the aches and pains, often impacting their

ability to live as actively as they would like. The limitations are difficult to accept and for the family to accommodate.

E: On the other side of the house we plant, my son, [Name] he digs that up for me every year rakes it out and everything. I think he does it to keep me busy. He wants me active. He don't want me to sit down.

I: What do you think about that?

E: I told him [Name] I don't think I can do it this year because my ankles and knees and back, I said, I have arthritis in my back and when I bend over just a little while it really gets to me. I said I don't think I can. He said, well I'm going to carry on. [chuckles].

My back is..that arthritis is gonna begin to bother me now. The doctor started giving me medicine for arthritis and I said, "Oh I don't need that." He said, "You are going to before long." It's right between my shoulder blades, in my spine. Oh it would just pain me one day, and I just touched where the point was hurting and it was right in the middle of my, about 5 inches into the middle of my spine.

This elder visits a childhood friend who has suffered from arthritis since she was young.

Ever since she was a little girl she has arthritis. Her fingers are just crooked and her ankles and her feet are just crooked. She had a knee replacement. They had to do surgery on some of her hands because they were just curling under her and she's really in bad shape. She's having trouble with her neck now. They said that its coming apart from her spine in the back of her head. It's not kind of lopsided like that her spine and the back of her neck. She's really suffering right now but they sent her to Minneapolis to test her and they said that they fixed her. She's in good shape but it's just this arthritis that got the best of her. Ever since she was little like 13 years old she's had problems.

While her friend is deformed from arthritis it is compelling that she notes her friend is in *good shape*, because there are other aspects to health that this elder takes into consideration, also that having one disease or condition does not spoil the rest of what they value in other people, like their company, their families, their shared experiences, their lack of other illnesses. They use this in determining their own health as well. They are "alright" because they are still able to contribute in other ways. The physical health is only one aspect of their lives.

Heart Attacks. The elders have shared harrowing stories of heart attacks and heart disease and how they manage that in a limited resource environment while also juggling family responsibilities, which often includes caring for grandchildren.

Three years ago,I was at Regional Hospital [in Rapid City] for a heart attack - at that time I was keeping all my grandkids. They took me to the – I walked to the clinic in December!

I called down there and they said "No CHR."

They always say that. So I said, "Oh well" so I tried to cross in front of the courthouse and close to the clinic in side yard.

There is a plum tree right there. ...here I got feelings to go lay down like that [gestures with hands]. But again it looks like somebody told me not to. I was all by myself! But it's like someone said "Keep walking, walking, walking to clinic."

One of those girls who bring those books - that thing that says you've already seen the doctor. She seen me, "[Elder's name]! What going on? What happened?"

I really looked at her "I'm really sick."

She just went like that [motions with her hand for others to come over here] and they're all running and they brought a wheelchair. And that Doctor, Dr....uh, Dr. Reeser, a lady. She checked me and she went and checked my hands and she went somehow and come up to me. [She was worried about her grandkids and refused to be sent to Rapid City]"I'm not going to go and I still have some kids in bed. It's so early."

"I'm going to send the unit out. Until you leave this clinic, I want the unit to go and wake them up and tell the kids that you are at the clinic, that you had a heart attack"

And sooner or later they said, "I'm out here now. "

"Wake them up."

He probably knocked and waked them up. I told them to [tell the children to] look for their clothes and thick jacket or whatever and I'm going to take care of the door and windows.

"Stand right there and listen to me and do what I tell you. Check the area at all times and take the kids to the other grandma" – my oldest daughter, she's a grandma too.

There are variations on this elder's story of walking through the snow to the clinic, as another elder related to me that she almost made it to the clinic and was laying in the snow and the man who clears the walkway found her and was able to get help. It impacted several elders in the community because they use this story as an example of how strong the elders are and how the CHR or other help was unavailable to transport her to the clinic. Also, the workers at the clinic were aware that her primary concern was her grandchildren above and beyond her own health and so the clinic sent someone to assist the children so this elder woman could begin to focus on herself.

For Johnson Holy Rock, we were talking about deaths and preparing for death when he told me a story of his first heart attack and how he changed some unhealthy behaviors as a result.

I: Are you afraid to die?

E: No. Nooo, I was almost there back in uh...let's see...winter of...19....49. soon after I came back from the service I got a few head of cattle. I wanted to be independent. I wanted to be somebody so I got a few head of cattle and I began to raise them. I worked hard day and night. Winter summer I worked my hand to the bone. One winter in '49, just soon after the winter of '49 there was a terrible blizzard. Snow was roof high houses were covered, snow was so deep horses couldn't travel they just sink in it. Snow 10 to 15 feet deep. Houses like these were buried. It was terrible. I'd hear the wind roaring in the night. Oh, those poor livestock. I borrowed money to pay for them and if they all die I still have

to pay for it. Uuuugh. Surprise of surprises, I didn't lose a hoof. I don't know why. I didn't lose one.

The year, two years following that '49 there was another real bad winter and I had my pasture, had my cattle pastured in another pasture so I had to haul my feed over there to feed 'em, and uh I had an old truck - flat bad and I'd haul, pile my bails on there and drive over there and unload my bails and feed 'em. Right in the middle of it. The wind was blowing. The wind chill factor was about 20 below. But I was dressed pretty low and I didn't mind. I put the truck in creeper gear, set the wheels straight and it started to crawl along by itself. I left the motor running. I crawled onto the back and started to throw feed out. Those poor cattle were starving and they were scared. The wind was really bad. All of a sudden my breath shut off. (demonstrates) No air. It was like somebody put a hood over my head. No air. Uh, I couldn't draw no air. I just let myself go, I fell over backwards. The wind was blowing, the cattle were hollering, the truck was moving, and I couldn't do anything. I was frozen. But I didn't panic that was the crazy part of it (we laugh). I felt everything but I wasn't scared. Talked to myself I wonder if this is a way a person died, tested for air, no air. I wasn't breathing. I thought *well its time*. All of a sudden the truck the front wheel, uh, bumped against the frozen ground or something. Anyway, higher than the wheel and killed the motor. All that, while I didn't breathe. I just let what little air in my lungs, uh, fluctuate in my lungs, my breath I didn't fight it. But I didn't move or fight for it. I let my energy lay dormant. All of a sudden this truck stopped moving. Killed the motor. And all of a sudden my body started to heat up like I was sitting next to a wood stove burning about 200 degrees. My body began to heat up and sweat began to roll down my face so I tested the air, drew in some air [demonstrates breathing]. Ahh, it's good to pull in some air. I wiggled my hands and I could move them. I sat up, the wind was blowing, snow was falling, cattle was still milling around the truck stalled. I stood up then all of a sudden I broke out in a sweat, sweat run down my face inside my jacket. It was just pouring out of me. But I didn't mind that. I was still worried about the cattle. I crawled back into the cab and turned the switch on again, got the motor started again and moved it in a different direction, more level, put it in creeper gear, started to move, I crawled back into the flat bed, cut the twine and started to kick the hay out. Went about couple hundred yards and I fed them out. I crawled back in and drove home. I breathed normally. My heart was beating. That's the closest I came, closest I came. I was so close yet something intervened, what? I don't know. I got another chance so went on home and I didn't tell my wife.

[She said,] "hey, we began to worry!"

No. "I just got through feeding and I just came home." I didn't want to come home and get them scared. So I didn't say anything but the next morning and the next morning I could smell bacon frying, uh, something else boiling on the stove. I got up and got dressed and, uh, started for the other room and all of a sudden I staggered and almost fell against the wall. *Oh that's funny. That's alright.*

So I start to walk again. My wife heard the noise and she rushed in "What's happening?" "I don't know. I'm on a cheap drunk. Someone slipped something in my last coffee last night. Oh well I'll get over it"

So I started to walk and I staggered and she steadied me. "After I eat I'll be alright" so, I eat breakfast and start to go out and check the cattle.

“You’re going to the hospital”

“Who is?”

“*You* are.”

“No I’m not.”

“Yes you are. There’s something wrong with you.”

So she drove me to Gordon and an old country doctor, I used to go to. Walked in. “yep you’re up early today. What’s wrong?”

So I told him.

“Oooh I could tell that”

“You mean you know?”

“Pretty close.” He put that little round listening device on. “Yeah, had a heart attack didn’t you?”

“Is that what it was?”

“Yeah. Damn near took you? How’d it happen?”

So then I told him.

“Yeah it could have been worse. But tell me this do you smoke?”

“Yeah”

“How much?”

“About 5 packs a day.”

“FIVE packs a day. You’ll have to cut out that nonsense. How do you feel otherwise?”

“Mmm, ok.”

“Yeah. You’re going to have to quit NOW. Not tomorrow, next day, next week, NOW.”

I thought just before that I had a birthday so everybody gave me a carton of cigarettes. I had 10 cartons. Oh beautiful stacks of cigarettes. “I think, uh, I’ve got ten cartons, Doc.”

“Well if you want to throw your life away. That’s your business. If you want to get rid of yourself fine. I’m not going to argue with you. I’m just telling you, you gotta quit (taps). If you don’t I might have to put you in the hospital OR better yet I might read about you in the obituary column.”

“That bad?”

“That bad.”

“Ok, I’ll think about it Doc. Ok.”

“I’m just telling you its your life if you want to throw it away that’s your business.”

I came home and that night I couldn’t sleep. I tossed and I turned. Oh...I couldn’t hardly sleep. Next morning I ran a little laundry in town, Pine Ridge. So, I took my wife to work and I run the laundry while I worked out in the hills.

“I took all those carton of cigarettes and anybody wants cigarettes give it to ‘em. Don’t sell it, give it away, just get rid of it.”

She said, “all of it?”

“Yeah.”

She couldn’t believe it. So all that day anybody who wanted cigarettes she gave away pack after pack after pack, got rid of it. To this day I haven’t touched a cigarette. I guess I wanted to live [we both laugh].

I: You were a young man when that happened? How old were you?

E: When that happened? Let's see....must have been about, uh.... About 40, 35, 40. I just quit. I guess it was just I just wanted to test myself see if I had it. I had it. I just like shutting off a faucet. To this day I haven't touched a cigarette. I guess that's why I'm, uh, my heart. I've had three heart attacks, two after that first one. Three of them. But I survived them. They weren't bad ones. I think its because I quit smoking so that made me 100% believe it. When I see the other guys stand outside and smoke I saw myself, "yeah that's what you looked like. Now aren't you glad you quit?" [laughs]. I'm 92 going 93 now. That's quite a stretch of time [laughs] (taps, taps). I've lived a full life and uh...

This story sheds light on so many aspects of experiencing a heart attack and this elder's value system and view of the world. These include: the adverse weather conditions, the importance of caring for the cattle, the desire to be somebody, the personal pride, his work ethic, the desire to protect his family from worry, the power of his wife to force him to care for his health, the distance to the doctor, his relationship with his doctor, the iron solid resolve to quit smoking, his resilience in facing 3 heart attacks and making it to his 90s. He had a great sense of humor throughout and was never afraid, and admitted his own surprise at that. The easy manner in which he tells a story with the colorful details is a window into the traditional ways of telling stories.

Similarly, other elders have experienced heart attacks, heart murmurs and high blood pressure. They report these conditions almost as an afterthought and without much concern. They adhere to their treatments and recommendations as much as they can or are able. Often they are chastised for their food choices but many of them have limited transportation and access to the food they want to eat is hard to find on the reservation. The long for the food they had when they were younger, the fresh vegetables grown by their own hands, the fruits harvested around the reservation, and the livestock and men who hunted so they could have meat for the winter.

In summary, this chapter articulated the physical health of Lakota elders, taking their narratives through their childhood, adulthood into old age. The elders shared stories of their lives, their childhoods of surviving in their familial plots of land by gathering and raising their own fruits, vegetables and livestock. Some families tried to eke out a living by being a ranch hand or farm worker for the white landowners near the reservation. In spite of the inherent hardship during their childhood, their narratives were positive because they had agency over their own lives. Yet Lakota families were irrevocably changed when the American government forced them onto reservation lands, forced the children to attend boarding school where they

were culturally oppressed, experiencing violence and loss of agency. This adversity and ensuing fragmentation emerged as a collective trauma that may not have physically harmed them, but certainly negatively impacted their mental and spiritual health. Their ensuing adulthood experience was further negatively shaped as they were faced with limited formalized healthcare and government food programs that were not based on traditional Lakota diets, or foods that contribute to a healthy lifestyle. As a consequence, the Lakota elders are struggling with chronic diseases in a context where the medical treatments are complicated and their access to healthcare difficult. The next chapter moves from the physical to the mental as the Lakota recount what happened to their mental health as a consequence of their life experiences.

Chapter Four

The Mind, Mental Well Being and Lakota Elders

Unlike mainstream American definitions of health, health for the Lakota people does not solely comprise the physical body; it instead includes the combined health of the physical body, the mind and the spirit. The three empirical chapters of this dissertation thereby articulate each of these three components that comprise the health of Lakota elders. In this chapter, I focus on the lived experiences of Lakota older adults in relation to a component of well-being that goes beyond the American focus on the physical health of the body: the well-being of the mind. Even though this component seems similar to the American conception of mental health, I argue that the boundaries of the Lakota mental well being expand beyond the mental health of Lakota elders as individuals; they also encompass the mental well-being of their families and also their communities. As such, Lakota elders' mental well-being is predicated on their Lakota consciousness, but it also entails the white consciousness regarding mental health that has been forced upon them. As a consequence, not only do the Lakota elders draw upon their traditional methods of healing, but they may utilize the counseling services that are made available to them in their communities by the IHS.

The chapter focuses specifically on the life course of the Lakota elders from the perspective of the mind across three generations; first the elders' own childhood experiences, then the experiences of their children, and finally the experiences of their grandchildren. It becomes evident that the experiences of all three generations are marked by escalating fragmentation and displacement, a process that in some cases can lead the grandchildren to violence. Yet, since many grandchildren are raised by their Lakota elder grandparents, some of the grandchildren are also healed by traditional Lakota practices.

Elders often raise grandchildren; provide financial support and housing to their younger children and grandchildren. The well being of the next generation is always on the mind of the elders as they worry for the children in the community, while the reservation is a large geographical place, they are very connected and when news of the death or harm to a child is

known, they feel the mental stress and weight of these tragedies. These interactions with their grandchildren build upon the Lakota elders' own lived experiences of the boarding school, loss of their parents, grandmothers, siblings and spouses, and their often traumatic connections with their own children. The elders often draw upon the Lakota life ways in negotiating the mental stress such fragmentation inflicts on them.

Part I. Lakota Elders' Childhood Experiences and their Mental Well-Being

During the interviews, the elders opened small windows into their own lives, to their families, schooling and marriages that revealed the manner in which their own experiences were so often wrought with emotional trauma, grief, loss and abuse. It should be noted, however, that I did not directly question the elders about these emotional situations; instead, they volunteered them while narrating their own life stories. This manner of narration reveals even more clearly the extent to which the elders' childhoods were woven with emotional grief, a grief that was never mourned, acknowledged, and therefore was never healed.

Many stories of emotional grief centered around two events, the trauma of going to school and the trauma of encountering illnesses and deaths in their immediate families. It is significant to emphasize that the first trauma was inflicted by the punitive measures of the federal government that intentionally separated the children physically from their families for extended periods in the name of providing them with an education. Even though the children did receive an education, the emotional cost and trauma they experienced has never been formally addressed and acknowledged. As a consequence, their mental well being was severely compromised due to this schooling experience. In addition, the illnesses and deaths the elders frequently experienced in their immediate families were also due to accidents and the severe lack of health care and resources on the reservation. Hence, these too were a consequence of federal policy, one that has not been acknowledged either. The frequent loss of immediate family members once again fragmented the lives of the elders, inflicting emotional trauma on them when they were merely children.

School. The educational experiences of the elders were traumatic due to the intersection of a number of factors. First, their traditional lifestyle was being undermined by capitalism, making it difficult for them to economically sustain their communal way of life. Second, the

U.S. government made it mandatory for the children to attend school. Since the distances within the reservation were vast and the infrastructure undeveloped, it was impossible for many elders to attend school from home so they had to go to boarding schools for extended periods. Third, even when they came home, they often encountered illness and death in the family due to lack of healthcare which disrupted their lives as they chose to care for their family at the expense of their education. Fourth, many adult members of their family were forced to leave and find work elsewhere, further fragmenting the children's education. The stories below discuss these adversities in detail.

Many of the elders come from very large families, so the family resources were often stretched very thin across all of the members of the family. Sometimes, the families lacked the financial and social support to attend school beyond the sixth or eighth grade. As a consequence, since there was no state support either, they ended up leaving school with only a few years education. One elder noted the following:

I¹: Where'd you go to school?

E²: Loneman [in Oglala]. Remember few, oh wait now, where we live about five miles, six miles out of there; you go down that hill, there's a big building and stuff out there; that's where I go to school and graduated eighth grade there.

I: You didn't go to high school?

E: I was going to, but you see, but nobody would help me pay my tuition and everything. 'Cause my grandma was there, but she didn't get that much money, and my dad, he has to pay the rent, gas, lights and everything. So he didn't have enough to do that for me. So I just went as far as half of ninth grade. If he helps me out like that, I could have made ninth, tenth, eleventh, twelfth. After my grandma died and they couldn't help with the tuition, so I said I might as well not go to school anymore. (Elder 3, 69)

Some elders in the study felt abandoned by their families, even when they were living with them. This elder was not able to continue her education, and she was dependent on her grandmother for financial and emotional support within her large family. Along with the loss of opportunity to continue her education, she also lost her mother and grandmother. In addition, the economic pressure on individual families to provide for their sustenance also eroded over time: the traditional life ways were steadily being marginalized due to the escalating force of capitalism and the need for procuring cash to support the family. As a consequence, the families became increasingly strained as they were living in a place where such job opportunities were incredibly

¹ I is the interviewer

² E is the elder being interviewed

limited. They could no longer sustain their communal system of living, and in order to survive, they had to relocate which ended up fragmenting the family, as adults traveled elsewhere, often leaving the children behind.

Some of the elders' families were fractured as the children were sent away from the reservation for schooling. They moved away from the reservation during their school age years. One elder noted the following:

I: Now you went to a country school? Was it like the one room school house?

E: One room school house.

I: How was that?

E: That was good; we didn't know anything different. We get there at nine o'clock and get leave at four. We never stayed any later than four and I went and then when I graduated eighth grade from the country school, I went to Pierre Indian School for two years. It's a government school and we stayed there Christmas, Thanksgiving and we never did come home. We never did. Anybody the employees or workers, *ever* tried to do anything out of the way and we were ninth graders and we went over there to Pierre Indian school. But our matrons, they were women and they took care of us. (Elder 6, 94).

The children who were sent away from the reservation for their education did not return home during the year, thereby losing the connection to their family for a full nine months. The emotional impact of missing their loved ones for so long at such a young age is usually minimized by the elders as they are often 70 or more years away from that time in their lives. The oldest elders tend to focus on the positive aspects of the experience and not relating too much of the negative aspects.

Others experienced the death of their mother, a remarriage, the birth of a sibling, causing them to leave the Mission school³, and attend their local day school, or to move in with an aunt in another state. Some quit and married young. As a consequence, the education of the elders was adversely interrupted by traumatic events beyond their control. In all, their lives and families were increasingly fragmented, especially as the official demands for their schooling intersected with the harsh realities of their lives. One elder stated:

And then I went to Holy Rosary Mission, for what? Kindergarten , One, two, three, four, five years; my mother died when I was six years old and um, so then my dad then all the - they used to come after all the Indian kids, you know, and they would take it to Mission or our folks took us and we went to school from September to Christmas. We never went home or nothing; we just stayed there and then we had two weeks vacation during

³ The elders refer to the Mission school colloquially. The official name was the Holy Rosary Mission and it served both elementary and high school grades.

Christmas and then we went back January 1st, and we stayed there until school was out. So I went there five years, kindergarten to first, second, third, fourth grade and then my dad remarried so I went and stayed with them, 'cause I had a little sister and I'd take her when her mother went to stuff at the school - a lot of times she would have to stay and stuff. So then I would watch her, so I stayed there. That was in Kyle, so went to Kyle [for] fourth, fifth, sixth, seventh and then um, I went and stayed with my Aunt and Grandma. And by the way, she was like eighty, eighty some; she lived until she was ninety, ninety-nine. Died. Yeah. So a lot of times, I would stay with them most of the time and um, then, then we went to a day school called Pourier school when I stayed with my Grandma and Aunt. Then I went to Nevada; that's where my dad and them moved, so I went down with them. And then, like my two brothers, oldest brothers, they stayed with uh, wait now...[Nickname], they called him, I think his real name is [Name] if I remember, so he kept those two boys during the summer and, like, they did help him do farm work and hay and work around the house because he didn't have no children, so he kept those two boys. So I had a little sister who stayed with Aunt [name], the one who owned the store. Then [two sisters' names], they were the oldest, so they stayed with dad most of the time, Dad and Aunt [Name]. Aunt [Name] was dad's sister, and she kept [brother], so then I and [another sister] went with my dad, and so I stayed over there. I went, when I went to Pourier school. I, uh, graduated the eighth grade there and then when I was after that, I went with dad and them, and then ninth, tenth, wait now, I went to school to high school ninth and tenth in Nevada. Then I came back and I wouldn't go back and I had spent eleventh and twelfth at Holy Rosary Mission where I first started [we chuckle] and then we just um, I guess we'd all get together at Christmas with dad, grandma, and my stepmother and we'd have Thanksgiving and stuff, but we wasn't really raised too much together (Elder 4)

Sharing the trajectory of her schooling years makes the changes and lack of stability in the elder's life apparent. The siblings were living with various relatives and the immediate family was moving away and then back to the reservation. The flow of the story itself reveals the disorder and the life of change the elder grew up in. Interestingly, the elder managed to remain connected to her family. Even though they were often apart, the elder was able to identify where all the siblings were living, when, and also where everyone went to school. The elder also shared wonderful stories of her father and siblings of their home life during the summers when they were finally together. So schooling kept children away from their families, but the elders not only cherished the summers and the time they were together, but sustained such pleasant memories to counteract the traumatic times they experienced the rest of the time. This coping mechanism may have helped enable the elders to retain enough mental well being to continue living their lives.

Among the traumatic school memories, some elders noted that when they got to school, there was a deep divide between the full bloods and the half breeds, a term elders use to describe

Indian people who had families with both Indian and white parents and family. Several elders described this dynamic which led to one of two outcomes; some quit while others persevered and finished high school. This emotional trauma reveals the power inequality between the Lakota and white consciousness: the latter was backed, supported by the federal government through laws and as a consequence gradually undermined the Lakota consciousness, leaving the children even with less emotional and spiritual resources to negotiate their schooling. When they encountered bullying at school, there was limited intervention by the school administration. One elderly noted the following:

I: Where did you go to high school?

E: I didn't go to high school; I went to the ninth grade and quit.

I: How come you quit?

E: I didn't get along with the people where I was going, and I got into fights; for me, it was a mixed blood group at OCS. I went to ninth grade and there was about five of them in the gang, and I got mad and quit. (Elder 6, 77)

Some elders experienced such disruptions during their childhood that they were unable to focus entirely on their education. They often left school in order to help their families. One elder grew up in Wanblee, that is the community on the reservation furthest from Pine Ridge, roughly 100 miles away, described as the "tail end" of the reservation. After noting that her parents had her later in their lives, she said:

I guess my mom had me when she was fifty-two years old...when I turned to be a teenager, my folks were old. *Old*. So I more or less took care of them, my mom and dad, when I was a teenager and we had to haul water to a spring so I do that every evening to make sure we had water and we had a good stove – wood stove and we would cook on the stove, but yeah I had to take care of them when I turned into a teenager. That's what I did in my teenage life. (Elder 22, 64).

It became more stressful for this particular elder as her parents' health declined rapidly. When she was thirteen years' old, her mother got sick and they "sent her someplace and cancer and they took things out of her breasts, but she healed" (Elder 22). Until the eighth grade, she attended the local day school, and afterward, she had to go to Pine Ridge to OCS⁴:

After I finished the eighth grade, I had to go [to boarding school]. It was the law then. You had to go. I couldn't even concentrate on my school work, and constantly worry about my mom and dad. So I went two years, and then that's where I met my kids' dad and he used to come and help and bring us wood, and he was a man, and so I got married when I was fifteen years old.

⁴ OCS is the shortened term for Oglala Community School located in Pine Ridge, which was the boarding school with both elementary and high school.

This particular elder cared for her elderly parents when she was young, sacrificing her own education for their betterment, thus once again living by her Lakota values, and doing so in a much more resource poor area of the reservation. It should be noted that the elder cared for her parents due to the lack of formal health care resources, other than families taking care of each other there were no respite or care giving assistance available. She noted that straddling the pressures of the modern life on the reservation and Lakota values was not difficult for her. Yet, the impact of her lack of education coupled with the financial instability she experienced was emotionally draining after her husband passed and she was unable to adequately provide for herself and her family. Still, her experience reveals the significance of the family to the Lakota people, and the sacrifices one makes to shoulder family responsibilities before all else, including one's own individual betterment.

The youngest elder in the study experienced several challenges that were layered over time, creating a very difficult childhood that left lasting emotional affects on him. He stated:

E: I grew up in two places: in Batesland in the summer and boarding school in the winter, fall, winter, and spring. I went to the boarding school as soon as I turned six, soon as I turned six, and I graduated when I was eighteen. Now one year, I was in San Jose, California, my sophomore year. I stayed with a friend of a family after my mother died when I was fifteen and then I came back and finished my junior and senior year. My dad was a farm laborer; earlier on, he owned his own ranch and something happened with the tribe and they had to sell the cattle. They took all our cattle and sold it. Never reimbursed him, so after that, he went to work as a laborer – a farm laborer and the rest of, all the rest of us went to work in ranches. Early in life, I drove tractors and worked on a ranch.

Yeah. That's where, that's where a lot of my problems started when I went to boarding school when I went they, they didn't want us to speak our language, and we were ostracized for speaking our language. They basically put us in a Marine boot camp when I was six years old. I'd have to stand up and fix my bed in the morning and stand at attention and, uh, march us to the dining room, march us back, cut our hair off, made us all dress the same, and uh, a lot of fights.

I: Amongst the kids.

E: Amongst the kids; sometime, it was encouraged by the staff

I: Really?

E: Yeah. A lot of you can't express yourself. It was like a little prison or boot camp and I shut down and on top of that, everything I read when I was at that boarding school listed us as savages – the history books. Yeah. So I had *an identity crisis* there early on. At the boarding school, you are only served three meals a day; if you miss, you will have to starve until the next time. There were two hundred boys in that dormitory.

I: All ages?

E: All ages, from six to, the first group was from six to about eleven, that's the first group; the next group was from eleven to fifteen, they were the ones that fifteen to

sixteen; the others were the seniors, the older boys. We had four dormitories growing up. We had a, at one time, there were eight of us [siblings] going to the boarding school at the same time.

I: Well, how come you went to boarding school?

E: Well, there was no roads out to our place, and not even to Batesland which is just ten miles down to the road; it was out in the country and at that time it was mandated by the BIA and probably still is; as soon as you are six, you have to go to school or they'll put your parents in jail. That's why they sent us to the boarding school.

I: Was it scary?

E: Yeah, it many boys you don't know. There's a lot of bullies. There's a lot of gangs and then was a lot talking, a lot of name calling. A lot of misguided - just like when you go into penal institution the same rules apply. Early on, *I learned not to express my feelings. I learned to stuff everything for fear that I would be labeled as a sissy*, somebody that – you had to keep your rank, the pecking order. Anytime you throw people together, you have to have a pecking order. That's how it was. It was very confusing over the years. I didn't even know what I did wrong for all the name calling I got, and for being a full blood. *I didn't understand why it was bad, being a full blood. I didn't understand why it was bad to speak my language. Everything I was taught seemed like it was bad when I went to the boarding school. So there was a lot of fear involved and uh, a lot of...a lot of resentment. A lot of rage.* I just couldn't understand how some of these kids came from the cities and they were mean. They were gangs; they were the ones that ran in gangs. [There was] a very good possibility that you get hurt sometimes when those guys jump you. I learned to take care of myself through that. And then it was safe, we'd go home on the weekends sometimes and it was safe at home. Go back to my traditional ways; my grandma, mom and dad and that's what probably really helped us out. My family at least was the structure at home. All of us are full brothers and sisters and uh, and uh, we didn't have TV. We didn't have any electricity or running water. We had a wood stove and uh, there was ten of us in that log cabin. (Elder 12, 55)

Again, it is significant to note that the violence and the trauma this particular elder experienced at boarding school was counterbalanced by the knowledge and comfort of the home nearby.

Even though the home lacked the basic amenities, it nevertheless provided much needed emotional comfort and safety away from the violence at the boarding school. The same elder noted that his grandmother was a very important resource for culture and support; she lived on the same plot of land and interactions with her occurred regularly.

For some the elders who came from large families, it was a relief for their families to have some of the older kids away at school while they cared for the younger ones. Their familial resources had become increasingly limited so many of the parents had to go find work elsewhere. One elder shared that her family would drop her off at boarding school and then go on to Nebraska to work at the potato fields in order to earn enough money to support the family. For

some families, boarding school or the Mission school served as support for the children in lieu of parents being able to provide for their children when resources were particularly scarce.

The effects of boarding school on Native people have been documented by scholars and Indigenous people globally. In this study, the oldest elders seemed surprised at the notion that there were lasting negative effects from attending the boarding school. One elder noted:

E: Well, to me, like I said, I was born as a Lakota and my, my mother, my grandmother gave it to my mother and my mother gave it to me. They taught me who I am, so I'm strong in that, in believing in myself. Like I said, you can put the best of what they have and weave it with yours, and you'll make a good life and I did. Whatever the nuns taught me; I took the best of them and used it. There's a lot of things that have been talked about and I've often wondered the abuse and so forth you know; I was never abused.

I: You weren't.

E: Huh, uh, I did what I had to do. Work I had to do. Even darning socks, patching clothes running to the laundry and machines and so forth, I did what I had to do. I wonder where how some, you know, some come up with that. (R19, 89)

It is interesting to note that this particular elder drew upon her Lakota identity to select the best parts of his educational experience. Especially the oldest elders seemed to take the work ethic and the discipline they encountered at boarding schools as a positive outcome of attending boarding school and the notion of any physical or sexual abuse was baffling. Another elder remarked:

They might have whipped them or spanked, but I never did hear that. That, that was going on in the schools at OCS and they couldn't be [going on] in the Catholic schools because the nuns never leave you. You don't dare do anything wrong or they spank you. I and I've had cousins that have gone to OCS up here until they graduated, and I never did hear that. I know they gave them whippings and spankings and punishments like that to do something like that, I never did hear that and if they did something like that, they would have said something. And that, that must have happened before our time maybe. 'Cause they were more rebellious, I think, the full bloods, the Indians that they had to put in the school. They probably wouldn't mind - won't do nothing, and that's why they did that. I never did hear. In my time I never did hear that. (R6)

The negative effects of the boarding school varied across the elders, with the younger elders offering more insight into the lasting effects of their school experiences. Later, the elders share explanations for the cause of the generational differences contributing to the mental and spiritual strain of the boarding school on their lives.

Deaths and Illnesses in the Immediate Family. Some elders shared their experiences with illness and how their families helped remedy them through traditional means as there was

no modern healthcare readily available on the reservation. Johnson Holy Rock, one of the most respected elders on the reservation, mentioned that the families that lived further away from Pine Ridge had to travel into the clinic. As they were often unable to do so, they tended to handle the doctoring themselves. Many elders experienced deaths of a sibling or parent when they were very young as a result of disease or lack of medical attention. One elder narrated the trauma of loss of a sibling as follows:

E: Yeah, we lost one. I lost my little brother. He was three and a half when he died of, um bronchitis.

I: He died of bronchitis?

E: Bronchitis.

I: Were there doctors then? When you got sick, what did you do?

E: Our parents, um, doctored us, themselves. They had some of the darndest remedies, but we always lived. (chuckles)

I: Do you remember any of them?

E: There was onions; they would boil onions for cough syrup and they'd put sugar in that, in the juice, and they would use that for, um, cough syrup, and...oh it was onions; then there was the onion part after they would drain the juice out of it to make cough medicine, and then they would put..what did they use anyway? Some kind of an oil, they used on us. It was real soothing. Gee, I can't remember it though. ...Skunk, did you ever hear of a skunk? They would kill the skunk, and they would roast the skunk, and they would take, drain the oil off. They used to use that for real bad coughs when, for like for pneumonia like, they used that, that way. And I can't think of any other remedies they used to use. I know there was a lot of onions used. And a lot of, um...I know it was sheep...something they used and fixed into a like a Vicks, and they used that on our chest but I can't remember. (pause to think). I don't remember.

I: Did the remedies work?

E: Oh yes.

I: Did they taste terrible?

E: Oh gosh, they tasted terrible. But they put sugar with the onion syrup, so that was ok. The other ones. They used to buy Vicks –oh that's what! Vicks! That's what they made that padding with for your chest. Vicks, uh huh, that was Vicks that they used, but they used that, sheep's oil also. Can't remember what they used that for now. And uh...they used sage for stomach aches; boil the sage and then you drink the juice and use that for stomach aches. There was another one, too. Oh, I know what that uh sheep oil was poison ivy and they used to use it. One time I got poison ivy on my face, and they used that; boiled that and they made like a Vicks-like grease and everyday they'd put that on my face, wash it and then clean it and then put that Vicks over it. I mean that oil. They called it wool oil, or something like that. That's what they called it, called that. That's what they usually used for medicines, mmmm hmmm. And it worked, and I never did have to go to the doctor unless you had...I had appendix and I went to the doctor for that. (Elder 1)

The elder also shared that she had her tonsils removed and was able to enjoy a treat of ice cream. So it seems that the parents would take their children to the clinic for medical interventions if the

illness was serious. Otherwise, they would often remedy them at home. Two elders also shared that their grandmothers would take a look at the health issue presented, and then go into the creek or the trees and search for a root that they would turn into medicine. The elders fondly remember these herbal and natural medicines. Unfortunately, neither the ingredients nor the preparation was passed down to these elders in this study, thereby silencing yet another Lakota tradition. Still, having experienced these remedies and knowing about the traditional ways of Lakota healing connected the elders to their culture and to Indigenous life ways. Such experiences with homeopathic medicine provided the elders with a sense of comfort, with feelings of emotional and spiritual support and nurture. One elder recounted:

E: But I said grandma used to go, and one time I kept telling her I had a toothache, but she looked and couldn't see nothing, so one day we went walking I swore. I'd say, "Grandma, I'm sick; my tooth hurts really bad."

She said, "I'm looking for a weed."

I said, "Pick any kind of weed."

She said, "You can't. It won't work."

We went and went, and finally got what she wanted, brought it back, and she washed it. She was peeling this stuff.

I said, "You ain't going to have any weed left if you keep peeling."

She said, "I have to get down to the root."

Finally, she washed it again, then she cut it up just so far up that weed, and then she put it in this pot and boiled it, and she made me drink about that much [shows 2 inches between her finger and thumb]. Here I laid down and went to sleep and got up, and here I didn't have [any more tooth pain], here it was my ear! I had an earache because we went to the doctor - every now and then he'd come, like once a month, and he said, "uh, what did you do? You really have - it showed little scars, I guess... "In her ear," he said.

So she said, "Oh, I fixed her [with] medicine."

He said, "You people and your medicine"

She said, "Well, we're not sick, are we?"

We never did have colds. Maybe because we were away from people, just the ones that we knew that came around.

I: You were self contained.

E: Yeah, um hmmm, and um, I remember in the winter time too, she would stand all of us before we ate too and it was called skunk oil. Don't ask me how it was made, but every morning, she gave us a big old tablespoon of that. I was always the last one; they'd have to fight me to take, and I don't know, I didn't just take it because I had to take it anyway. But I don't ever remember ever having colds or like that stuff. But I used to think probably because we aren't around, you know, all the, like, in the city, like, how you are all together and there's a lot you don't know and stuff like that. She used to fix our sores and everything. (Elder 4)

That this elder's grandmother was chastised by the western medical doctor demonstrated the negative attitudes the Lakota people encountered when they revealed that they were using their traditional medicine to remedy sickness. These negative attitudes coupled with the eventual ease of purchasing medicine at the store or acquiring it at the clinic have unfortunately led to the decline of these traditional Lakota methods of healing. Another elder related the use of what would be deemed herbal medicine, or alternative medicine, by today's medical standards. She stated:

I: Hmm... So when you were little, did your family, if you got a cold, did they have remedies for that?

E: Yes. Vick's Mentholatums! [laughs]

I: You didn't use skunk oil?

E: No, not really. Not unless we had sore throat. Well, then, uh, they might have some jar of skunk oil. And then they give you spoonful, almost spoonful, then the rest they put sugar in it. And then they give it to you and tell you to swallow it real slowly. They don't smell like skunk. The body part of the skunk smells bad. But it's the point, enit? (We laugh)

I: Were there other things they did if you got sick?

E: Yeah. Uh. Pine balls. Cedars. You break off a little bit and boil it, make a tea out of it. There's a lot of medicines. There's a lot that I know, but they're not- they don't use them any more. You just run to a clinic and get some aspirins, or Tylenols.

I: Do you think the old way's better, or the new way?

E: That's the new way.

I: But which one's better?

E: Well, new way is handy. There's medicine right there. (Long Pause)

I: Do you remember any of the other ones? The other remedies from the past?

L: Yeah.

I: Oh, can you tell me a few?

E: No. Well I uh, I can't explain it. Because green leaves are all green leaves. Only different sizes. Some, they use roots a lot. It's something in the roots that will cure you for a certain reason. (Elder 5)

Many elders and younger generations who remember their grandmothers going out to harvest a root or plants and leaves know what these looked like, but they are not able to name the plant or the method for extracting the medicine from the plant. Yet, it may be argued that the knowledge of the traditional Lakota way of healing is not completely lost; the elders may not have wanted to share this knowledge with me, but may have done so with their family members. Sometimes one member of the family studied with their grandmother or auntie to learn the traditional medicine and those elders did not participate in the study or did not disclose their knowledge with me about this.

The elders who attended boarding school often lived there from August to mid-December; they were able to visit home for two weeks before returning to school. While at school, the administration managed the health of the children. Only one elder briefly offered insight into what healthcare at the OCS boarding school was like and how it differed from when they were home during the summer months. He noted:

E: Usually the advisors put us in isolation and only took us to the hospital when absolutely had to. Lot of kids died them days.

I: If you got a cold, did you just tough it out?

E: Yup; sometimes the whole dorm was sick

I: Were there nurses?

E: No such thing as nurses, them days in our schools.

I: During the summer months, what did you do for your healthcare?

E: Grandma. Grandma was our doctor. (Elder 12, 55)

These windows into the elders' lives reveal that the grandmothers used their traditional medicine of gathering plants and natural ingredients as remedies to heal the children, often resisting the health care provided by the government in the form of a visiting physician or nurse. Instead, the grandmothers chose to rely upon the medicine that had sustained them for centuries. The elders comprise the first generation of Natives who had to really grapple with balancing the two systems, the traditional one practiced by their grandmothers on the one side and the modern one provided by the government on the other. As the Indian Health Service (IHS) was formed, more modern western medicine became available on the reservation. Elders indicate that modern mainstream medicine began to take hold, leading to the loss of the traditional Lakota ways of healing in individual homes. It is also important to note that the mainstream modern medicine does not serve Native people in the holistic way; the nurturing grandmother, the joint trips the grandmother and children took to collect the remedies from Nature, the attention paid to the children during the healing process did not, and currently does not exist in modern western medicine. So the loss of traditional healing also meant the loss of the emotional connection and nurture the children experienced. In addition, there were many barriers Native people experienced in receiving adequate modern western healthcare. The plant and animal based medicine had been readily available as it grew on the land where they were living. In addition, Lakota women were not only physical health practitioners; they were also spiritual health practitioners. As they practiced their traditional healing, they connected their grandchildren to their traditional medicine and therefore to the many generations who lived before them. Traditional medicine was thus a significant part of the Lakota identity. These women are fondly

remembered and revered. Women are a great loss to the Lakota ways of living and especially emotional healing.

Many of the elders also encountered frequent illnesses in their immediate families, illnesses that often descended upon them very rapidly, often ending in death. A case in point is the elder woman whose parents were older when she was born; she took care of her parents when they were challenged with health issues. The health issues that eventually robbed her of her family were often related to heart disease. Such losses created significant emotional trauma as many deaths occurred during short periods of time. She recounts how these losses suddenly emerged, causing her to literally run for help:

My mom likes to sew and here we were sitting – [I was sitting] beside her and looking at her and something happened, and here he was slumped over and I ran in town it was, that wasn't the road that time. When you leave from here, it goes up; it used to be straight down there and that school wasn't there then, and then I think, what did they call them? They are like CHR⁵, but it was another name. There was a colored woman that lived in town. It was on a Sunday, Fourth of July was on a Sunday that year. When I was running, I could see my dad lying on the ground face down. I told her, and I told her that my dad was old, but he was tall, but you better get help; my dad is a big man and here at that time the police had to come all the way from Pine Ridge [100 miles away] if anything happened; they had to come all the way from there. And here, somehow there was one in town and they came back, and my mom was sitting, and she was just crying, and he died then – a heart attack. I went to save him, and just ran in town. Almost 89 years old. And I lost my mom when she was 86. (Elder 22)

Heart disease also eventually robbed this elder of her husband. Still, it is clear that the available health resources changed somewhat over her lifetime. The ambulance services became more available in that area of the reservation. She continued:

E: ...he had high blood pressure and diabetes, heart trouble; he had seven bypasses on the heart right after our son died.

I: What do you think caused that?

E: They said stress. He didn't do; you are supposed let the bereavement [of the son go] and he held it. He had two heart attacks. One on Thanksgiving, and my son died September 28, and October, November [she counts with her fingers on the table], and he was going to go hunt. We lived housing at that time; after he retired, we lived in housing and that morning, he said he was going to go hunt.

“I'll be back about the time you'll be done cooking.”

My mom was still alive then, and here I was cooking, and he picked up my nephew and I was sitting here cooking, and my nephew just ran in and he said, “Auntie [her name] you better get the ambulance.”

⁵ CHR is the acronym for Community Health Representative, a tribal paraprofessional who worked in their communities, assisting with education, transportation and assistance with health matters.

I said, “What happened?”

“Uncle had a heart attack out there. He laid down for a while, and then he felt better and he came back in.”

I said, “Where is he?”

“He’s coming back in.”

In November time, the snow is bad and here he come in, holding his mouth; he sat down and put his head back.

“Call the ambulance or somebody” and he said he was going to have another one and his leg just went down and his head went back. About that time, my oldest daughter called the ambulance and they came. At that time, we had a station wagon. We always had station wagons. So me and my oldest daughter followed him, and they went Hisell road and they got him, and just as they were going to put him on the stretcher on the ambulance, he had another one. So he had three – one out there, one in here, and one at the hospital. So they stabilized him so he laid over there until he got well and they scheduled him for open heart surgery; he had to have a seven bypass and after that he went down. He always provided for us and it was really hard. I looked to him for anything and geez and [inaudible] after he died. He died June [date], 1993. (Elder 22)

The elders experienced a lot of losses. Other children, their mothers and fathers, grandmothers and even their own children died before their eyes. They had great difficulty dealing with the grief and loss and it is clear that the unresolved emotional grief has lead to other physical health complications like heart conditions and alcohol use, thereby further complicating the physical and mental well-being of the elders and their families. When recalling the deaths in their families, the elders cried during the interviews. Others were unable to talk to me about their losses – these sad events either too recent or they had coped with the losses by turning to the use of alcohol. A few elders were related to spiritual leaders in their community, but the emotional pain of their loss was so great that they relied, not on their spirituality, or other cultural methods to heal themselves but instead to drinking; they were therefore unable to share their stories. Such untreated emotional trauma reveals a major gap in the health resources available to elders and their families. These continuous emotional traumas that destroy their mental well-being need to be addressed by professionals. Since such services do not exist, many of the elders instead seek relief in substances that only further complicate their lives and health.

Part II. The Impact of Lakota Elders' Experiences of Raising Children on Their Mental Well Being

Perhaps the most significant generation that one could refer to as the 'lost generation' refers to the generation of the children of the elders. The elders experienced a life preceding the

violent, displacing intervention of federal regulations upon their lives through mandatory boarding school education. Hence the elders could remember and find emotional solace in what their traditional lives had once been like. Likewise, since the generation comprising the elders' grandchildren was raised by their elder grandparents, they were protected by their grandparents and therefore they too could find emotional solace in the stories their grandparents told regarding a peaceful, uninterrupted past. Yet the immediate children of the elders bore the consequences of the emotional trauma of the federal government's interruption in their lives: no longer able to survive in their traditional ways of life, not knowing how to be parents, many of these children had to move away from home, looking for menial jobs in the market in order to support themselves and their children. This financial burden prevented them from seeking a decent education on the one side and from making enough to take care of themselves and their children on the other. What they made was often just enough for their own sustenance; this financial stress combined with the emotional and cultural trauma drove many to alcohol and substance abuse. In addition, many had to leave their children to the foster care of the state or the care of their parents. This forced abandonment of their own children negatively impacted their mental state even more. The narratives below reveal the emotional trauma many suffered.

Some mothers turned over their children to the grandparents for reasons other than their own issues related to substance abuse or gambling: instead, they were attempting to give their children the opportunity to better themselves with higher education and employment away from the reservation. As one elder recounted:

The grandchildren don't want to ride horses. The ones that I raised are - I've got a daughter that is, she's the sixth one of our children and she joined the service but she was married. She got married and then her husband got killed in a car accident. So she came back and she asked me to take her kids. So then she said, "Please take them. I enlisted in the army."

So I said, "What?"

"I enlisted in the army. Can you take care of my kids? That's all I ask. We'd have to go in to sign the papers and I'll turn them over to you."

That's what happened she turned her kids over to me and she's went into the service - she's still in the service so I raised her two kids - a boy and a girl. (Elder 10)

Later the same elder mentioned about her raising grandchildren and the difference between the generations as follows:

... I think the world is going too fast, and the generations are different, and a lot of them don't talk to their kids. They don't have time if they aren't working. They go to the

casino or to the bingos or they go drink, and I used to think, “Am I put on this earth to take care of kids while their mothers drink?” (Elder 4)

This insight reveals the reality of parenting on the reservation. It is well documented that Native American children are overrepresented in foster care; this fact is partially attributed to historical and cultural trauma, and modern traumatic events. As assimilation strategies have removed Native people from their culture and ways of living, the children are bearing the subsequent burden as the grandparents try to raise their grandchildren to the best of their ability.

The elders offered very little insight into their parenting practices or the conditions unto which they parented. They offered small windows into how they tried to eke out of living, multiple divorces, alcohol use of their own and their spouses. One elder provides insights into the many female headed homes and what impacted his views towards parenting as follows:

E: yeah, yeah. There’s a lot of widows around, you pry know that... yeah. There are lots of them. [clears throat]. Two of my sisters are widows and they were young widows – 40s. My mom was about 50 when my dad died. They weren’t together but they were still married. Life expectancy of men is really short.

I: How come?

E: A lot of it has to do with diet. A lot of it has to do with depression. Depression and alcoholism. Along with depression you are going to talk about diabetes and heart disease. Depression is brought on by loss of self-worth – early, when they are young.

I: Are you we talking about boys?

E: Right now yes, but it does work with women too because they become the bread winners early. They are the backbone of the family and the bread winners and yet nobody really recognizes that.

I: How do they lose their self-worth early?

E: There’s not there is no employment with no employment for us, very little, no life skills, it’s tough. I came right out of boarding school and had no parenting skills, no nothing. It’s what society wanted us to do and yet the culture was trying to when I was a little boy I watched my, my - when I went to boarding school I watched the little guys get beat up for talking Lakota –whipped [by] the matron and the boys advisors. The same thing pry happened on the girls’ dorm too... My dad wouldn’t teach us [Lakota language] because he was abused when he was little my grandpa said, “you don’t need to know that.” (Elder 21)

Later the same person continues by noting that he had children that he did not parent as a result of lifestyle choices that emerged from the negative effects of the boarding school on his family. Importantly, he notes the impact on the elders in helping to shape his confidence in his job as a tribal council member during the turmoil on the reservation in the 1970s, referred to as the second Wounded Knee, or the Wounded Knee incident. He notes:

They would encourage me – don't give up. That's what kept me going. They were in their eighties, seventies, eighties. They would see me on the street and corner me and talk to me. They always told me "Don't give up. We depend on you" and now they're all gone. I can look around and see the economy is better than it was when I was growing up and the only bad problem is the crime, bad drugs and crime, alcoholism. Even that can be taken care of. It's been a journey to get here. I didn't get to watch my kids everyday to grow up, I only saw them occasionally because of divorces and I kept the oldest one and I raised him and uh, hope I did a good enough job but I don't know. (Elder 21)

Another male elder struggled with alcoholism as he was trying to maintain a marriage, raise a daughter and attend school, which he shared that a man in his life recognized that he was intelligent and could further himself, beyond the meat packing plant they were working in. He continues:

I went a year and half but that drinking was just too much I had to drop out then my daughter's mom and I broke up and I went on a downward spiral and I ended up living on the streets in Denver. There's a thing that they always say in the program that I'm in you come on a moment of clarity at a moment in time and the creator will smile on you and I was standing on a street corner and we just got a jug of white port, that's a wine. Took a drink and I started throwing up and I was standing there and I was looking around and I said, "I'm tired I had pretty much been out on the streets since I was 18, I haven't done nothing and I was tired and I just want a better way." That same guy that talked me into going to [Name of School] came looking for me. Somebody was calling me from across the street, he adopted my daughter as his goddaughter, so we're pretty close, like a brother to me came looking for me and talked me into going to detox and, uh, from detox I went to a 90 day halfway house and I found out there's nothing wrong with me and I always thought there was something wrong with me and that uh, uh, so I have when there are good dedicated counselors they can save lives. [Name of friend] saved my life and this lady was the first time in my life that someone told me there was nothing wrong with me. At that time in my life, the perfectionist family that I had, all of the boarding school, everywhere I went there was something wrong with me and she's the first one that said there's nothing wrong with me. (Elder 12)

This elder began to heal and reconstruct his life from the damages from his family, the boarding school, and the effects on his self-esteem that led him down a self-destructive path, he continues:

When I found out there was nothing wrong with me and I could pretty much do what I wanted to do and that opened the flood gates for me and I could start looking people in the eye and the face and, um and that I had some goals in life that I had to take care of them, one of them was to find my daughter, be the father that I was supposed to be and the other was to get an education and turn my life around. And so for once in my life since I was - when grandma died I started listening to the elders and following directions again. So I went back to school and back when I was younger I could look at a book and tell you right word for word, remember it all when I went back to school I couldn't do that anymore. All the drinking took that out of me. I did learn one thing that not many people get second chances in life and I got mine. (Elder 12)

Fortunately, this elder was able to reconnect to his daughter and raised her as a single parent. The journey to a healthier mind and more solid mental well-being was arduous and affected many people in his life. The elders in this study share the challenges they faced and how at various times they were unable to parent. The elder women, as has been woven in their narratives throughout this dissertation, were often left to parent on their own. They often offer only brief descriptions of their husbands and causes of divorce as, “He drinks too much.” Most of the elder women in this study were single, many were widows. Given their lower levels of education and limited job opportunities, the financial and subsequent emotional burden was upon their shoulders. The strength of tenacity of these women should be lauded as exemplified by the following story from this elder woman as she strapped her infant child to her back and in the middle of winter set out to trek forty-five miles to Pine Ridge in hopes of obtaining a job at the moccasin factory. She managed to successfully acquire the job of sewing moccasins in her home.

I: Well, how much did you earn making moccasins?

R: Good money, like they paid by dozen, like how many dozen I made, that was probably like \$22 or whatever. There were baby moccasins and you had to keep everything neat it's a hard job.

She attended a training session and had to pass a test in order to make the moccasins in her home. The factory would drop off the materials and pick up the finished moccasins on scheduled intervals. The children would often help in order to maximize profits. She continues:

...So we laced moccasin. My kids helped me. My kids helped me cause they never went to go test, but after they seen me and helped to explain with the papers works, they it's really hard to tie at the end like this – its so fancy but I passed that too. I start at this corner and this way and side and make a knot. They're really cute - the baby moccasin. The moccasins belong to the baby and they're supposed to go to a foreign country. (Elder 11).

These elder women took jobs as cooks, did home services like cleaning and ironing, as CHRs and they struggled to raise their children and the elder women often chose to do it alone as one elder shares,

If I married anyone he would have to have a kind heart because I don't want my children cussed at or abused or I don't want to be abused anymore either. That's the way it was after he'd start drinking. (Elder 10)

Only very small windows were offered into the lives of the children of the elders and the conditions in which they were raised. These small insights demonstrate how the effects of the boarding school, family dysfunction and alcohol use led to these children abandoning their

children and the elders raising these grandchildren. The elder men who traced their journey to healthier mental and emotional well-being were directly related to the teachings of their elders, participation in Lakota ceremonies, and effective counseling services. The elders refrain from mentioning anything negative about their families or living conditions because families are sacred and they convey only the best aspects of their families and by focusing on the good they are able to sustain themselves and negotiate the hardships. There are also cultural mandates of generosity and helpfulness, families support one another and share resources despite any hardships in their families.

Part III. The Impact of Lakota Elders' Experiences of Raising Grandchildren on Their Mental Well Being

Given the trauma that the children of elders suffered trying to make a bare living, it is no accident that many of their children in turn ended up in the care of the elders. These grandchildren often had the care of grandparents that their own parents could not provide. Yet this condition also placed additional emotional burden on the elders. While the elders were able to uphold the values generated by the Lakota sacredness of the family by taking care of their grandchildren, doing so at an advanced age did also place additional emotional stress upon them.

It is therefore no accident that several of the elders live in multigenerational households and they either directly raise their grandchildren or provide financial and emotional support for them. One elder has spent her entire life raising children and grandchildren and continues to do so. She notes the following:

I: You raised your grandkids and your own kids; have you ever had a time when you didn't have kids in the home?

E: [shakes head no]

I: No. How do you feel about that?

E: It never did bother me. I mean and then I'd see other kid and I see them leaving their kids. We were just talking about that last night. He said, "How was my mom?" First time he ever mentioned her. It was a no-no with her. He'd just get so mad. He said, "How did you get me?"

Well your mother used to drink a lot and your dad went to Pierre, and he drove Dickie Hagan to one of those conventions, remember? He was gone three days. Here one day, I went to work early that morning, a nurse said, "They've got two of your grandkids up here." Some people that drink a lot and were walking around between the hospital and that trailer house, then that trailer house wasn't there. They had been froze to death if it wasn't for those dogs. Those stray dogs. There must have been a lot of them because their temperature was normal and it took them about a half hour to get them away from those

dogs. They growl and run at them and stuff so there was three of them and got their attention and these other two grabbed them and put them in their car. They were looking for cans and they called the cops too, but by the time the cops got there, they had gotten them away from the dogs. The cops took them to the hospital. Those dogs saved them because it was winter time. I could imagine. They were two little boys, and right away I thought, *Where's the third one?* They didn't find no third one. She has another one. They must have been 2 and 3 and he was what 2 months old? (Elder 4).

While many of the stories of parents raising grandchildren are not as harrowing as this one, many of the grandchildren are without their parents because parents often have to leave for employment, they are too young to be parents, or they are dealing with their own emotional and psychological issues related to mental illness, abuse, addiction, alcohol and substance abuse, grief and trauma. What is left behind are three generations that are struggling under the strain of the abandonment. While the grandparents are willing to assume the role of raising the children, the strain of the emotional weight is spread across three generations, often leaving the grandchildren carrying the accumulation of the intergenerational trauma.

Another elder woman comments on the raising of her own grandchildren and others who were doing the same as follows:

E: ...but my grandkids are always happy to see me. I raised three of them, no, four of them and they're still here, but they don't bother me that much. If they really need something then...

I: How come you raised four grandkids?

E: Their dad and mom were living in Chadron – no Rapid City, and my son was going to school to school of...[pause]

I: Mines?

E: No, the other one, the vocational training over there. So, he went there for three years. But his kids had to keep them over here; they had two, three kids over there and I got the bigger ones, so they could go to school over here. I kept the three oldest ones. After they came back, they didn't want to go back, so I just stayed with them until they graduated.

I: Do you think it's a good thing that grandparents raise grandkids?

E: I don't know; *everybody does it, it doesn't bother them*. It seems like they enjoy that. Once they are gone, and once they grow up, you can't enjoy them - look at me, I'm all by myself. But then, I don't want to babysit little ones anymore. I said, "I went through that a lot!" I love my grandchildren, but I can't raise them anymore. Oh, I buy clothes for them, you know. (Elder 9)

There does seem to be a point where most of the elder women mentioned that they were either no longer able to or desired to raise their young grandchildren. However, one elder woman did express the mutually beneficial relationship that may result from having family in the home.

I: It seems like a lot of grandparents raise their grandkids.

E: They are. I read in the AAA paper; it shows that the man is 98 and the woman is 95 and they have their little grandson is six years old and it says, "how old is too old?" to raise your grandchildren or your great grandchildren. As long as you can get around is how I feel. Children bring happiness. This other way, how could you be happy without a family? Because a lot of these people don't have anyone to go home to, like some there is no use to rush home; there is nothing there. (Elder 10)

The elders do seem to indicate that raising children is a large responsibility, taking a lot out of them. The difficulties associated with the raising of grandchildren impact their physical as well as their emotional well being.

The question regarding how old is too old to be raising grandchildren is compelling. There are a variety of views on this issue; still, regardless of the age boundary, the reality is that the distance between the generations is often hard to bridge. The elders did not directly discuss at length the challenges of raising grandchildren as they are content with the fact that the grandchildren end up staying in the family rather than foster care, and that they as grandmothers are helping in that process.

The elders did not address the impact on the grandchildren of being raised by grandparents instead of their parents; they also did not comment on how the presence of the grandchildren affected the elders' mental well-being. However, one of the elders did share a story of a confrontation she had with her grandson when she was much younger, more than 30 years ago:

...The only time you get punished if you are doing something out of the way and you don't listen. How else do you correct your child? That's why a lot of these kids are out of hand because they take up and they give; if you try to correct them, then they say, "I'll turn you in for child abuse." I know, because I raised my two grandkids and the boy became a teenager and got with other boys. He came back and demanded money which I didn't have, and he said, "That's my money you get" and I said, "Sure, and I gave you your share already," but I said, "I have to buy your food and for the house, so you've got your spending money already; I gave it to you." He said, "I'm going to turn you in for child abuse;" I said, "You do that, I'll turn you in for elderly abuse." I turned 55 and I got smart too. [laughs] After that, I didn't have a hard time with him because I told him that like he uses bad words and raised his hand to sock me, I guess. I grabbed him here and I threw him in the bed, and said, "Don't you ever raise your hand to me. I took you in and I raised you, and you treat me like this? I'll use a belt on you if you aren't careful." But after that, I didn't have no problems with him. (Elder 10)

This possibility of physical abuse increases when the grandchildren the elders raise get older. As the grandchildren are also frustrated, they project their violence to those closest to them, in this case his grandmother.

Given the high rates of substance abuse and alcohol consumption on the reservation, the overcrowded intergenerational homes can result in the elders being exposed to situations where their health and well being are in danger. Also, there are children with emotional, behavioral and developmental issues that result in more intense physical and emotional commitment on the part of the elders, which may be more than they are able to give.

Unfortunately, Native people have high rates of accidental deaths often leaving their children without parents. The elders have been there to pick up the pieces.

One daughter had a car wreck and died and this one [grandson, now 30] was eight months old and another one was five years old, and I raised both of them. Her mom was working at...uh...[inaudible] for I don't know how many years, but these two were raised by Social Security when I had them. Their mom was a jailer, and she had a car accident and died, and these two were getting Social Security and I raised them. (Elder 7)

Obviously, resources are limited and this elder was grateful for the financial assistance through Social Security, which enabled her to raise the grandchildren. The impact of raising grandchildren as a single elder woman could potentially cause a great deal of stress and strain on the elder depending on their physical health and vigor. Additionally, when deaths occur frequently, there are often limited resources for the funeral services and give-away ceremonies and gatherings. One elder lost a grandson and the financial strain of providing a "proper" service for him left her scrambling for funds and sacrificing her own money that was earmarked for groceries and utility bills.

The elders did not mention how they helped their grandchildren deal with the grief and loss of their parents. Several of them experienced losses of their mothers and grandmothers when they were children and continue to feel the loss. In one conversation, an elder cried heavily when sharing the story of the loss of her mother and grandmother; the unresolved grief and loss are still being carried by the elders more than fifty years after such traumatic events. The unresolved emotional issues remain and accumulate across the generations. There is thus a great need for mental health services that would address the unresolved grief and loss in this community, especially among older adults and that would also help the elders cope with their grandchildren's emotional health.

As elders end up supporting their grandchildren and sometimes even their great-grandchildren, those elders who were able to work in a career and therefore have retirement benefits do not enjoy these benefits in their old age, but instead fill the gaps for the younger generations and sacrifice their own material and mental wellbeing. As one elder stated:

E: I have to buy everything. I put my grandson through school. He just came back from Creighton and I help him. It's a big scholarship. Gates.

I: Bill Gates!

E: Yeah, the Bill Gates scholarship⁶.

I: They get a full ride?

E: No, they don't. They get their tuition and schooling, and their books and their room, but nothing for their personal things. Then nothing for washing, you know.

I: Transportation.

E: Yeah, getting from here to there.

I: So you help him with that?

E: I want him to be a doctor to go on. I told him I would help him to the end.

I: Who lives with you?

E: My granddaughter and her kids. The one little one, the college student, and another girl – she's a junior; she's getting ready to go into her senior year. She's the one that says she's going into the service.

I: How come she doesn't work?

E: I don't know. We wonder, and we wonder. (Sounds weary, talks low)

I: Do you ask them for help?

E: Uh, huh. They say the grandma is supposed to support them. She says that, "grandma is supposed to support them, that's what a grandma is for."

I: That's hard, enit?

E: It's very hard. I try to send him \$200 or \$250 every month. I got him this jeep to go to school in, I pay for it. (Elder 1)

This demonstrates the extent of the material strain the elders are willing to live under, sacrificing resources they need for their own material and mental well being. And in turn, this particular elder does not even feel appreciated for the sacrifices she makes. This case also demonstrates how the traditional Lakota life ways of respecting and caring for their elders have been reversed; this particular family thinks that the elder is supposed to provide and care for them when the grandchildren have the educational capital to at least support themselves, if not their elder. Yet the manner in which the Lakota elder sacrifices her material and mental well-being is also part of the Lakota life ways: the elders believe and invest in nurturing the generations that follow them and they will therefore sacrifice for the greater good of their family and community. They regard the accomplishments of the younger generations to be more important than their own

⁶ The Gates Foundation Millennium Scholarship

physical and mental well-being. They think that their grandchildren deserve the option of becoming a doctor, and the elders will do everything in their power to make the path to success easier and possible for the next generations as they did not have the opportunities their grandchildren are sometimes afforded.

The distance between the generations can be hard to bridge, both socially and emotionally. Since some of the grandchildren were intentionally or unintentionally abandoned, or they came from unstable, fragmented homes, they bring to their elder grandparents a large, unresolved set of emotional and mental issues that have not at all been addressed. One elder commented on her grandson, the baby from the earlier story that was found near the dumpster at the hospital, on how she sent him to treatment, not for substance abuse, but instead to help him work through his anger:

E: He really needs help. That anger is so bad in there, when he was in treatment. What he was there about three weeks, I'd say and I'd call him. It was a different sound of his voice and you could even feel it. It looked like he was free of something, and now it's getting back to that, and now you can hear the hatred.

I: Would he see a medicine person?

E: He goes with [her daughter] and he sweats and he feels different; you can see the way he walks and everything when he's angry, and stuff you can tell that too like, he's like he's someplace else. He's just really mixed up. Otherwise, when he's a good feeling, he's the best kid. I told that guy, his counselor that time. He said he's really doing good, but he's really going to need help because he's got that whatchum⁷ about his mother and it's all bound up in there. Its going to take really long time to get that out.

I: How old is he?

E: He's seventeen. I think we better get it out of there before. He gets mad and I think he could really kill someone and not know it. When I was going to Mission, that's how I was too. I was so angry and Ooh I just hated god everybody.

[cries] I know what he's going through, and I can't help him. Cause one time the priest, if I didn't get, I could kill somebody and I wouldn't even know it. [crying] (Elder 4)

The burning anger within the grandchild due to his abandonment by his mother thus not only sears him, but also creates a lot of mental anguish and anxiety for his elder grandmother. Thus bringing up her own feelings about the Catholic boarding school she attended as a child. When she was discussing her school years, she did not share these deeper feelings. She related and has great insight into the anger and frustration her grandson is carrying inside. And the resource-limited environment in the reservation leaves the elders and their grandchildren to desperately

⁷ This is a filler word that this elder in particular uses frequently, similar to whatchamacallit, or what do you call it?

struggle on their own to relieve the emotional weight of their stressful lives. Another elder observes that this is a community-wide issue where he shares:

E: The underlying things I saw here were depression, it underlying just about everybody has it. A lot of anger ...yeah, lots of anger its underlying and uh, economics are terrible. You have federal help here but it doesn't last long. The programs turn over every couple of years. There's no stability. Somehow we get on. (Elder 21)

The elders are resourceful in using both their Lakota ceremonies as well as seeking modern counseling services to negotiate emotional stress. Since the experiences of the grandchildren often bring to the fore the unresolved emotional trauma the elders experienced during their own childhoods, the elders are then emotionally weighed down by the grief of their own experiences as well as their feelings of helplessness at watching the traumatic experiences of their grandchildren. Also, it is important to note that the elders often raise more than one grandchild, so their mental strain can be doubled or tripled.

In addition, Lakota elders also mentally consider the younger generations living in their community as if the latter were their own grandchildren. As a consequence, their mental burden at witnessing the despair of the younger generation increases even more. The elders speak frequently about their varied experiences with these younger generations, often expressing the sentiment that they worry for them, and want the best for them. One elder woman recounted that when she is at the gas station; she will frequently see young children unsupervised who will always ask her, "Grandma, can you buy me some chips?" And sometimes she will buy them the 39 cent bags of chips and the cheapest cans of pop. She has a limited income but will help the little children and admonish their parents for being selfish and not parenting or meeting the needs of their kids. As this elder recounted such instances, she took pains to tell me that this problem is not unique to this reservation or this country. She stated that she's seen on television third-world countries that are similar. The fact that she compares the situation at the reservation to that at a third-world country is tragic in that the reservation is located in the richest country on the world.

During the time I was at the reservation, several incidents occurred over the summer where young people were either injured or killed as a result of accidents. The reactions of the elders captured how they regarded each and every one of these children as their own, thereby escalating the emotional anguish the elders felt. When one elder woman living in Kyle heard about a young man being run over, she shared the following with me:

There is a lot of concern going on in some kids, especially in Oglala, in daytime, a woman run over a boy just fourteen years old, daytime. She don't stop and check. She run over that boy, and second [came over the] hilltop and run over this boy, and third one come and he don't know so he run over [as well]. Fourteen years old. And I was *really* angry when I heard about it. That first woman that driving to Pine Ridge; she's not blind, she's not blind; how come she went and run over that fourteen years old boy walking along that road. That happened this winter. I'm going to dress warm and go to Oglala and I'm going to see that boy; I don't know, what's his name or whatever. My grandsons called from over there, "Grandma, they're doing ok, so you don't need to come. I know that you are angry, everybody's mad when these three cars run over him." It was daybreak and how come that middle aged woman run over that boy walking in the road. I wonder how come she did that. She thinks she's well educated, holding that steering wheel. (Elder 11)

This incident is significant in revealing the expansive boundaries of the mental well-being and consciousness of the elders. The elders not only care for their children, grandchildren and great-grandchildren, but also for the children, grandchildren and great-grandchildren of the entire reservation community as well as the community members who live in nearby off-reservation towns. The well-being of the younger generations weighs very heavily on the elders and when these incidents occur, they become upset and aggravated. The elders discuss such incidents amongst themselves at the meal sites, at community events and at other places where they congregate and run into each other. The elders also attend the funerals and wakes, supporting one another in their feelings of helplessness and loss. This sense of collective responsibility and emotional care embedded within the elders is very different from non-Native communities due to its vast scope. Communities on the reservation can be separated by as much as 100 miles; for instance, Rapid City is roughly 100 miles from the reservation. Yet the connections between the elders and the people on the reservation are so close that they care about and grieve a death that occurs 100 miles away. In the white world, the boundaries of collective responsibility and emotional care are much more narrowly drawn; they certainly do not extend to encompass all those living in such a long range of settlements.

It is also important to emphasize that the very expansive loving and generous spirit the Lakota elders possess is the result of the values embedded in their Lakota culture. One elder shared the following story that exemplifies this spirit of emotional care and concern, and of the willingness to be present there for the next generation, even when the elders do not know those they encounter personally:

...One day I was going to work one morning and...um, I start going down that hill and I thought *I wonder what that dog is draggin'* but it was the weeds were high and all I could see was this blond, a blond and the grass moving, so then I went down, and there was a road like this [gestures], and I turned there, and I was going, and you know it was a two year old baby dragging a little tiny one. That baby had her by the diaper, pulling her with him. Oh, my god, I was so mad. I just flew through; I didn't care if I went through somebody's yard, and out the other, and went right to the police station. And I told them, I said, "look what I found." And it was five o'clock in the morning cause I had to go like almost five miles to work, but ooooooh I never did find out who they were; they should have been whatchacum, and they just leave their kids; they don't even have a reliable babysitter and off they go. (Elder 4)

Despite the many heartbreaking situations like the one described above, there are elders who are thus doing their very best to intervene in order to protect the lives of the children and adults in their communities.

The elders also try to educate the children and adults in their communities; they try to provide an environment that allows the children to experience some understanding, also providing them with opportunities to learn from their mistakes and grow. One elder is a leader in her community. As the Elder Representative, she fostered, among other community resources, the development of the Elder Meal site. A church group from Oklahoma donated a television to the Elder meal site. And the elder continued to recount the following:

They brought, uh, a little donation, a TV and here, uh, the other, about six months ago; they brought us a new TV - a big one. So we have that. This is really something. We put our new TV in there. Somebody broke in and stole the TV, and this cop happened to be there. I went to the cop and I took pictures of it, and where the wires were torn out and said, "Check over to that house, four or five down; some boys were carrying a TV in that house."

So this cop walked in, and sure enough there was a TV, right on the floor. So he said, "Isn't that the elders' TV?" [The youth] didn't say anything; he put his head down. "I'm going to give you a half an hour to take that TV back over there if that's the elderly TV."

He said, "I can't myself; it's too heavy" [we laugh]

Whatcallit [the policeman], he said, "Who else was involved in this?" So he named three other boys, you know.

He said, "You call them, I'm going to go visit them and send them over and you carry this TV back over there." [She laughed].

So I don't think anyone would ever want to break in and carry anything out because, you know, they probably *shamed themselves out*. "It's too heavy [chuckles]. Did you carry it yourself? No, three others." So I went and put screens on the windows, and cost me about

\$300 to fix the door, where it can lock. So, we're safe now. We keep our door closed, you know, and our screens, so we're alright, we're doing alright. (Elder 19)

Later in the conversation, this elder and I talked about how the systems in place are not based on Lakota values, and how they therefore debase the Native youth's self-esteem and self-worth. In this case, the elder did not press charges or demand the youth be arrested; instead, she relied on an adaptation of Lakota values and traditional Lakota ways of punishing: she made them right the wrong they had performed. She did not talk poorly about the youth who took the TV. Instead, she employed the principles of accountability and shame to positively impact the Native youth. And the elder shared the story with me to demonstrate that children will make mistakes. And in their response, the Native leadership needs to respond in the Lakota way that allows the community members to learn and grow.

Part IV. On the Emotional Significance of Respect for the Elders

Lakota cultural values include respect for the elders. Yet the experience of the elders in relation to feeling respected varies widely from person to person, revealing that this practice that is so significant for the mental well being of the elders is slowly eroding as well. It is true that some Lakota families are still able to instill and uphold these values and the elders may feel respected within their families. But this experience within the family is at times not reproduced within the community where in some instances the elders feel that they are not respected. One elder noted the following:

I: Do you feel respected as an elder?

E: Mmm hmmm

I: You do?

E: Yeah some people, you see how different ones are treated and I wonder why they are treated so mean? I always think maybe they treated them mean. And that's why they are... I don't know. I was never, everyplace I go, they help me if I can't get up and they are all willing to help me. "Gee, you think I was an invalid or I can't do it myself." [she jokes]

"You are old enough so you can let us help you."

It's weird, but I was never cussed at or they haven't ever said anything mean or ornery. I always think why do they teach, or why are they mean to them? There must be a lot of reasons why.

I: The young ones take their money...

E: I noticed that too where we lived. One day, this guy hollering and they even took the boards off the trailer, and they took them. I went in the back bedroom, and then over here, then the water tower, and then there was a trailer real close, and then there was a lot

of trees, but they cut down some of the trees because a lot of old people who walk through there. And here this man was just hollering, and they were just beating on him I said, “What the heck do you think you are doing? That’s an old man!” There was about six of them too. This little man was trying to hide and they were hitting him with those sticks. And pretty soon I got that dog with that chain, and I said, “Go!” He went and boy, you should have seen them scatter, and that little man was all bloody. That’s what they were after and he was seventy and barely walking anyway; he used to walk through there anyway. When you are going to walk through those trees holler and we’ll walk with you. He said all he has was \$35 and they took it and his cigarettes. All he had. I went down and talked to, that president, what’s his name? [Name]. That other man was a dead head too. They don’t do nothing; they don’t get nothing done. (Elder 4).

As this instance indicates, not only are some elders not respected, but they can be preyed upon by younger people in search of money and valuables. Still, especially the elder women bravely stand up for each other, demanding respect, teaching lessons to the younger ones, and intervening on other elders’ behalf. As such, they are resources for each other.

Still, many elders often talk about how things have changed, searching for answers and trying to understand how these cultural and social shifts in respecting the elders has started to slip within the community. The stories they narrate are often couched in violence with which the resources of the elders are taken away from them. These violent incidents stick in their minds as they egregiously violate the significant Lakota cultural norm of treating elders with respect. Yet the elders also recount the smaller, everyday ways through which that respect toward the elders is conveyed, such as by letting them eat first, helping them walk, giving up your chair for them, giving them rides, and the like. One elder stated:

I: Do you feel like the young ones respect elders?

E: Noooo, some do, a lot do, but a lot don’t. One time we were, went to uh, what, some kind of a dinner, and they said all the elders first, oh to a powwow; all the elders come up first – be served first. And here, about three or four kids back there, I heard them say, one of them say, “well the...the elders, why would they let them go first, they’re too slow. They should be last,” so I looked at them and they are getting very disrespectful.

I: What do you think is causing the change?

E: The parents let the kids go, let them do what they want, you know. They don’t even mention how to treat the elder good. They just let them go. Even in the schools, they don’t respect the teachers, a lot of them. They’re not all like that.

I: Do you feel like that is a loss for our people?

E: I think so. I think too that’s what is causing all this; they get into dope and they don’t listen, and they get all wild, and they do what they want to do. I think it all comes from that. They take this dope, and they kill and they fight, and they kill somebody and they say, “Oh, they didn’t know what they were doing;” there’s a lot of that going on the reservation. They’re even killing the old people. Over here at Manderson, this old man,

he lived by himself and here they went; he was a grandpa, and he didn't want to loan him his pickup and here they killed him with an ax and took his pickup. But this one guy was friends with him and here he said, when he went over there to see them and he called them and told him to come and see. He was coming to see him. He had a cell phone I guess, and when he got over there, he was all chopped up and the pickup was gone. They knew who they were because they disrespected him in front of him. There's a lot of that; that goes on. Stabbing. Right now in Rapid City they are having a hard time. They go around stabbing – these young guys. (Elder 1)

The cases where the elders experienced violence stand out and remain in the collective memory because it is in such a contrast to the Lakota cultural values and the teachings of respecting the elders. Many times the elders live remotely and after hearing these stories of violence are left feeling fearful and vulnerable. Therefore, it is inescapable that when the topic of the lack of respect experienced by elders come up, those violent, terrible stories are immediately shared. Another elder noted:

I: Do you feel like kids respect elders?

E: No, there was an elderly who got raped one time. She went to old town, and she went to visit her daughter at the housing, and she was walking back to her place down to the... and between there, these two boys raped her and tortured her and nobody didn't find her until early the next morning, and she was dead. I always wondered who did that to her. (Elder 11)

Such negative changes in respect expressed toward the elders are hurtful. The role of the elder in Lakota, and other Indigenous and Native American societies is one that is traditionally revered and held in high esteem. Yet the changes to Lakota society over time led to the loss of the status of the elders, emotionally hurting their self-esteem. Even though the elders did not articulate their pain so plainly, even hearing comments about not allowing them to eat first adversely affects the elders because they were raised knowing that they would grow into the role as elder and they expected to be respected when they became elders. It should be noted that the elders are at their most vulnerable as older adults, the women often widows or not currently married, and facing violence or derision instead of respect greatly strains their sense of mental well-being. Still, I should note that despite these adverse changes, there is an incredible amount of respect shown toward Lakota elders at social and cultural events, especially when compared to the treatment older adults receive in the white world.

Another positive development is the interest expressed by some Lakota youth in learning about their tradition from the elders. There is an intersection, a meeting space where the younger generation approaches the older generations with the intent to learn the practices rooted in their traditional Lakota spirituality and values. It should be noted that the younger Lakota generations are free to explore these options; they have not grown up experiencing the oppression of Native American spiritual practices when it was literally illegal to practice their Lakota spirituality in public until 1978.⁸ The younger generations are seeking the knowledge and connection to these practices and have recently become the main force behind participating in these activities. One elder was discussing her son and his participation in traditional ceremonies and the values and principles that one has to live by and how to do so in the modern context. She noted the following:

You have to get along with your family. You have to have respect for your family and other people – neighbors and especially the elderlies, and you have to learn how to share things with others. If you have a piece of bread, you give half of it to whoever. [My son] knows all that. If he happens to [inaudible], he prays for them. And then he probably does stuff like that. If it happens, he's always there. Sharing with other people, that's how we do, we share, we share with other people. We keep our relatives, and our aunts come to visit us. My mother keeps them about a month – two months sometimes. Our whole family; we're a big family. They all come from communities all over; they come and stay for awhile; they stay for two weeks. So our family was really close to her relatives and my dad was. Now you visit for a little while, and they go and you don't see them for a year. But we didn't grow up like that. Sometimes I remember my nieces in Portland, Oregon. Always remember them and sometimes they come and visit, and they don't have money to go back and I have to shell out money to get them back. But I enjoy them for about four days. I know how it is to live in a city like that; it's fun, but it gets to you. At least over here I don't have to have money all the time. Somebody comes in and says, "I want to go here, but I need money." I have to shell out whatever I have. (Elder 9)

It seems like an intersection is emerging between traditional and modern values, where one side may be living in accordance with the traditional values of generosity and respect, and the other side may be taking advantage or benefiting from the generosity. Optimally, both sides need to develop mutual respect and operate in accordance with such values. This is especially crucial to instill in the younger generations. Yet while some have it, it appears that many do not. One elder stated:

⁸ The American Indian Freedom of Religion Act of 1978 allowed for the legal practicing of ceremonies and other religious events without any interruption from the authorities.

And some of the young people that have this traditional upbringing will have the respect and treat me with a lot of respect, and there is a lot of young people that don't know.
(Elder 21)

These descriptions point to how the younger generations struggle to maintain the traditional values of the past within the context of modern life. Some youth are able to live in their Lakota way, others incorporate some of the values, while still others were left without the teachings altogether. The elders comprise the generation straddling this shift in culture; depending on their age cohort, they still retain the memory and thereby the consciousness of when the traditions were being lived. Yet the younger generations do not have that memory and thereby they often lack the consciousness, or are only able to gain it through the stories of the elders. Some of the elders try to instill this consciousness into their grandchildren who are so many generations removed from "the old days" or the time before Lakota society was affected by white people and Christianity.

Traditional Lakota culture encompasses many aspects of respect – respect for self, respect for others, respect for elders, respect for the animals, respect for the home, and the like. There are many areas for the youth and younger adults to learn and practice their Lakota values. As one elder noted:

E: There are a lot of kids going around that don't know their language and don't have respect for the elders and don't even know how to work; and it's just a snowball effect and, uh, we know where to stop it and stop it. There's no other way.

I: So, you feel like kids today are different from the way you were raised?

E: Well, I was taught to respect my elders and I don't know about, and I was taught to work no matter what, and I was taught to be clean no matter what, and I was to watch my vocabulary no matter what; I was taught not to assault any elders. I heard a lot of people beat up on their elders and that's not something I would do. I was taught don't do that you know, and still we had a lot of structure in them days. It's getting worse in one generation to the next. When the boarding school went away, we're still feeling the effects. They are building a boarding school to reverse that, taking those kids that have nowhere to go. (Elder 12)

One of the younger elders offered insights into this multifaceted and complex issue of the change in the culture broadly, because as previously mentioned, there are still some spaces where the elders are respected. The impact of the declining respect for the elders affects them emotionally and spiritually because the role of the elder is a social position held in high esteem and when those expectations are not met, it is another moment of the feeling of the loss of the traditional culture. One elder stated the following:

I: How do you think elders are treated here? The culture is changing.

E: They are being put on the back burner. A lot.

I: What do you think that does for the culture?

E: [pause] Um...we are not using our knowledge. I seen that happen to my in-laws and now it's happening to me. I saw it happen to one of my fathers-in-law. He had so much knowledge and yet they shoved him off. He was head of the National Congress of American Indians and got home and he was nothing and they never used him. It's a lot of jealousy and fear. You might take something away from them and there's more young people than old people, especially here on the reservation.

I: Yeah, the majority is under 25.

E: I think the median age is 19. That's amazing. 19 years old. What the hell do we know at 19? [we laugh]. Jamming to music and looking at the opposite sex, and you aren't paying attention to life. You are paying attention just not to...

I: Not to things that are important later. I see some of my elders get taken advantage of by the younger ones; they care about the kids and they want them to eat and you see the young ones take advantage of that.

E: Yeah. They don't take responsibility for raising their own. I seen that happen the other way too. Other families the in-laws step in and take the kids away and get financial aid and stuff and the dads and moms had nothing. That happened to one of my uncle and he was pretty mad about it. I had to just let it go. He died of a broken heart – young. But I see those kids turning out pretty good. They were really nothing traditional about them and now they are Sundancing and sweat ceremonies. It kind of knocked me off my feet. They talked to me and my cousin; they are younger. I was just amazed that they do that now. I think their dad would really be proud of them. That's good. Their mom abandoned them when they were little and just took off. Grandma took them and run everybody off, including dad. So...yeah I see that. I watch it. (Elder 21)

Often one way the elders respond to the loss of cultural values, of respect for the elders is through encouraging and mentoring the young ones into ceremonies and cultural activities. These include Sundancing which requires a grave commitment that generates learning and healing for the community. One elder noted:.

I: Do you feel there are any kids that respect elders?

E: Now there are, I noticed that in the last two, three years; before that it was really, now there's a change coming from somewhere and it's when you go to the Sundance and stuff; they really treat you good and stuff. It started three, or four or five years ago, and it started with the young guys themselves being exposed to the Sundance and there are very few churches open anymore. They all pretty much went by the way side and the Sundance came back and the beliefs.

I: But that happened after the second Wounded Knee⁹, right?

⁹ Also referred to as the Wounded Knee Incident of 1890. Hundreds of Oglala Lakota and American Indian Movement (AIM) activists occupied the town of Wounded Knee in response to the failed attempt to impeach the tribal Chairman, Richard Wilson. The intertribal tensions between the mixed race Lakota people and the full bloods were central to the Wilson administration. He is accused of corruption and favoring the mixed bloods and limiting job opportunities to the full bloods and oppressing the traditional Lakota people. The activists controlled the town

E: Yeah. Up until then, it was pretty rough to be an Indian. Even on the reservation and around here. But I see that now it's starting to get a little better; there are times when I'm doing something and somebody throws stuff in the back of the truck for me, and they call me uncle, and they'll do whatever; even where I work, they don't let me do anything, but all of a sudden times are a changing and its turning around and it takes some time. (Elder 12)

In spite of the positive experience this particular elder experienced with pleasant surprise, other elders are often frustrated with the younger generations because they feel disconnected from them. A tension emerges as the elders try hard to provide the connection to the Lakota culture while the young ones care more about modern aspects of life – like television and modern foods. One elder stated:

So as the generation went – my uncle, my aunt, and my cousin, they all told me what was going to happen with that generation and its true. Yeah. We're there now. And these little babies, they're losing their traditions, their language, their respect for anything. They use bad language now. They are mean. Gee! Can't even tell them anything and like our kids, they think they know everything. They don't know everything. All they do is watch TV, walk around like this, and don't even try to help *Maybe there's a grandma out there that needs some help, and you can't get them to do that.* They just hang around and look, they're all gone. Tonight they will be around. *On the first [of the month], they come around to the grandma's for some money and a place to sleep, for stuff like that. They don't even have respect anymore.* They don't eat at the table like we used to – sit at the table and laugh and be healthy and food is the one that keeps us healthy, and now they just they don't do that. Geez. What's wrong with them? *They walk around out there with sandwiches and pop and that's all we see.* Nobody cooks anymore, just us, we make bread. We make soup. We make *wojape*. We make oatmeal, boil eggs and make bread and now, geez I don't know what's wrong with them. Something is brewing in their lives. It's the alcohol and drugs. So we try to stop and elderlies used to go up to KILI and a lot of them used to talk on there and these young kids don't want to hear that. They turn their radio or they shut it off and turn on the TV. That's why they can't learn. Just certain ones – little ones are talking. They are just cute. We hear them. Yep. They are learning the language. They are the ones that are really interested and it's really hard to find that now. Kids that are interested. Teach them when they are first born and when they can sit up and start talking to them. And the mother has to, you know has to think and speak to that baby will know when it's born. Now we can't even take our grandkids; only when they go out and run around and get crazy, and then we are stuck with the kids and they are spoiled. What can we do? They won't even let us take care of them anymore. Only certain ones will take them and some they don't, so how can we teach them. We take

for 71 days until the federal government, including the FBI, exchanged gunfire. The violence escalated on the reservation for several years after this standoff leading to more deaths on all sides.

It should be noted that this is a very brief description of a complicated political and cultural situation that had lasting repercussion on the Pine Ridge community, some would argue continue to this day. This was a key event in wave of Native Activism and cultural pride, which some argue led to the passing of key legislation in the 1970s that benefited Native people, such as Self-determination and Freedom of Religion.

them when they are babies and we raise them and we talk to them and we teach them and we show them and tell them it's not good. All that stuff and now we can't, and they're just raised by their parents who don't do it. So we just let them go. You can't teach a kid when he's nine or ten years old to learn something we learned. They won't right way they run and then their parents say, 'Oh grandma is just old. Don't listen to her.'" Stuff like that. (Elder 16)

Interactions between the elders and the younger generations is at a cross road, bringing about strong feelings of unexplained grief and loss for the children. The elders were raised with a consciousness of the past, with the traditional ways of living and practicing spirituality. Yet the youth are raised in a modern society filled with housing subdivisions which separate families from the communal ways of living, television, technology and the like. The elders wish for them to be connected to their Lakota language and culture, yet some of the children will never experience those connections. The elders struggle to make these connections and worry for the next generations living without Lakota values and practices. The loss of the pieces that the Lakota people have been able to maintain for centuries are gradually eroded in an environment that is not only averse to such significant pieces, but are in fact actively working against the Lakota communal nature of living, values and practices. Not only is this a great loss for the Lakota people, but the elders feel this loss even more deeply.

Some elders do not only draw upon the Lakota values, but often combine it with the elements of Christianity that has seeped into the reservation for centuries. They focus on a combination of Christian faith and Lakota values, where Christian values and Lakota values intersect, as they do, for instance, around the practices of generosity, respect and prayer. As one elder noted:

I: Do you feel respected as an elder? Do you feel that kids respect elders today?

E: Well really, most of them do around here. But a lot of them, there's probably that hardly ever go anyplace, and when they do, you never know. Most of them are when they help the elder. I feel like they respect the elders a lot of these kids. My grandchildren, I always tell them, I tell them all the time to be good to people. I don't care who it is. It doesn't matter what walk of life, you be good to them. And if they need help, help them. And if anyone needs anything and you have it, you give it because you will always get some more. Don't think you will be left empty handed your whole life. You have to learn how to help people. That's how I brought my kids up, to respect people no matter what walk of life it is or what religion. It don't make no difference, but you were brought up in the Catholic church – don't wreck that, don't try other religions; you have the Catholic church. But I do know a lot of the kids don't encourage their children to go to church. I don't know if they teach them religion or not. Last uh, last year, they had summer school at the Catholic hall and a lot of those kids didn't know who Jesus was. Well who is

Jesus? Who is god? You know? They don't know the saints or nothing – nobody to teach them, so we should have more like, uh, summer school for kids or religion like. Some people say there are too many churches, you never have too many churches. There is a lot of kids around. And a lot of kids need that attention you know, you come and talk to them about religion and that helps them and a lot of them don't know religion.

I: What about Lakota values?

E: That's another thing too. The way some of them bring some of their children up in Indian religion; like they have in their mind that is the only religion to go by. Like my kids, one of my daughters said that because her husband's mother was a medicine man, or his grandma and I told her no matter what, we still pray to the same god – there is one god; you can't change that. That's all it was and all its going to be, and you are going to keep your religion. And there is another thing; I don't care what religion comes in when someone is preaching or what they are saying. Never make fun of them because that is their way and you have your way and they have their way. I said we all pray to one god. I don't know how other parents feel about their parents and grandchildren, and now they – I have some *takoja*¹⁰ I teach them how to pray – it's the cutest thing when you teach them how to pray. (Elder 10)

Indeed, this combination of the best elements of all beliefs the Lakota have encountered through generations may be one way in which to bridge the traditional values with the modern ones instilled by the church.

There was a wide variation among the elders when they were asked about respect. Some elders regard younger generations as never doing anything out of kindness. One elder woman simply stated “I don't know. They always want money, money, money always comes first.” (Elder 7). Yet another elder framed her interactions differently, trying hard to see the good in the young people – seeing them working for their money. And she did so even though she lived in Wanblee where some elders are afraid to be away from home because break-ins are prevalent:

E: Huh uh, I have a lot of respect, a lot of - some of those boys, there was one here who was asking what he can do. I said, “I have some tall weeds that need to be cut” and I gave him a little, it's my daughter that always pays them, “Thanks for helping mom, grandma, you know” and they come back and they “Can we do something for grandma?” So you can teach them that they have to do a little of something good to get paid, you know, and other children, some children [ask] “Why do you accept them in your home? They are naughty; they might break in your house.” I said, “No, my daughter pays them a little of what they can you know.”

I: I see a lot of...a lot of younger family members take advantage of the elders

E: Yeah some are doing that. Some are doing that

I: What do you think about that?

E: I think we need to teach younger generation. That's what I'm trying to teach here. I have a room. I have all the elderly pictures and so forth and then they, “Grandma, what is

¹⁰ Lakota for grandchild. *Takoja ki* is the plural but often is mixed with English and said as *takojas*.

that picture; what is going on in the picture?” and I sit them down and I tell them, “You know, grandmothers had a really hard life, just like me. You know that massacre and the takeover and all they went through; it was hard you know to see that happen to my people and they had a hard time taking care of you, so you can be happy.” In this way, you respect, and let that respect build back up . (Elder 19)

Mutual respect seems to be the lesson this elder draws upon in rebuilding the respect. I attended the dedication of the newly rebuilt Oglala Senior Center where Teresa Two Bulls, the Tribal President, gave a speech directed at the elders. She shared the following:

She went to a meeting in Rapid City and the youth from Pine Ridge were there said that they don't feel respected by the elders, so they don't respect them. She said that the elders have a lot of wisdom that needs to be shared, and that they need to teach us right from wrong; the wisdom and knowledge is probably the most important aspects of kids' lives. We need to get kids away from being adults when they are really small. The parents aren't around and the kids need support and we need to bring them back to the positive. She said that its up to the elders to start building that bridge. She said that when she was younger that visitors would come over and they would try to stand around and listen, and they would shoo them away and that they knew their place and would respect it. Kids today interrupt and don't listen. She thought that it was strict but that she's thankful for her parents because it taught them values. She said that one of our virtues is respect and that we need to teach it. She said that they need to start programs that include the children. (Fieldnotes 6/17/09)

Understanding and gaining perspective on this speech has been a journey because it is unusual for directives to be addressed to the elders. This speech was presented to the elders in this study and they offered their opinions. Some elders felt that the children need to respect them and that it is not their job to build the bridge. It needs to be emphasized that both the youth and the elders feel disrespected. Neither side feels important or respected. The message about raising children in the Lakota way emphasizes that children are sacred, and yet elders are to be revered and respected for their knowledge, especially as they relate to children. Since elders are in a position of leadership and have the life experience that is so valued, in this speech, the Tribal President is asking the elders to help influence these children and youth for the better. Indeed, as previously discussed, some elders do play an important role in living by example, thereby leading the children to a better way of living based on the Lakota values that have sustained them for generations. Indeed, the Tribal President conveys that the influence of the elders is imperative for the health of the Lakota Nation. I should also note that in other parts of her speech, the Tribal President mentioned that the Lakota people were mighty warriors who once held the largest land

base in the western part of the now United States. She extolled the virtues of the people who lived before them, thus bringing the consciousness of the time before the white man came, when the Lakota people were whole in their body, mind and spirit.

As evidenced by the themes in this chapter, the elders are not only concerned about the well being of the youth and the next generations, but the elders' mental well being is predicated on the younger generations' well being. In a broader sense, one elder in particular has given a lot of thought and time to generating avenues for bringing out the best in the youth and creating an environment where they can thrive. The following are her thoughts:

A long time ago, we lived in tents, you know, tipis; that's where I was born in that era. My grandmother's era because she delivered all of us. She had three daughters, but she delivered all of her own grandkids. So really, um, I'm not you know. I don't know, but my kids have their life too, you know. You see it changed to my children and now to my *takojas* and my great grandkids coming in. They have a world of their own to live and we need a lot of education – we need a lot of education for the young generation, but they want to belong that's what I say, *they want to belong*. They have that feeling. Everybody has that feeling. They want to belong to someone or some group or something, but we don't have that in the young generation today. We don't know which way to go. They're not accepted on the – in the white man's world, and they don't want to be, and they don't understand who they are, so they're you know, the belonging feeling and that person is not developing right, so what all the monies that we have been getting to be educated in the white man's way.

I think we need to develop something – build our self esteem and who they are, believe in themselves -- that I can do. I'm Indian and I can live that way. I think if we develop that's the feeling I have. I am Lakota and you know still feel that I am who I am and I can do it, you know. That's why maybe I have this going and going, you know [we laugh]. So I speak Lakota, you know, and a lot of people today don't have the language that my grandmother, my mother gave me; they don't have that language, it's more like a slang language. They try, but you know. So I'm doing alright, you know. Crazy Horse School is really a nice school we didn't have uh, they uh, a schooling, a school that was down here at the eighth grade level was more like um, you learn to figure, you learn to write the numbers, and you learn to read, and you learn to understand, but it didn't feel like anything so when we walked for the high school, we decided to put a science room in there and outside of that we have welding and carpentry.

I: Like trades

E: Art, music, we try to bring all of that up. A lot of children; their handwork is really good and a lot of them can study. (R19)

As this chapter demonstrates, the strains on the mental well being of the elderly Lakota people are the result of their boarding school experiences, the grief and loss of their mothers, siblings

and family members, illnesses in their families, caring for grandchildren and great-grandchildren, and especially the loss of the respect for elders. Their mental well-being is supported and fostered by the younger generations that live according to their traditional values of respect and reverence, through their own participation in traditional medicine. What restores the mental well-being of the elders is seeing the younger generation thrive and succeed. Yet the gradual loss of the Lakota ways of living and values has led the youth and younger generations to be left to figure out how to live. When they adopt the white ways of living, they remain unsatisfied, and they still have identity crises because they are not fully accepted by the white people and feel discrimination. It is apt to conclude the chapter with the narration of the elder I cited immediately above because she notes the following: finding ways to incorporate Lakota values and supporting the youth in learning and participating in the ways that they have practiced for generations will draw on their talents and innate abilities, and build their self-esteem. As they grow stronger, so will the community. And as the community grows stronger, the mental well-being of elders will improve as well.

Chapter Five

Spiritual Health and Lakota Older Adults

The third component of the health of Lakota elders comprise, in addition to body and mind, of the spirit. The spiritual health expands beyond the physical body of the Lakota elders, and includes the entire environment, the land and the community. This is the case because the separation of Nature and Society that is the fundamental premise of all monotheistic religions does not exist in the Native conception where Nature and Society are one and the same, the boundaries of humans well expand from the physical body to the natural environment, encompassing all. Initial contact with the colonial settlers followed by the intervention of the American state into Native communities through massacres, territories bound and forced movement to reservations, and educational obligations altered dramatically both Lakota land and community. Such alterations of land and community in turn damaged the spirit of Lakota elders. Part One of this chapter discusses the alteration of Lakota land and community, followed by the attempts of the Lakota elders to provide informal support for each other. Part Two articulates the existing services including the Indian Health Service, Community Action Program and Community Health Representative, elder meal sites, and limited transportation. All of these remain woefully inadequate.

Part I. Destruction of the Lakota Land and Community

The being of an Indigenous person extends outward to include the land. This connection to the land has sustained the Lakota people for centuries. Much of their land was taken away from them by white settlers, removing them to the present reservation that lies on a small portion of the vast land the Lakota people once lived upon. This connection to the land still remains: being on the land, constantly seeing the land and its people contains within the spirit of the community and the Lakota people. One of the oldest and most respected elders on the reservation illustrates this spirit so beautifully in the following story [emphases mine]:

So like yesterday, I was at Manderson [community] and I talked to their fifth, sixth, seventh, eighth grade children on our treaties: what our treaties with the federal government mean and what their role is going to be in it after they get past high school. It's a little earlier; they're at the age where, uh, uh "I couldn't care less what the (taps) President of the United States is." I was more interested in people, places and seeing things like when I drive down the road. Time and again patrol man would pull me over.....

She said, "Uh, you been drinking?"

"NO. I should stop and get a drink I guess, No." What she meant was, "Have you been imbibing in the spirits?"

"I got a report you were weaving in the road."

"That can't be. I stayed right on the right side of that yellow line (taps loudly). Who said that?"

"They radioed me to uh apprehend you or to detain you."

"Well, as far as drinking. I welcome water or a bottle of pop if you would buy me one. But when I down the road I don't watch that yellow line. *I like to look at my country. This is my home, trees, nice houses along the road; I like my country, officer. I wanted to see what the hell it looks like.* I don't drive down the road like I'm on a 500 mile race like the Indianapolis. *I like to see the country, see the people. See the houses, see the horses, the cattle, sometimes the buffalo; other animals. I don't race down the road and disregard the country.* Why would I go and race from here to there and race back without seeing anything? You can put handcuffs on me right now, but I'm going to tell you, you are crazy, Mr. Officer. *I like to see my country. I like to see people.* And this car has positive steering and can hold steady and keep that right side of the yellow line, right in line. But if I look to side, I tend to move my steering wheel a fraction and I pull it back and look around the other way and it starts to go that way and I pull it back. In the period of time somebody saw me, viewed it. if they don't want me (taps!) to have the positive steering I'm going to tell them in my next car, if I live long enough to own a new car. I don't want positive steering. I want this car to stay on the right side of the line *while I'm looking around and enjoying my country.* Do you disagree with me?"

"Well when you put it that way, no. Go ahead get on. Look at your country. But just try to keep your car on the right side.

I do officer, but when I take my eye off of where I'm going the positive steering if I move it a ¼ of an inch that's what it does and I have to put it, get it back in line again. But I haven't been drinking. But you don't have a bottle of water with you do you?

"No, just go on."

[we laugh] (Elder 2, 90s)

This story reveals many aspects of Lakota values and insights in terms of what nourishes the spirit. Being on the land, seeing the land and all the life that lives on it is more important than many other aspects of modern life. What the elder does in the car, looking into the environment to nourish his spirit and how his actions are interpreted by the police officer who is merely instrumentally concerned with drivers obediently following the yellow line on the road capture the vast disparity in meaning between the Lakota way and white rules that not only but also

gradually undermine the Lakota spirit. As modern life was forced upon the Lakota people, the Lakota elder in this case adapts to the use of a vehicle, but does so while still seeing his land and his people. Yet even this is not permitted according to the white men's rules as modern living takes the elders away from the simple element of being connected to the land in the ways that the people before them were able to do. Another aspect of this elder's narration concerns his efforts to connect to the younger generations by going to schools and talking to them. This communication to the younger generations is also spiritually fulfilling.

Unlike the young students, the younger Lakota elders attempt to sustain the spirit by listening to the stories of the elders who came before them, especially in terms of how the Native people once lived off the land, thereby keeping their spirit intact. A younger male elder shared a story of how Lakota people lived after being bounded by the reservation: they attempted to maintain the natural flow from the people to the land by not fencing off plots of land as practiced by white people. They thus preserved a sense of community and spiritual freedom. The younger elder shared the following story:

They moved out here and they built a house in the wall side of the – he dug a hole in the side of the hill and built a house in the wall and it was cool in the summer and warm in the winter and that's where they made their home. This was all open and no fences, you could ride for miles and miles, you could ride to reservation line and there'd be no fences. Everybody's cattle mingled with everybody's and every spring would sort the mothers and the calves with the mother's brand and then brand the calves. So, they made their living my grandfather that side became he was well to do and they had a big garden and he had cattle and he had horses. So everybody came to him when they needed something. He'd sit and listen to them. My grandmother, she being traditional she knew everybody. Everybody was her relative. (Elder 21)

These families were able to maintain the communal ways of raising cattle and sharing in the workload in order to sustain themselves collectively. These connections to the land being open and raising the animals in this way sustained the peoples' spirit and kept them connected to the ways of living that made them whole in body, mind and spirit.

Another elder who was also a spiritual leader in the Lakota community sustained this connection more formally; he participated in the ceremonies, organizing and mentoring the Lakota youth and young adults in learning their Lakota values, spirituality, and ways of living. One of the lessons he employed in teaching the young men related to growing and harvesting a garden: the Lakota elder stated that the food that is grown in the earth by their own labor not

only tasted better, but connected them to their elders and the ways of living off their land. (Elder 17). The great significance of the connection between the Lakota people and their land made their removal from what once nourished them all the more traumatic.

Removal from land and the loss of spirit. The elders experienced trauma to their culture, families and to themselves through the assimilation strategies of the federal government; in addition, they also felt abandoned, betrayed and traumatized by the Tribe that collaborated with the government. Woven through the elders' narratives is their sense of being betrayed by the tribe: a family's cattle herd was sold without permission or compensation; they were promised care, but when they fell ill, they did not receive any help. A large trauma they experienced was the forced removal of families from their homes and familial land on the reservation. Two elder women who shared their stories revealed that their families lived in an area of the reservation that is referred to as "the Badlands, Bombing Range. They call it Bombing Range now. They call it North Medicine Root and Upper Medicine Root" (Elder 11, 79). Hence, they were removed from the fertile lands they lived on, splintering the community as it scrambled to secure housing in other areas of the reservation and into Nebraska and other Non-Native communities.

Two of the elders narrated how a surprise forced removal from their homes and land and the details of their experiences in the following manner [emphases mine]:

I just turned eleven, but we moved out in July and that was a mean thing for a [Tribal] Council Representative because they did not meet with the people and let them know that the U.S. Air Force base was looking for a place to practice bombing. The Council went to Washington and signed a paper for that area and what they did was come back over here and they - everyone to that one room school and auditorium - it's still there. Everybody gathered there that they had to go in *ten days*. (Elder 10, 82).

The news coming down, they said, this was going to happen in *ten days*, they already gave the BIA¹ some tents and enough money to survive but the BIA spent all the money and those tents, tent that was supposed to buy for them, one hundred. From Interior into Red Shirt Table, they all moved out, over 158 families, or whatever. Only *ten days* so they all took off and we don't know what happened to the money that was supposed to buy tents and bedding and whatever. After that, they don't care. No, none, Army officer come check up on us or nothing. They didn't try to make them check up on us (Elder 11, 79)

¹ Bureau of Indian Affairs

Hence the Tribal Council Representatives not only signed away the land, but after the whole removal occurred in ten days, the Lakota people did not receive the tents they were promised, but did not have any support from the government or the tribe once they were forcibly removed. Because of the rural layout of the lands, the distances in between the homes were long and the number of families that were impacted was large. The narration of the elders continues as follows:

...even the corn was that big that time, corn, everything, onions but we just let it go everything and took off because the soldier men walked down there all by himself, no car. We were playing outside and here, um, the dog seen something and it used to be a heavy wooded area and you cannot see nothing. And here after that, people stealing trees and stealing stuff, whatever, everything wiped out. And here that dog seen something in the creek and it looked at us again and barking. So one of my brothers were [inaudible] and said, "Mom, dogs are after something." "Get over here maybe it's a bobcat or porcupine." So we didn't go to the creek anyway. And here it was still barking and we went back to the log house and here my dad put on his shirt because he was writing letters. And here, uh, there he is, that soldier was coming from the creek, with papers like that [gestures with her hands], so my dad came up and he mentioned his name and whatever and he was passing words down there that its suppose- they gave them thirty days and no phone, at that time no radio, that time so we don't hear nothing. So the soldier boy went to the house and they both shake hands with dad and mom. He told them that, uh, he's going to walk *waaaaay* north to that river, to the houses over there. So my dad said, "You are in a car, son?" "No, I'm walking." He told him that there was an old bus road and not to the river, but just to the corner and he said, "No, I am walking." But he's a soldier boy carrying a bag. Uh, young. So we really sized him up. So my dad said in Lakota, he told us, "Not to be sizing him up, he's Army." It was 1942. Seemed like that [something] bad happened to us. (Elder 11, 79)

The families struggled to move their entire lives away from their homes. And they did so by leaving behind all they had nourished, all the food they had raised, behind them to rot. There was no alternative housing for them to readily or easily move to; they just knew they had to get out and they had to figure it out for themselves. The narration continues as follows:

E: No one was ready because this was in like August and we had a big garden and the potato field was covered three acres and the corn was another three acres and squash, watermelons and we were growing that and the potato and the fields and no cellar to store our stuff like that. So, when they told everybody ten days that was too short of notice and they asked for thirty days and they extended it for another thirty because you couldn't get your cows situated - the fence for your cows. And my brother, we were, my brother and I had to herd cows. I herd the cows all day long and he herded them all night with my dad

because we had no place to put them – you know to keep them all together, you know to fix the fence. Try to get everything going and then they had to haul the posts and the wire and everything by wagon. There weren't no...

I: Cars or trucks

E: There were. The government was supposed to help the people, but they weren't. They told the people that they were going to come to their place and help people and that wasn't true. You had to move out the best you could and they started shooting, you know, practicing and a lot of people still had cows in there because they couldn't gather them up like we wanted to. Like if you are playing and you gather your toys up and get out. Those are the Badlands and people had a hard time and they moved everyone out of that place and when we moved out, they moved everything in a big hayrack that we had what we could in the wagon and in a hayrack and another wagon. My brother and I rode horseback and drove the cattle and we stopped right here where this housing is, this used to be the rodeo grounds and we put the stock in there and we had dinner and we didn't know where we're going – us kids, we didn't know where we were going and we didn't even know where we were going to spend the night! You know. We kept going and we went up this way to No Flesh [Creek], my cousin lived up there we got up there and they made camp that night and we stayed all night there. We stayed there a couple of days too so we could locate the plan where my dad leased the place to live. It wasn't easy; there was many a tears shed, made you feel bad because you lost some of your stuff. What happened to the chickens, whatever you had – the garden -- all wasted. At that time probably thousands of dollars – all the vegetables and sweet corn and ear corn. (Elder 10)

All the fruits of the land were wasted, with the removed families set on a road where they did not know what their destination was. Not all of the removed families had family close by where they could stay, regroup and secure new housing. The move was gut wrenching and confusing for the families as their lives were debased by this surprise move. One elder shared the following story:

Right here [Kyle] where this flat area, not only us that's when there was no houses. Some of them got tents, uh, and some of them got horses ready and they load up their stuff in the high wagons and they used the high wagons to haul hay, but the family they give each other rides. Us, way down there, we didn't have no ride. *It's a terrible story and I can't forget about it.* My dad when we were on top of the hill, my dad said, "Turn around all of you kids," talking Indian, "Turn around all of you kids" so we turned around and here my mom cried, "Turn around and check the house." And here the dog was way down there [inaudible] and here the dogs were sitting in the shade looking up and the chickens are in the pasture in the chicken yard and those dogs are laying in the shade. We start crying. We start crying and my mom said, "In the evening the cattles are going to come back to the creek and they are going to drink water but we won't be down there." My dad said, "Maybe forever we aren't going to see this home no more." I really kind of, I was really mad but now I got my mind older, older. When they hauled us to a meeting, I mentioned that, they made us sign our name. They didn't force to sign our name but the paper came so we signed. I mentioned that. From the beginning, I am a Wounded Knee² survivor, second time I am a gunnery range survivor. Everybody -

² Wounded Knee Massacre of 1890.

Everything is still down there. Everything, baptismal, [papers], everything's still down there. They didn't help us. (Elder 11).

What does a family do when they have nowhere to go and the only things they had are their belongings from home that could fit on a wagon? Some went to the rodeo grounds, or a flat area where current housing and IHS clinic are located in Kyle. Also, the same elder shares how an elder helped them, one she calls "Grandma" merely because they are related to each other in the community as if they were a large family. The Lakota people refer to many elder women as Grandma, regardless of biological relationship. The elder conveys the rest of the story as follows:

I³: So then you lived in tents?

E⁴: No tents, nothing. We slept over there from that clinic, you come from that clinic, they built that a little while ago, kind of deep here like that. We all sleep right there. Mosquitoes really beat us up. Mosquitoes and we see a wagon and we watched him come from way up there [gestures in the direction]. And here, it was just Grandma [Name], um, Mary, uh, Mrs. [Name]. But only one team⁵. But the buggy was small as this bed⁶. The wagon sit right there and back here was small and only one team. Grandma sitting on top and we could not fit all of us cause there's 5 or 6 or 7 of us. She took them back two at a time down there where the log house [was] down there. If you go this way and that way, there is a log house right there and that's where we camp. There are two tents south of that log house down there and she said, "We are going to sleep in one tent and the other one would be kitchen and here my dad wants to go back to Wounded Knee⁷ and she said "Stay here. Stay here. I'm going to fix my paper and you are going to own that land up at the corner, along the creek."

I: So how long did you stay out there?

E: We were in Porcupine⁸; my auntie built three tents, one kitchen, one bedroom and one to take a bath in there. We were small kids at that time. Even people donate tents, they call it tent stoves from the ground like that you could dig and make the tent warm one was that kind and one we slept and one like a kitchen, but it was given to my mom, her in-laws in Porcupine. They're old. After that right, um, right after Porcupine school vacation, we, we, uh, my dad got a house in Gordon, Nebraska⁹. So we all stayed over there in Gordon. And here in Nebraska state they were looking for peoples, defense – no, defense, no, um....I think the train goes back and forth and they send them to Omaha, Nebraska. Yeah! Defense work, defense work. Trains go there and take them this way and, and this way again. My dad joined it. He's got a pin, they gave him a pin. So they're

³ I denotes the interviewer.

⁴ E represents the elder responses in the interview.

⁵ A team is a pair of horses, in this case one team pulling a small wagon with a female elder at the reigns.

⁶ She referenced a full sized bed.

⁷ A district on the reservation that includes the area where the Wounded Knee Massacre of 1890 was located.

⁸ Porcupine is a community and district on the reservation

⁹ Gordon, Nebraska is a non-Native border town, 65 miles from the reservation town of Kyle where the family originally lived in tents and roughly 40 miles from Porcupine where the children attended school.

going to work two weeks over there and come back and then they're going to go work, they transfer them like this. They paid he bring money back, the rent money and food; he pays the rent and go. We were doing ok in Nebraska.

I: And where did you go to school?

E: Um, Porcupine.

I: A regular school, not a boarding school?

E: Like this one here, a BIA school. And sooner or later its going to be a bad winter so they said some kids wanted to go to OCS¹⁰ boarding school so instead of going over there, um, the welfare help us. The people wanted us to go to school. They aren't from the gunnery range. Instead of taking them to boarding school, they took them to Holy Rosary Mission¹¹ and the parents went and got them and enrolled them in OCS. The same church! I don't know why they did that. We pray one foundation, one Christ, they're both Christians. But the state removed the Episcopal kids from Holy Rosary to OCS. I really like Holy Rosary because they feed us late at night too. They pass around apples and oranges with peanut butter sandwich and they moved us and took us to OCS.

I: Did you go to high school?

E: Huh uh.

I: So you went to the eighth grade?

E: Yeah, uh huh, not only me, everybody else. Cause we couldn't afford clothes. No income at that time. No money. The government stopped everything. They used the [ration] book to buy stuff.

The changes came fast and impacted all aspects of Lakota family life. Again, we see how a Grandma, or elder in the community with her small wagon and team of horses assisted a family in their time of need, helping them get settled into their tents. The support of a community's Grandma was an integral aspect of the narrative and memory for this elder. Not only did this elder have the trauma of forced removal on the reservation, but also, once settled into a new school, she was removed by the state from the school she liked and put into the boarding school. It is significant that these elders and their families had little agency in determining the course of their own lives. Also, because of the extremely limited resources, this particular elder was unable to continue schooling. This family was able to secure housing off the reservation where they left everything they knew and were then living among white families. She lost the daily presence of her father as the father had to travel to another state to work for the government in order to support his family. Once the removal was set into the motion, the life course of the family was changed forever. This Lakota community was shattered, leaving many families scrambling. The entire reservation community suffered as families were forced to leave the

¹⁰ Oglala Community School, the boarding school located in Pine Ridge which was an elementary and high school.

¹¹ Also referred to as the Mission school, the Catholic school that was residential and was an elementary and high school.

reservation to find new homes. From the second elder woman's perspective, the narrative continues as follows:

I: Where did the people go?

E: All over. Up here and like [Name of family] - they lived on Red Water, but then over by where we lived and some went toward Rapid and some toward Interior and Hot Spring and that way and moved away. Some went to Nebraska and some just kept on and worked over there in the potato fields or wherever they could find jobs. They raised their families there. I know some of the [Name] moved to Nebraska quite a few people; they just broke up a nice community.

But we moved out of there and moved up to No Flesh [Creek] so that's where and that's where it was hard going to school at that time. Because we didn't have - our house wasn't finished close to Christmas and it was cold and we lived in a tent and we about froze up in the winter time. I guess we survived, but I went to school here at Little Wound [in Kyle] after my dad and them moved over to below St. Stephens [Church] there that I went to school over here. My sister and them used to go horseback to school, my sister and brother. My brother didn't want me to be doing was riding horseback to school. So that's they moved over here so I'd be closer to school over here. I went to school here at Little Wound, you know.

Hence the forced removal of the Lakota community not only severed their spiritual connection to the land, but the community itself became fragmented as many had to leave elsewhere in order to make a living. The forced removal added another layer of trauma to the trauma already carried by the Lakota elders. This event served as a catalyst for a cascade of even more change and loss; it should be once again noted that there were no formal resources to support the families as they worked through these changes that had adversely impacted their lives. The forced removal was also at the hands of the Tribe and the elders have not resolved these feelings and carry the grief and loss as a result of the tribe's unilateral decision.

Massacres and the Impact on the Lakota Spirit. The massacres led by the United States government on the reservation have irreparably impacted the Lakota people. In discussing Lakota historical trauma, one elder immediately referenced the aftermath of the Wounded Knee Massacre of 1890 as follows:

Yeah that you can see that still that still is. Because in my life that Wounded Knee Massacre, my grandmother had a daughter living into a - marrying into an American Horse family - yes. Right above Wounded Knee area and so, when, you know, it's not by telephone, but they tell each other and they told him that where his daughter close to there where they had, they killed Indian people and at that time they had whatchacallit - Buggies - yellow wheels and a little box and very light. Anyway, he said, he harnessed up and he put a saddle horse on the side and he started out and as far as he can you know he came and went to her place, but she was alright, her and her kids were alright. 'Cause

he slept there that night and somebody came and said there was kids out there and some are wounded and they are laying out there; some were picked up and some were, you know, and it was really cold. So he said he went down there. He went down there and he said there's a little hill, a knoll, you know, and he said that he seen something and he watched it and there's a child so maybe one day to [inaudible] is about 4 years old as he got closer he'd go out of sight and then he'd come back up and he was watching. He waited, he waited and he went down so he went up and he followed the track on the hill there was...what do you call it? Um...water washed out, you know, and grass or the weed was over it like that [gestures] and here he seen that little boy go in there like that. So he went down there and he opened it up and here there was a mother laying there and one breast was out so he must have been living on that. So he said he grabbed [the child] and took his coat off and wrapped him and put him in that car and came back to his daughter's place – American Horse. And he said, "I'm going to leave right now." And it was late but he said that he's going to leave and he told them not to mention what he did – picking up the child - and he told his, his family the Bear Shield family that they're not supposed to *ever* mention that. We, even up to us we never talk about it because he, at that time, you know, the soldiers, you know, they can – like Hitler, remember Hitler was doing that, *we lived that life here, it was our land!* But it happened to us. So nobody ever knew and as small as he is, he can't talk and he can't say who I am or my dad or my mom or nothing. So my grandfather raised that boy and my grandmother so he was part of the family and he died, he died. You know, he grew old and he died, but he never ever found his family I don't think. Because a lot them were killed and a lot of those in the enrollment they don't know who died or you know, it's a terrible thing you know. (Elder 19, 89)

This personal description of the narrative reveals that many young children, women and families were also killed during the Wounded Knee Massacre of 1890. And a young orphaned child who did not even know his family was adopted by yet another family because all the Lakota regard themselves as part of one community. While the child was saved and grew into an old man, he never knew who his original family was, and his origins of being near the battlefield were a secret that was necessary for the child's safety and for the safety of the family who took him in.

One of the oldest elders also recounted other massacres, sharing stories about her family's connection to Crazy Horse, a revered Native leader who was killed in 1877:

Like Crazy Horse. I know where he was buried, because my grandma was there when she was little and he was killed at Fort Laramie- or wherever- and they took the body back to the reservation. Deep, in the deep reservation. And then he was buried there. She was there with her mother on horseback on the funeral. There's a whole bunch. She said a bunch of horsebacks on the funeral. And it had to be right after midnight. They have to watch the star and there was a star that goes on- the little one and it's midnight. So they watched that and when it was there then everybody got ready and they took the body and they already did the grave hole. So everybody was there and it was quite a ways from the place where they were camping. And they leave the old people behind and some children,

because, you know, they have to be look out for soldiers or be sneaking around it. So they leave them behind. And then they went by themselves. And sure enough. After they buried him and- they put twigs and grass over his body, but he was already dead long before. So many days before. So they had hides over him and they sewed them closed together so the odor don't come out real bad. And um they put dirt over him, and then twigs and grass, and then uh rocks and then they tromp on it. And they put clumps of dirt that they saved them on the side. They put them back on there *reeeal* nice, so from a distance you look and you don't see that there's a grave there. She said then they took off - the announcer said- "You all have to go back scattered. Don't follow each other back because then they'll - suspicion you know. They follow you - your tracks, if the soldiers come." *Just* as they got back why here come over the side of the field, all horsebacks. The solders from Pine Ridge. And they got there and they said to the old people, "Get up and tell us where the body is!" They were hollering, "Where's the body?" And they were just hollering, but they just keep their mouth shut. So they didn't even tell them where the body went to. And then-or what they do with the body. And then they said, "You didn't tell us where the body is." and they squashed down the coffee pots and then you know, pots and pans. They just damaged everything. The soldiers -- they done that. And then the little old people get up and then they pushed them down. Knocked them down. And then pretty soon they said nobody want to talk so they got on their horsebacks and then they left. So that was the end of it. That Crazy Horse. And *NOBODY* took his pictures. Nobody. My grandpa said that too. My grandpa was a photographer. It's a kind that- the three [legs] and then they have this camera up there and then they cover themselves with a black robe. And they take pictures that way. He had one of those, and - but then he couldn't take his picture even though he wanted to pay him and all that, but he wouldn't let him. But he - I seen that in the whole bunch of column of chiefs pictures in a cat[alogue]- in a magazine, and he was sitting at the end, Crazy Horse, they said that was him, he was down there. But they told me that they never took his pictures so... (Elder 5, 94)

This secret burial of the Crazy Horse away from the gaze of white soldiers also reveals the inability of the Lakota to mourn and properly bury their dead, especially one of their revered leaders. Because they were unable to openly bury him, the story above is one of three possibilities and the true location of his physical remains continues to be cloaked in mystery. His death marks an important moment in time for the Lakota people, because Crazy Horse and his band were surrendering to the inevitable life on the bounded lands of the reservation. He died at a time of tremendous change and the oldest elders in this study had parents and grandparents living and experiencing these traumatic events and have passed them down to their family members. The not knowing where a great leader is buried can diminish the spirit of the people, but the stories of the Lakota people secretly taking his body and respectfully laying him to rest nourish the spirit. They put their own lives on the line in order to do the right thing for their leader on their own terms, even under the duress of the Calvary. The gradual elimination of the

Lakota warriors and leaders accompanying massacres further sapped the strength of the Lakota, damaging their spiritual well-being.

Elders Mending the Spirit. For the elders who are in the oldest age cohorts, they are heavily influenced by their grandparents and even some had parents who were the generation who faced the massacres and shift to living on the reservation. Their interactions with white people and representatives from the government were not always pleasant. One elder shares the wisdom and teachings of her grandmother in the following story:

And so its, it's a hard life, it's a hard life. But that's one of the things that happen to me when my brother, from that day forward, I think that's what really made me strong. We went to school. The day school and the teacher, they brought a little *takoja* in, oh she was so pretty I never seen anything so pretty, real light skinned and blue eyes and blond hair, she was just like a doll. And uh, that teacher said, "You can't play with her." We're all Indians you know, that was a day school you know, and of course we had different color too you know. So my brother reached over, you know to ask her to play with us and she brushed him away and said, "Don't touch me; you are dirty." And he started to cry and he's my big brother older than me so when he cried, I grabbed his hand and we started running home, back to grandma, I was like, the policeman and the teacher were chasing us and they couldn't catch us, we were fast. We got there and my grandma was standing outside and she told them to stop, [repeats in Lakota], "*Takojas* are going back, stop over there and go back. I'll see, I'll see you, you know." In Lakota, [Lakota words] "I'll see you" and we went back in and my brother was crying so grandma asked us, this was really something that stayed with me through my life.

She asked us, "Why, why were you crying? Why are you crying?"

So my brother said, "Oh geez she said..." he described that little girl and how pretty she was and the little dress you know and the way he really watchcallit, she had a big ribbon up here, a blue ribbon and her little eyes were just blue and just, so my grandma's listening, "*Han, han*."¹² You know and he said he cried because he offered her, you know, his hand but she, so...she said "*Han*," she listened to us. And she said she asked me why I was crying. I said, "I cried because my big brother is crying. *He's my big brother, if he's hurt, I'm hurt. You know I will cry with him.*"

So she gave us water, she wiped our faces and we never had chairs to sit on we had little pads, sheepskin pads, you had to sit on that. She said, "Get your pads and go outside and sit down on the ground and I'll come out." So we both sat down on the ground waiting for grandma. I don't know what she was doing, but she came out and she said, that's when she asked how she looked and why we cried, so my brother told, "oh grandmother. We've got [something]"

She said, "Now listen very closely, what I'm going to tell you. Today and through your life you'll carry this, the words I'm telling you, reach over, reach over the pad and get a pinch of dirt." So we did, "Put it on your skin." She said, "Rub it." We did that. *Mother*

¹² *Han* is a Lakota word in this usage similar to OK in English.

Earth blended in with our skin, same color. She said, "That's who you are and peoples are going to walk all over you and sometimes you are going to fall down and cry and sometimes your shoulders are going to be pained because of burdens you have to carry for your people, that's the color of your skin will never change. No matter how I wash you, you will never change. That's the skin, the great spirit gave you and you are going to carry it because you are going to give thanks for your life and thanks for your people, wopila you have to walk with that."

So we didn't cry anymore. She walked us back to the school. But before, someday gave us a little kitten, a little white kitten, so we made it a box and put that little kitten and gave it water and milk and we just loved that little kitten so Grandma said, "the way you tell me about that little girl, *igmula waste la* [cute little kitten]. Maybe she looks like that little kitten that you loved. So my brother said, "Han!" So we laughed you know so she really didn't turn no hate she didn't tell us [inaudible] or nothing like that. *All she did was turn that bad feeling back to a love* how we described that little girl. So we never hate anybody even though they are different colored skin. You are going to walk with the people like that.

I: It's hard though

E: Sometimes it's hard like [inaudible]. Yeah, *being Lakota is not easy*, I'm telling you. It's very hard so we, we didn't feel bad about her and just love her like we did our little kitten. *So she just turned a hate into love, that's the way I understood it. And that's how you, how we have to live as Lakota so I said virtues and values of the life of Lakota is very hard.* (Elder 19, 89)

So unlike the generations succeeding them, the Lakota elders certainly had the resources located within them to not only contain but also heal some of the spiritual damage generated through the encounter with the white world. Especially the prejudice and discrimination that wounded the spirit of their children could be healed to a certain degree through such measures. Also, they had the nurturing love of their grandmother to explain and show by example the real lessons of life that are now shared in this dissertation.

A younger elder shares his journey to wellness through spirituality and how his grandmother provided a solid foundation. The introduction of the church and Christianity brought to Native people by the white men and women:

E: When I sobered up in '79, these two eagles came and sat out on these posts, not the same ones [currently there] and on the posts and, and they sat there and when they walked out they never moved. They stayed with me for over a year, all around me. You probably heard spiritual stories, lots of them...Several years ago there was a buffalo, before we had the buffalo up here, one came camped out on my lawn.

I: A big one?

E: A big one.

I: That's impressive.

E: It just stayed [we laugh]. So, those things I knew were messengers of change...to change or something was going to change or I was going to change. And it made me

more aware of our traditional belief system and whenever I talk to younger people and if they want to talk about traditional stuff. I just remind them who they are and they like to hear that, when we do this historical trauma grief recovery work and if we do it here or with any other Indian Nation, *don't forget what runs through your blood, you are all warriors every one of you and you are also medicine people, you are also healers and whatever you need to do you can do because you have that power. You don't know where its at yet, it just comes to you.* Being an alcoholic and being in recovery I had to work through the system, of AA to get where I am now. AA itself is a spiritual experience because we find god as we understand him.

I: Or her.

E: Or her. I used the Virgin Mary as my god when I sobered up. I said the Hail Mary every day, many times a day. And I still believe the Christian way in many ways goes hand in hand with Indian religion because everything is similar...so whatever works for a person is important. I see a lot of people don't have a religion to believe in and they are real standoffish and they don't have that sense of belonging. Some of my ex-wives, *untreated trauma and they have no belief system that they could really believe in.* They go to church but its...

I: An exercise.

E: For me I know its there but if you don't work at it. It can slip away. The culture that - the religion that they tried to take away from us went underground for a lot of years. When I was a little boy my grandmother used to take me to Calico, just north of Pine Ridge and they would have ceremonies there at night and by daylight, we'd be gone headed up the hill. We lived north, well west of Calico in the hills, north of here about 3 and ½ miles. So I was introduced to it early, being little, I'd go to sleep. So I was really fortunate. My brothers and sisters were never allowed they were too little, I was little myself, you know. And uh, so when I started to Sundance my brother said, "Why are you doing that?" He said, "You are going to hurt yourself." They did a number on his head too, my sister too, my sister [Name]. Even [his wife's name] church did a good number on her head until she figured it out. We don't hate the church. We believe both ways.

The suppression of Lakota spirituality and ceremonies had a damaging affect on the spirit of the people. They persevered and were able to maintain many of their ceremonies and belief systems outside the gaze of the federal government authorities. This elder was able to nourish his spirit, restore his own health and then go forth to work with others and share the teachings. Instilling the values and connecting Native people to their traditional belief system is imperative for the spiritual health of the people. Not privileging one spiritual belief over another, but allowing the freedom to believe and practice both traditional spirituality and Christianity, or other spiritual practices seems imperative. Nurturing themselves spiritually allows for healing emotionally and mentally with the trauma and other damage that has occurred in life, thus connecting the physical body, the mind and the spirit holistically. Also important to note is the times in life when he was rebuilding, the eagles and the buffalo visited him assuring him that he is not alone and connected

to the spirit world where those generations before him were available to help him and be there with him.

Nurturing the spirit and reinforcing their spiritual strength through private prayer and community ceremonies is a theme that appeared throughout many of the elders' narratives. Attending to their spiritual health is important for surviving a wide range of adversities. An elder woman who struggles financially and is often negatively impacted by the blizzards and limited resources on the reservation during these emergencies, shared the following:

...I'm Episcopal but other than that I'm traditional and I think that's why I can survive because they just have the Sundance there and I had the prayer because I don't ever want to go through what I went through last winter and I didn't have no food... I just pray to be strong and it helps, I know it helps. (Elder 22)

She has a close relationship with the medicine man, or spiritual leader in the community, which she seeks help with both physical and spiritual needs. She shares his method of healing.

He's just an interpreter of the spirits. They come and they do the doctoring. He's the interpreter. (Elder 22).

The elders find spiritual support and healing through the teaching they learned from their elders, by practicing Lakota ceremony and spirituality and they seek the help of the spirits through prayer and through the facilitation of a medicine man, or spiritual leader in their community.

Elders Struggling Independently/Alone. The reaction of Lakota elders to the adversities they have faced throughout their lives varies. As everywhere else, some elders are grateful for anything they get, regardless of how infinitesimal it may be especially when compared to the majority white population. Other older adults are never content and keep complaining, regardless of how generous their compensation may be. In general, however, all survive on very little financial support; and they usually spend the little they get not only on themselves, but also on their children, grandchildren and even great-grand children because that is the Lakota way: their spiritual well being contains the well-being of all those around them, both their biological as well as their communal relatives. Sometimes things could get so desperate that one elder called the tribal president for assistance.

...So we don't have that much money to buy our food, or pay for something. We're low. So it's really hard but the tribe don't see that. You know, we are having a hard time. Why can't they provide us with extra money, give us some extra money? Like look now I called Teresa and told her that my lights were shut off for 5 days and my food is gone and I asked her for help to buy food and she said there's no money.

I: When you say Teresa you mean the chairman?

E: The president, yeah I called her. (Elder 16)

As mentioned in previous chapters, there are several elders who struggled to adequately support themselves and their children throughout their lives. The thought of retirement or saving for the future do not exist for many of these elders. Several of the women have meager social security benefits from their own earnings or that of their husbands. In this study, the impact of the lack of resources was gendered; it impacted the women differently than the men. The women were all widowed or divorced, heading the household themselves. The women had little formal education, often working as homemakers, cooks, odd homemaking jobs like ironing and sewing for others, and as CHRs¹³. As a result, there are elders who are left with little or no cash, often having to prioritize the utility bills that are most necessary over others. Still, utilities get shut off, blizzards leave them stranded without heat, food gets spoiled in the summer when the electricity is shut off and sometimes the elders go without food in order to pay a utility bill. One elder described the dire situation of elderly men and women as follows:

E: Yeah, yeah. There's a lot of widows around, you pry know that...yeah. There are lots of them. [clears throat]. Two of my sisters are widows and they were young widows – forties. My mom was about fifty when my dad died. They weren't together, but they were still married. Life expectancy of men is really short.

I: Why is that?

E: A lot of it has to do with diet. A lot of it has to do with depression, depression and alcoholism. Along with depression you are going to talk about diabetes and heart disease. Depression is brought on by loss of self-worth – early when they are young.

I: Are you we talking about boys?

E: Right now yes, but it does work with women too because they become the bread winners early. They are the backbone of the family and the bread winners and yet nobody really recognizes that. (Elder 21)

It is significant that the elder mentions the loss of self-worth, as this is often connected to the spiritual loss they feel as their communities and lands were fragmented over time from both historical and present day situations. Some of the elder women shared their struggles to support their families when they were single mothers as a result of their husbands' absence due to alcohol, work, divorce or death. One elder was a cook at the elder meal site and would often go in after hours to prepare the next day's meal. She shares the following:

¹³ CHR, colloquially shorted from Community Health Representative, paraprofessional health workers in the community. "The goal of the CHR Program is to address health care needs through the provision of community-oriented primary care services, including traditional Native concepts in multiple' settings, utilizing community-based, well-trained, medically-guided health care workers." (www.ihs.gov/nonmedicalprograms/chr)

I didn't get paid for it, but for me that was to serve the people and make sure your food is good you know? Another thing that we had family problems and the kids' dad left and... I had five more to raise and they still had to finish school and I kept on going. I was working and the income wasn't very high either, but it was better than nothing and I had a home. If I didn't have a home and I had to move somewhere else then I'd have to pay rent and I'd be wondering where my children are over here because my aunt wanted to send me to Utah to work with my niece. She gave me the money and wanted me to work over there. I thought about it and thought about it, but my kids weren't finished with school, see? I thought, *well I had to stay*. I talked it over and my kids would have no place to stay and if I left I didn't know how my home would turn out and that's when I just toughed it out over here and raised my kids and they finished school. I had a – we had a set of twins too. They went to grade school here and when they finished grade school here I sent them to go to [Holy] Rosary -- that's the Red Cloud Indian School.¹⁴ I sent them over there and they all finished high school and that was the main thing that I looked forward to and worked towards was to have – to see everyone of my children finish high school and take up some sort of training so they wouldn't have a hard time. They all done alright there are a couple of them that I would say, thought their dad had done some good. (Elder 10)

Sacrificing a better financial situation for herself and her children, this elder made the hard decision to raise her children on the reservation where she was raised. She thought it was best for their development to remain where they were, as they had an alcoholic father who had left the family, a move may have been another large disruption in their lives. By doing so, she chose her own and her children's spiritual and emotional well being over financial gain, a decision based on Lakota values. One elder was widowed when she was forty-three years old, when she had the last of her ten kids a year earlier. She narrates:

So and then [her husband's name] died what? In '78 so then after that I just had to raise all those, those little ones I had by myself. I was scared to death at first because I never did have to worry about a bill because he figured everything, paid everything and when I had to, ooh my god, I thought I was going to die. “[Her oldest daughter], you have to teach me how.”

She said, “Mom you can do it. Just make up your mind.”

“I can't, I can't, I can't.” Ooh that was...then I come up here and I tried got into the bank and boy and I'd keep track of every little thing. “Why do you do that?” So I said then I go back and make sure that I don't. I don't want to make [mistakes]. (Elder 4).

The widows, and other women who were divorced, bore the entire burden of raising a family and attending to the details alone. The support of the adult children was essential for this transition since the elder had to deal with a new baby and the loss of her husband. The spiritual strength,

¹⁴ Holy Rosary Mission school, the Catholic residential school was renamed Red Cloud Indian School.

tenacity and independence the elder women demonstrated when faced with a husband who was absent or alcohol-dependent is significant. An elder woman offers insights into her hardships:

E: ... but he drinks a lot so I left him and I raised my kids on my own. At that time there was no food stamp or no nothing like that. So I had to - like I told you I did ironing for the neighbors or I helped them in the garden to get money to feed my kids and my mom and dad never fed them. I did my own. That's why I came back over here with two of them. [names of the kids] and brought them back over here.

I: So when you lived at Rockyford you had your own house?

E: No, I lived in a tent. Not with my mom and dad. Huh uh.

I: Whose yard did you pitch your tent?

E: I put it outside there by the - its on field what do you call it? Just like this so I lived far away from everyone.

I: With your seven kids?

E: I took care of them. It didn't bother them. My mom would come over and tell me and say here's some food you can eat and feed them

I: Did you garden?

E: Yeah I made my own garden and my mom helped.

I: How long did you live in a tent? It's cold in the winter!

E: No, I went to Pine Ridge and I got my own house.

I: So you lived in a tent temporarily?

E: I lived in a tent until August or September when it started to get cold. (Elder 16)

The elder raised her kids without any support from her husband, stating "These kids don't really know their dad," but she left because she did not want them to grow up with the chaos that resulted from his drinking. The elder women who had husbands who abused alcohol never said a negative word against their former husbands. They simply rose to the responsibility of raising their children and finding ways to support themselves, with or without the assistance of their families. As a result we see the weight of the child rearing falling on women's shoulders and they are thus considered "the backbone" of Lakota culture and life. The burden seems to be quite heavy throughout their lives because they raise their own children, and then their grandchildren and sometimes their great-grandchildren bearing the burden throughout their entire adulthood.

Three of the men in this study struggled with alcoholism in their younger years. Two of them shared some insights into their side of the parenting which was largely absent for some of their children. One elder was a single parent to one of his children. He noted:

It's been a journey to get here. I didn't get to watch my kids everyday to grow up; I only saw them occasionally because of divorces and I kept the oldest one and I raised him and uh, hope I did a good enough job, but I don't know. (Elder 21)

Another elder only had one daughter, but lost track of her since he was living as an alcoholic and even ended up on the streets of Denver. Someone intervened, helping him get off the street into recovery where he was able to resume his education. He stated:

I had some goals in life that I had to take care of them, one of them was to find my daughter, be the father that I was supposed to be and the other was to get an education and turn my life around and so for once in my life since I was when grandma died I started listening to the elders, and following directions again. (Elder 12)

He reconnected with his daughter and ended up raising her as a single parent; then she became a teen mother and he helped her raise her children as well. It is noteworthy that all these instances not only reveal the ravages of Native fragmentation that often ended up in depression and alcoholism, but many attempted to maintain and reconnect to their spirit by returning to the Lakota ways and lean on their spiritual beliefs to carry them through the healing. Among them all, the elders discovered and appreciated the significance of the body, mind and spirit connection to heal themselves. In this healing process, they often turned to support each other.

Elders' Informal Support of Each Other: As evidenced throughout their narratives, the Lakota elders cared very deeply about their peers; they went to great lengths looking out for each others' well being. Service to the community and considering the well-being of the community is an aspect of the Lakota values and ways of living. In the context of teaching the Lakota principles, one elder stated this very succinctly, "you have to help others in order to help yourself" (Elder 17). Thus, they created an important spiritual support network that protected the elders. A younger elder, who had a number of health issues that inhibited him from providing physical help, nevertheless provided support in other ways. He noted:

...because these elders all support each other and...I went to a guy's place out in north of Oglala and he had no insulation and it was November, the end of November. An old guy, I called up a couple of people and by that time I had to leave the area for a little while. I look back over there and he [has since] passed on. He had a stack of wood, a huge stack of wood, kept his fire going. (Elder 22, 63)

Hence this elder was able to mobilize others to ensure the well-being of one in need. Indeed, the social networks among the elders enables not only their physical, but also mental and spiritual survival. Johnson Holy Rock is described in particular by one of the younger elders as a "real elder" because of his wisdom and service to the community, partly his terms as Tribal Chairman and Tribal Councilman. He is a respected leader who forms a significant node in this social

network of elders in his community. As a result, other elders will ask him to speak on their behalf. He illustrates this situation in the following manner [emphases mine]:

...Settle back to I'm true to myself, I still feel good enough, satisfied. So...at chosen times, I test the atmosphere. I test my fellow man. One wanted to debate a point of issue and I'm familiar with the point of issue. I'll debate with him like two lawyers before a judge and assert my knowledge (taps taps). I won't let them (taps) talk me under the table (taps). So in instances like that maybe other people have enough confidence that I will speak for them. And I would, I will speak for them. Then, I'll take it from there if the person, uh addressing take belligerent and I'll debate the point of issue. I'll even offer to go see the Superintendent. Let's go see the Supe. Let's go debate the point of issue for that lady. They simmer down. Well what does she want? So find out there, it shouldn't be that way. *They are discriminating against their own people and nothing can be lower than that. I detest anyone with that attitude because their elders before them went through the same treatment they shouldn't treat their elders like that.* I guess, uh, I'm just a person that wants to test what is right and what is wrong. I should have uh stayed in school and bucked for lawyers' qualification, defend people. But...instead I chose to, uh...uh...*I chose to, uh, help people who depend on me not because they need it because something causes them a - to lower themselves in order to be served by their next door neighbor so I rise to the occasion.* I speak for them. It's an ongoing thing, unfortunately. I've seen it again and again and again. By seeing me on the street if they talk rough to me, I say, "Hey man, go home and get up on the right side of bed." They get the message, but unfortunately life is that way. You have to assert your rights and you have first rights...*LIFE. You are who you are because he gave it to you to take care of, protect and defend.* If worst comes to worst, fall back on...so, somewhere I guess I ran off the track and uh, so...but it's a feeling of, misplaced feeling of, *a feeling of superiority* compared. It's a good feeling to have, but the right place to apply that an occasion that demands that you assert yourself. You don't develop that to look down on your next door neighbor, that's discrimination. You are no better than he or she is. *You're teaching, treat someone with respect, consideration.*

This quote reveals the manner in which some of the elders are able to retain their spiritual well-being by helping others, advocating on their behalf. Advocating for himself, for other elders, for his people in general and challenging the practices that result in disrespect for the elders is part of the spiritual values that guide the life of this special elder. He believes and acts upon these social justice values for the greater spiritual well-being of his people.

In addition, there is evidence of resources that come to the reservation from the outside through a variety of conduits, like church groups, individuals, and donations to churches. One

elder, a recipient of such resources, nevertheless does not consume them alone, distributing them to all others in her district of Oglala because doing so improves her spiritual well-being. She states:

E: Some white guy sent me heaters and I pass them out. I get calls all the time, “We’re out of propane” and then the next year they are in the same way.

I tell them “You should try to take care of your heaters! What do you do with them?” I bet they sell them. No, somebody sold them. [Elder 7] is that way, every time I give her something new, she doesn’t have it for a second. She’ll ask, “Do you have another one?” I said, “Quit selling them! I can’t be asking for them all the time. “

This year I only got eight so I give them to the big families, the ones with babies or just elderlies. I used to give it to [elderlies], but now I give it to families. It’s too expensive and they can’t afford the propane, that much.

I: Where do you get the heaters?

E: From a guy in Indiana sent them. Not this one [points to the one in her living room], I got this from Wal-Mart. That’s an older one and this is a newer one. But every year I get one and I got an extra one and someone ran out and sent the kids over. Whoever runs out and I tell my son to take it to them. (Elder 9)

An important element of this story is that the elder cares about her community; her spiritual well-being is very closely interconnected to the well-being of others. She herself does not keep the heater, but gives them to others who need them more than she does. She mothers the community when they ask for the heaters by scolding them and trying to get them to care for the resources they have because they are finite. Additionally, the interactions between the elders and the ways in which they repeatedly help each other and ask one another for help is demonstrative of the cultural values of generosity, kindness, respect and care for others, values that nourish the spirit, in themselves and others. Sometimes, however, some elders may start engaging in exploiting resources.¹⁵ One such elder (Elder 7) shared a story with me about baby diapers that were donated to the church; she was able to get up there, alerting others who could use them. We went to the Senior Center to pick up her meal where they had commercial size jars of food for the elders to take; she took a few jars and said that she was going to give them to her neighbor who helps her. She makes bread every morning and she sent some home with me after our visit. She enjoys rummage and distributes it to her neighbors including [Elder 7] who shared the following story:

¹⁵ In defense of [Elder 7] mentioned above, it should be noted that I do not know her as well as the elder who claimed the former was selling the heaters. She can be characterized as someone who has her ear to the ground and keeps track of the available resources. She often can be found spreading those resources to others in need, not hoarding them for herself.

She likes to go to those churches that are all around here because she gets rummage. She really likes rummage. [laughs] I don't know what she does with it. "I've got some rummage for you" and I said, "No, I don't want it -- give it to somebody else."

"No I'm saving it for you."

"Eee! Well, don't be doing that." Some of them belong to some dead person and she's crazy about rummage.

"Let's go to yard sales."

"I don't wanna." (Elder 9)

Initially, I thought the elder woman only distributed the heaters. Yet she helps others in just about every way that she can, even if at times she does so grudgingly and the recipients are not as responsible as she would like them to be. The boundaries between mending the Lakota community and occupying a node in the elder network by engaging in rummage quickly become blurred. This elder continued to note the following:

I help other people going to clinic when they don't have enough money; I know how it is. I used to work with people like that. They have gas money or not. Gas is really expensive now. They say that if they bring something, then I buy it, I like to buy beadwork so they are always in line here. I haven't bought any for awhile. [pause] I have some money, save the rummage. That box in there is full of baby clothes. That girl of mine with the daughter-in-law. She's going to have a baby -- that's going to be her ninth one. I said, "She don't even have no baby clothes. I'll take that over there." So she's going to take that I don't know when. I got tired if she don't hurry up and take it. That's full of baby clothes [points to a big box]. Somebody sent me those the other day. I crocheted her a - what do you call it? The yarn, those little baby blankets I throw them in there somebody sent those to me. Give those to the children, "oh that baby could have this" and I throw it in there. I don't use them at all. "They have babies they could use it." Sometimes they ask me for Pampers too. That's one thing they hardly send me every once in awhile.

I don't want too much rummage. I used to get a whole bunch of it and give it out, but I can't do that anymore, tired. I get older [and] I don't want to do a lot of things. At Christmas, they used to send a whole box and now I just say, "Come and get!" My son has one - he's giving out toys and stuff like that. One lady gave a whole bunch of boxes and she said to go to the thrift center in Rapid and pick up a whole bunch of fruit so he went and here he bought about ten boxes of apples and got some baskets, "Oh no, I can't do that anymore, take them to the district and give them out." So that's what he did. He gave them to the district. He was giving out apples, bananas, oranges, all kinds of fruits at Christmas time. I gave everything to every one of them. They all got something. They always send it to me. They must tell each other because different people ask for them. Now I can't handle the toys and things and I ask at Loneman's¹⁶. We don't have books. I said maybe we need books. So [she] send it to Loneman School. She sent about 15 boxes, big boxes all full of books that I got so tired of it. We put them away but there's no room.

¹⁶ Loneman is a Day School, or elementary school in Oglala.

“I’m sick and tired of these books,” I said. So now I’m giving some of them away. “Take whatever you can, for giveaway¹⁷”

Parents would have food and so I’m still putting those books away. I still have about ten boxes to go through. But they steal them and kids take them back and don’t return them. So we don’t have nothing so boy! She gave us. She’s a retired teacher and she gave us all the books and even head phones and they are all they probably lost all of them now.

I: Seems like we’re really hard on stuff.

E: Really hard, cause we are. On Christmas, we are hard on toys for the kids and they expect so every year I have to send toys over here and especially the older ones are wanting toys too. I only get toys for the younger ones – teddy bears and stuff like that. I used to visit like that but anymore I lost interest in that. I let the young girls do that because they are there.

Even though the elder attempts to contain what is sent to the reservation by distributing them to the rest of the community, it is evident that these are often charity items that are sent without any recognition of what is actually needed by the community. This expectation of annual charity, this dependence on it reveals once again the lack of self-sufficiency in the community; what they get is not what they produce, but what is donated to them. They still attempt to keep the Lakota spirit alive by distributing these resources and sharing with the entire community.

A male elder has established an organization in the community where he specifically helps those in need. He connects donations and resources from Denver and Nashville, then filtering it to the community. He noted the following:

E:…The most important part of being an elder is being a roving angel. Do you know what a roving angel is?

I: Huh uh.

E: Its uh, you give uh, you help people, you feed people, you take care of children and elders, and when you see a down-and-out person you give them a couple dollars. Once that money leaves your hand, it's not yours and it doesn't matter if they eat or drink it, but you are doing your share of what you are supposed to do under god. That's how I teach people now. I have Buffalo Foundation that I feed people here on the rez and all the elders give out turkeys and feed people because I didn't have much growing up and we were very poor and we were never given anything from the government and never did accept anything. (Elder 17)

Sharing all the resources they acquire with the community in this manner not only helps the elders' spiritual well-being, but also uplifts the spirit of the community. What is significant here

¹⁷ Giveaway is a ceremony or gathering where a family or individual gives away gifts and items to those present. This often occurs a year after a death, at celebrations, Sundances, Pow Wows, and anytime there is gratitude to be shown in the community.

is the pride the elders have in not relying on government funds; never having any previous experience with governance except at the level of tribes, they perceive the government as unrelated to their needs. Instead, they rely on donations from elsewhere that they can then distribute as they see fit. This notion of not receiving and not accepting anything from the government is a strong idea found in two male elders' narratives as well:

My dad wouldn't take commodities and he wouldn't take welfare. We always worked. That's probably what saved us. We didn't have to reach out and beg for anything we could always work and work our way out of it...uh, so what I thought was bad at the beginning in life being poor and not having anything ended up being good for us, but we never did get that outside help that everybody is getting now. We didn't know what welfare was, we didn't get this commodity stuff, we didn't get none of that. (Elder 12)

Self-sufficiency is very important to the elders and in a broader sense the importance of working hard and providing for oneself and their family is valued for spiritual well-being. These two elders are in a position of privilege because they both left the reservation and had successful careers working for the federal government in different capacities. One provides service to the community, but the notion that they did not accept help should be placed in the context of their gender and financial situation. While their families of origin did not accept any help from the food programs or the cash assistance, which perhaps was less available then than it is now, is admirable but should not be in judgment of those who do accept commodities or help from the federal programs. Nevertheless, it is significant that they spiritually share what they receive with their entire community. The next part delves more into the support that is available to elders, assessing in the process whether this support addresses what the Lakota community really needs and to what degree.

Part II. The Spirit of Community and Care for the Elders

Service to the Community. As evidenced by the elders' teachings, service to the community is a cornerstone of Lakota spirituality and ways of living. The service comes in many forms and seems to stop only when the elders are no longer able to continue. Throughout their narratives, it became evident that the elders protected the vulnerable in their community from harm by stopping a robbery, rescuing children, starting a food bank, feeding children at the gas station, distributing donated goods, mentoring youth and walking each other home. These actions are large and small, ranging from spiritually impacting one individual to impacting the

broader community on the reservation. An elder from Wanblee who is in a leadership position, but seems to have dedicated her life to serving the people in various capacities shared the following story:

E: It's here - sixty-four houses; we walk from here to Pine Ridge to get this for our people. We asked for a housing, a high school, a clinic – healthcare, and water and sewer system and employment. Five things that we needed for our community to be developed. So there would be more people here – have a house to live in – have a healthcare, educate the children, water and sewer for health – that's healthcare, you know, we need that. So, I was one of the main person that walked I had my pictures and everything you know.

I: When was that?

E: That was when Robert Kennedy was...going to run for...presidency. Yeah, that was in 1960 something, so we went over there and we showed him our little flat and he understood. We got everything. The last thing that was built was our high school. That was beautiful and we have all these houses – sixty-four of them here right on this side, but there's more building and there's one by the grave yard, one by the grave yard. This one is Lakota homes, a grant developed housing. You know, so that's different from this, these are the low income houses we are talking about and then there's one out there as you come in from over there – Georgetown we call it. (Elder 19)

Securing housing for the people was an important aspect for the communities that were far away from the town of Pine Ridge, which was the place where the BIA settled its headquarters, where the hospital is located as well as the OCS boarding school. Members of the Wanblee community organized themselves and marched more than a hundred miles to garner attention and demand that these needs were met. Hence, the elders organized, thereby asserting their agency in having their community's needs met. Additionally, this particular elder sought to build a proper building for the elders to host their meals and other activities. She noted:

I: You are the elder representative; how do you become one?

E: I was the president first so, and I put up that nutrition center, through the health center, they helped me, you know, go to the state and talk to the governor. [Name of other community member] and [Name] helped and I used OLC¹⁸ for the uh, the work, they gave us the money for lumber and everything. So the carpentry came from OLC to learn how to put a building together

I: That's brilliant.

E: Uh huh, so we really - the only thing that was just a torn up building, just a maintenance building. Just the studdings and the only thing that was there was a toilet seat. There was only one bathroom and everybody made fun. Ooh! That's been there for over a year; you'll never get nothing out of it. They had a district meeting and they gave it to the elders. So then I went to [Name] and I started working with him, you know, and we went to the governor and the tribe. That's all they had to pay was \$3333...but the

¹⁸ Oglala Lakota College, the tribal college located on the reservation near Kyle with satellite classes held in districts around the reservation and in Rapid City.

state side was \$10,000 so I met with OLC and they put the carpenters out here to learn and there was a guy by the name of [Name] and uh, [Name] and they did the electric work. So we kind of help ourselves.

This elder demonstrates how she collaborated with others in order to garner the support of the tribe, appealing to the state government in order to gather enough funds. She also used this as an opportunity to rely on the knowledge of the people and of those learning through the talent from the tribal college. In this manner, the elders led the community in deciding what they needed. They refrained from waiting for the Tribe to help them instead, employing all the resources they had in the community especially in terms of hard work to make life better for the community. In this manner, they were able to teach others how to retain their spiritual well-being by becoming conscious of what their needs were, seeking solutions to have their needs met, and maintaining their spiritual well-being by relying on their own labor in getting things done. The satisfaction and pride of self-sufficiency and networking led to a great degree of spiritual well-being as this narrative was told by several people in the community.

Johnson Holy Rock, in his capacity as a Tribal President also fought for housing for the people. He shared the following [emphases mine]:

...uh, I've rubbed elbows with politicians, Senators, Representatives; I stood in the White House, in the oval office and shook hands with John Fitzgerald Kennedy. I went there when I was Tribal Chairman. I begged him to give us better housing than our grandfolks have. He responded and that's how come we have houses now, better houses. We lived in tents and old car bodies, uh, anything that would serve as a house. So I grew up in a tent and part way when I was...school age, uh, was the first time I lived in a regular house so I came up the hard way, but I wanted to exist in a world that I could live in comfortably. *The only way I could do that was to shift back and forth between culture.* Many people can't. They want to hang tough and they suffer for it, but I can't change them so that's the way.

This narration captures how the elders were eventually able to negotiate with the state and government to have their needs met. This engagement spiritually empowered them as they were able to make life for their community better than their own. Such negotiation 'between cultures' captures the manner in which some elders were eventually able to negotiate both. Later the elder elaborated further on his service to the community as follows:

E:...I accomplished what I wanted. But it takes person a goal; you have to set a goal. You have to develop one thing at a time. I accomplish it to completion, a finished product. Help the people to get services that was needed. It's a piecemeal thing. Also, I had

housing. I don't know how many trips I made to Washington. I told the Council,¹⁹ "I'm going to spend some of our money to make trips to Washington to get houses." The Council was very helpful. They said, "go ahead." They left the budget open so if the opportunity appeared, "Move!" and they left the judgment up to me. I made several trips; there's a picture in my house now it shows me standing there with John Fitzgerald Kennedy in the oval office in the white house. There are very few Indians that have ever stand in that inner office of the president. I made it.

I: What did you talk about with him?

E: Housing. I told him I wanted houses for my people. We have had a treaty since 18[inaudible]. [I told him,] "You guys haven't done anything. You haven't *even* replaced our tipis; you didn't do anything. We need help now. *NOW*. Not tomorrow, next day. *NOW*." He didn't tell me himself, but he told my lawyer, our lawyer that "I'll work with him. I'll do whatever I can." You see all the houses now. Improvement on housing for the hospital - for personnel so they could live close to the hospital and the old age home across the street and then the moccasin firm.

It is interesting to note that some elders eventually learned to negotiate with the state and government to help the community with their urgent needs. This negotiation also spiritually empowered the elders, probably helping them overcome some of the destruction and fragmentation they experienced while growing up. In return for such engagement, all the elders wanted was respect from the community.

Caring for Elders in Nursing Homes. Caring for elders is an important aspect of Lakota culture and values, thereby ascertaining the spiritual well-being of the entire community. There are families who do indeed care for their elders; one such elder woman was described as her family's 'queen' where her children and grandchildren surrounded her, assuring her needs were met in every way. Yet other families struggled with social, emotional and financial issues that created barriers for them to care for the elders. It was important to gain insight into the perspective of the elders in these cases. The elders participating in this study all lived independently in their own homes, except for one who was living at a nursing home in Rapid City. Each of the elders had family around them; many have adult children or grandchildren living with them, others have siblings, or nieces or nephews who provide assistance when the elders need it. This family support provides more than physical support; their existence also spiritually nourishes the elders.

When asked about what they would do if there was ever a time when they were unable to take care of themselves, not surprisingly all of the elders wanted to remain in their homes as long

¹⁹ The Tribal Council is part of the governing body of the tribe. There are 2 Tribal Council representatives elected from each of the 9 political districts on the reservation.

as they were safely able to do so; beyond that, they were willing to go into a nursing home. One noted:

E: I already told my kids that I'm going to a rest home.

I: Really, how come?

E: I don't want to bother them.

I: Which rest home?

E: I don't know; they have a lot of them in Rapid. I could go up there, they take your retirement. You pay for it, but I won't need my retirement if I go up there. (Elder 1)

This notion of not bothering or burdening family and going away when they are no longer able to be an asset to the people is rooted deeply in Lakota spiritual practices as well. Johnson Holy Rock gave insights into the Lakota cultural practices that go deeply into the past regarding the older adults in the following account:

I used to sit by my mom when my father would butcher a cow or a big steer and they used to, uh...take the meat and make, uh, dry it, sun dry it until the meat is so dry you can break it off and chew it. That helps your teeth, that's why our old ladies used to wear their teeth down right to the gums and there wouldn't be one, uh, uh...(taps taps taps) teeth problem in the old lady. But they get to a point where they can't travel. Their joints begin to fail. So they used to sacrifice themselves. They would tell the chiefs, "Just leave us enough meat that we can live long enough. Go on. Go on. Leave us. Make us a good tipi. We will live as long as the Great Spirit will provide." So they used to sacrifice the elders. *In fact they demanded to be sacrificed.* So they would leave them at the last camping spot and promise, "We'll be back." Sometimes they did and sometimes they didn't. When they did, the elders were either not there or they might find a bone or if they came back to the same camping spot it would bring back memories. They didn't want to come back the same spot again. *So the elders were sacrificed; they didn't want to burden the whole camp by having to drag them along from camp to camp. So they chose to sacrifice themselves because they were an imposition on the life (taps) of the descendents, of the little ones.* It was a tough life, a tough way of life. But they were ready to go when it was ready to go; they were ready.

So not only did the elders work for the well-being of their communities all through their lives, but when they got too old, they then sacrificed their own lives for the well-being of their community. The elders did so because they did not want to impose on the lives of their descendents on the one side and the young on the other: this perception reveals how the elders regard Lakota life as one spiritual continuum that extends from the ancestors through them to their descendents.

A short time later, Johnson Holy Rock continued to demonstrate how he prepared his own family for when it will be his time "to leave." These teachings were very much rooted in the

Lakota consciousness of the time before the white man arrived. As he was one of the oldest elders in this study, he remained very close to the generation of Lakota people who lived in that time. He stated:

I: If you weren't able to live independently, who would help care for you?

E: If I chose to, uh...sacrifice myself?

I: Like you can drive and you live alone, what would happen if you weren't able to do that?

E: As I told my family, "I don't want to be an imposition." See that comes from way back there. "Family, you have little ones that you are responsible for. (taps). Think for them, help them. My time is very short; you don't have to worry about it." That's why when the elders used to say, "Leave us enough food and leave enough wood piled up close to the tipi so we don't have to go far. Go, go on. Don't look back." Now that's a hard position to take, but it's easy because they expect death to be waiting at the end of the line. It's going to happen. You can't wish it away. You can't stop it. All you can do is get ready for it. Make it easier on those whom you are telling, "Don't look back, go, get out! We're not going to drag you back. You have the little ones to worry about. They will live the longest. Worry about them. Don't worry about us." For them, that was life. They weren't afraid of it. So that's the way I am. I told my daughter, "Prepare yourself, my daughter, the day is going to come and you aren't going to hear my voice anymore; you aren't going to see me. Get ready for it. It's going to come. You can't stop it. Look at Grandma and Grandpa; you saw them leave. You know where they are. But they're not here. And you are alone. So, when my voice is stilled, whose voice will you listen to? And your children are going to listen to you if you are going to be responsible. Don't worry about me. My worries are ended. You don't have to worry about that because I'm in a place where I don't expect the sun to come up the next day or the moon to rise at midnight."

But it's the people that's important; that perpetuation of a culture, of a people, of a species to be maintained. When the time comes all of a sudden at noon hour, everything will go dark, the earth will start shaking, there will be lightning flashes, thunder rolling...earth will begin to have cracks in it. The end has come. Prepare for that. Me? All of a sudden surprise! Surprise! I came back to life. Much to the disappointment to many people, perhaps, but there I am. [we laugh] So I've prepared them. "Don't feel bad. Only a short moment."

This Lakota perception of death is different in that death is viewed as a natural occurrence of moving onto nature until a time when the earth ends. Once death occurs, the teachings of the elders are passed onto the next generations to ensure the perpetuation of the Lakota culture and people. Then the next generation takes on the responsibility of teaching the Lakota way to sustain the community. The naturalness of this cycle of life and death reveals the manner in which Lakota spirituality extends beyond mere humans to envelop the Lakota as a people through time and place. It also explains how difficult it is for the Lakota to adapt to the white

way of living that stresses the individuality of each person that does not expand into the past and the future.

The care for elders is not only physical but social as well. Elders expressed several times that they like to spend time with others in their age cohort. With the changing times, however, the gap between the generations becomes increasingly fragmented where the continuity of the Lakota spirituality is interrupted. Younger Lakota generations are not interested in talking about the past which greatly disturbs the elders who may be removed from the interests of modern day, like technology. As a consequence, in some cases, going to a nursing home is undertaken for the social outlet more than the physical support. As one elder noted:

E: Well, I am able to care for myself.

I: Do you think there will be a time when you won't be able to?

E: Oh yeah sure.

I: What will you do then?

E: I'll go to a home with other people, someone to visit with; you know nobody wants to visit with a 100 year old woman... but I don't, you know...there will come a time when I thought about moving this spring, but I think I'll stay another year here. But I want to be around other people my age; *I get lonesome*. When you are alone like that, nobody likes to come and visit you know. There's nothing to talk to about with them. You know? You know. They have you know how young people are these days. They like to be on the go and you know they are different; even my grandchildren are like that. They don't care to sit and visit, you know. But you don't visit. You don't visit about the same things when you are old; you kind of your mind goes back to a long time ago and they like to visit about things now; it's different. (Elder 6)

This lack of sharing Lakota values across the generations reveals how much the elders feel disconnected from the younger generations, a disruption that fragments Lakota spirituality in a manner that endangers its continuity across generations. And this is the case because younger generations are more interested in modern things, in technology and the elders may feel that some of the youth no longer seem to value the Lakota traditions. Although, as mentioned previously, there are youth who are participating in ceremonies, but these elders are missing the visiting and the telling of stories that they experienced with their grandparents when they were young.

The one elder who lives in a nursing home in Pine Ridge confirmed the financial aspect of this situation. She gives up her retirement to the home and they give her \$60/month for personal use. She is active in the activities there. She has made the nursing home her new home and voices her concerns freely as follows:

E: It's better. It's better cooked. But first time when I was there, gee, potatoes weren't done and they put sugar in. Gee, who ever eats fried potatoes like that? And uh, macaronis too, they're not half done. So one time they had community building - community meeting. So I stood up and told them what was going on about the eating. And even the bread. So now we eat good!

I: Oh good. You made a change!

E: Yeah I did! I'm kinda outspoken. A lot of them, you know, they don't want to get their record bad you know, so they don't want to even open their mouth about one thing.

Hence the elders try to make the best of this new situation where rather than sacrificing themselves for the Lakota community by awaiting death, they instead move into the nursing homes where they are able to get care. Yet such a move only maintains their physical well-being; their spiritual well-being suffers because they no longer have the connection to the rest of the community, especially the younger generations. As a consequence, a common narrative surrounding the Lakota elders is that they are lonesome. The elder at the nursing home is able to visit with other people in her own age group. Still, many people from the reservation go to Rapid City for shopping, health care, and social activities. As a result, unlike the case with some other elders, her family is able to visit her frequently. She notes:

I: Do you miss the reservation?

E: Yeah.

I- Do you?

E: I miss my friends.

I: Did you go visiting a lot?

E: Yeah. They come... I stay in my bedroom and they come and visit me.

I: Do you get a lot of visitors?

E: Yeah...I don't have time to get lonesome. (Elder 5, 93)

The brother of this elder is also living at the facility and she mentioned other Native elders living there as well. She enjoys life there and had no complaints about the treatment she received. Fulfilling her role as a Lakota elder, she helped the activities director incorporate more culturally sensitive aspects into the activities. She wanted to share some of the traditional stories with the other residents. So she was able to maintain the Lakota spirituality, but only with her peers. In relation to her brother, she mentioned the following:

E: And the one [brother] that stays here with me at the old home. My brother. He's the only living one. There's one or two of us left in our family. And he's got arthritis real bad. When he came in, why this was all swollen big in his elbow. And his knees. So he have to stay there at that old home too.

I: Ah. And he lives at the same place that you live?

E: Yeah...He's uh- he was telling me May 15, "I'm 70 years old today," he said.

In relation to feeling lonesome, this elder has children who are well educated and who hold well paying jobs. Given that nursing homes or long term care facilities are away from the reservation, other elders whose families are out of work or have more limited resources may struggle to maintain such visits and connections, thereby once again disrupting the natural flow of Lakota spirituality across generations, where the generations visit and share the wisdom of life and living, connecting as family.

All of the elders who said that they wanted to go to the nursing home stated that they wanted to be with other Native people from their generation; they also desired to not have to go off the reservation. Currently, there is not a nursing home on the reservation, however. So their physical removal from the reservation to a nursing home off the reservation reveals how the nursing homes are not set up in a way that takes into account the needs of the Lakota elders.

There is the Cohen Home which was a long term care facility for older adults on the reservation, but over the years the tribe loosened the criteria and allowed younger age groups to reside there. One elder had lived there for a few years stated the following:

E: I was in Pine Ridge; I lived in Pine Ridge at the Cohen home. For three years. For three years I was in the Cohen home...

I: The Cohen home is like a nursing home?

E: Yeah. After I found out what it was, I didn't even stay there.

I: Were they good to you?

E: Yeah the cook and the boss they were nice, but some of the people that live there...

I: It wasn't good?

E: No.

I: Was it safe?

E: Yeah. I didn't want to live there.

I: It's not just old ones.

E: It's the young ones from down there. It's the old ones even though they lock the gate I don't know how they get in, but they are around.

I: But young ones live at the Cohen home too; it's not just elders.

E: Yeah before it was there wasn't hardly any kids around there, but lately when the kids were starting to come around and get into the apartments and stuff I said I'm not going to stay there I'm leaving so I left. (Elder 16)

Generally, the narrative regarding the Cohen Home is mixed. As people of all ages started to live there, it felt unsafe to the older adults who have noted a decline in conditions as well. Once again, it does not appear that the needs of the elders were prioritized. Depending on the point of view of particular elders, negative comments were shared. Still, others accepted the conditions

and were grateful for the housing. One elder used it as temporary housing while her house was being renovated by the Tribal Housing Authority. Another elder shared the following:

The Cohen home, they are really treated bad in there. It's really pitiful. Before it was treated good. Early in the morning they could have coffee and sit around and not they can't have that and they don't feed them good. (Elder 4)

Several elders mentioned that they wished the tribe had converted the old hospital into a nursing home facility, but instead it was converted into office space, once again not taking into account the needs of the elders. Johnson Holy Rock shared the following regarding the old hospital:

I: You mentioned the hospital should have been an old age home.

E: It can happen...

I: Do we need that here?

E: You bet we do.

I: Can you tell me more about that?

E: The answer to that question is the state government has blocked it. They want nursing home or old age development here, it would reduce the need in larger areas and larger areas complain to state government that they are undermining local enterprises; they blocked us off over here so we have to send out old people over there. The money goes with them. So if we develop it here, we get the money but it takes investment.

Hence the profit motive of the nursing homes off the reservation takes precedence over the spiritual needs of the Lakota elders. There are mixed feelings about the quality of care from the off-reservation nursing homes and the need for it on the reservation. There are stories of Native people not receiving good care in the nursing homes nearby; this condition is further complicated by the feelings of elders who want to stay at home, but who have families that may be unable to provide the care. As one elder explained:

E: I think we need one [nursing home] on the reservation. The reason they told them because there is one in Hay Springs [NE], one in Gordon [NE], one in Rushville [NE] and one in Martin [SD]. I don't know why not, there is enough land and stuff.

I: Would the elders use it?

E: Yeah more than Gordon or Rushville. They say when they go there they're not treated right and this guy that lived by [her daughter] and he used to tell me that "My wife is in a nursing home and I want her to come back."

"[His name], you can't take care of her. You are old."

He said, "I've got two big girls" and I said, "Yeah, but look how they drink."

The other day I went to see her and she was in potty clear up to her neck and she was all wet. I went and complained and it stinks so bad it burns your nose.

When [his wife's name] was in there, she said, "They are mean to me and I'm always in the chair or always in the bed."

[The staff said] "We ignored her and thought she was just wanting to go home."

They made a visit [unannounced] and her hair was all bushy and her bedding hadn't been changed; she had sores on her hips.

“Don’t you clean her?”

“Every three days we do, but she’s so ornery.”

She moved to Rapid and they found a sore that big [makes a circle with her thumb and finger]. They called the health department and it's pretty nice now. They don't care if you are Indian just so you are changed.

Unlike this case, there is an elder and her brother living in a nursing home in Rapid City who is satisfied with the treatment and accommodations. Much like nursing homes anywhere, the care and the quality vary. Yet the Elders are often concerned about racism and the harsh treatment they receive due to being Lakota in a non-reservation facility. Also important is the role of the elders supporting one another and following through when proper care is not administered. Still, such discussions reveal that the elders needs are not taken into account in providing them with long term care facilities.

There is a great need for nursing homes on the reservation, as the elders and the community would benefit from having their elders remain close to where they have lived all their lives, or if they moved away, where they grew up and consider it home. The elders would then be ensured that they continue living with their friends and with those who have experienced a similar upbringing. At the time of this study, the tribe was making inroads to having a nursing home facility built on land owned by the tribe in Nebraska, in the town of White Clay. The number of elders with families who are unable or unwilling to care for their elder family members does indicate a shift away from the Lakota culture of ensuring the well-being of the elders in the community. One complicating factor is the fact that the elders also live with multiple chronic diseases which in their advanced years may require skilled nursing care that is beyond the abilities and resources of the families. Still, it is evident that the spiritual needs and well-being of the Lakota elders are not taken into account in the provision of nursing homes. They are often separated from their families as well as their peers as they are assigned to nursing homes off the reservation.

Providing Social Support for the Elders. Generally, there is at least one person that the Lakota elders identified that helped them or will do so when they need them; this person often turned out to be one of their children. As previously indicated by the Lakota elders, however, there is tension between the younger generation and the elders due to changes in norms, values

and priorities in life. The Lakota elders are often left on their own to fill in the gaps, or the pressure to help falls on the shoulders of one family member. As one elder noted:

I don't know 'cause you know my other sister is around, or my other daughter is around and fixed the shower there and put a chair there in front and makes me sit in there and help me wash. Helps me do anything you know, helps me out with washing you know. This other ones says they would do that, but they're always going around. They have a car so they jump in. (Elder 3)

The Lakota community spirit that once enveloped the generations is no longer fully there; the young generations no longer feel the obligation and responsibility to take care of their elders. The context and social conditions have changed from when the elders were young. As a consequence, only some continue to do so while the rest simply get in their cars and leave, thereby abandoning the elderly. Such abandonment is spiritually worse than the traditional Lakota way of abandoning the old because this new abandonment occurs when the elders are not spiritually ready for it. Also, this new abandonment is due to the diminishment of Lakota values that are gradually replaced by individualistic ones actively promoted by the modern way of life. Still, other elders have adult children, or grandchildren who are very helpful and provide help when the elders let them. As one elder stated:

E: The housing. We ask for renting these places that we have to keep it clean.
I: Well your house is really clean.
E: Mmm hmm, I needed to clean up 'cause it was running around here all three days with all this mud and everything and I said I need to mop the floor again.
I: You do the housecleaning yourself?
E: Yeah, I do it all myself, well sometimes my son does it. On Saturdays and he'll throw everything outside and start mopping; other than that, I have to do it myself. It don't take much work.

Sometimes such support comes from outside the family, even when they have adult children living with them. As one elder shared:

E: ...but couple live over there and came by not too long ago and she's a Indian lady, but her hair is just white. She really helps me out. She's still with a Mexican. He really cooks and when they make – they call me over to have some. I go with them and I told her to bring their clothes so they wash their clothes here.
I: It sounds like you have people who help you out.
E: They help me out and my daughters help me out.
I: Are there other people who help you?
E: Not really. (Elder 7)

The help of the community in checking on the elders and assisting them in their everyday lives and tasks are very important to the well-being of the elders, not only in their physical needs but in their emotional and spiritual needs as well because only then do the elders feel a sense of belonging to the community; they are reassured knowing that there are people who are there to fill in when the elders need support. Such support is voluntary however, depending on the willingness of some family members and some members of the community who still sustain the Lakota way. As such, it does not systematically take care of the needs of all elders. It is in this context that the existing formal support needs to be discussed further.

Existing Formal Support. Although there are limited resources on the reservation, there are formal resources provided by the IHS, the state government and the tribe. Two elders have or have had help with light chores around the home – a service provided by social services in Pine Ridge. One elder noted:

E: ...and now every Thursday that lady that comes to clean up that comes from homemaker and she'll bring my meals [from the senior meal site].

I: Who's she?

E: Mona something, I don't know. She's a homemaker.

I: Homemaker.

E: She comes and clean up every Thursday.

I: Where does she come from?

E: Pine Ridge. DSS²⁰ ... She comes from...

I: She cleans your house and other people's.

E: Yeah. She goes around to the ones that can't, you know, clean up or like if they have surgery or anything. I called the DSS.

I: Where's that?

E: Pine Ridge! The welfare office, way at the end the last door, that's where I go. Before I was out, I was out of help and so I did it myself until this Jennifer, she works there. She's the boss and I went and got hold of her through adult aging and here that's how they got me... So I called them and that's how I get on there. Asked me how old I was and what my handicap was and all that, and that's how I got that one and they came up here and took everything.

I: Do they charge you?

E: No, it's state so they don't charge me. It's the state welfare and that's how I got on, otherwise if I was in a wheelchair or I really couldn't or if I was in bed, they would put me in a nursing home, but I was I could do certain things, take a shower. (Elder 16)

For the elder who receives the homemaker services, when her pick-up truck was broken down, the home health worker would go to the store and pick up the mail. The worker no longer works

²⁰ Department of Social Services

for the agency, so the elder is left to fill the ensuing gap. She relies on herself. She performs the cleaning duties, exclaiming, “I’m not going to wait around for someone to do it” and her neighbor picks up the mail and groceries when her pickup is not working or in inclement weather. She noted:

I: But you go and get your own groceries now?

E: Oh yeah.

I: To Sioux Nation? [the grocery store in Pine Ridge]

E: Yeah just to Sioux Nation. Maybe once a month my cousin that lives out the country might stop by and we might go to Chadron and mostly to Chadron to Wal-Mart. We don’t go to Gordon very often we go to Chadron cause that’s where Wal-Mart store is. The closest other one is Rapid City. We don’t go over there very often. (Elder 6)

This elder was unclear about where her home helper came from, but she mentioned that “I have to pay \$6/month and I have to send a check, check to someplace at the state.” (Elder 6) This service is as close to home health services that are available for the elders. For those elders who need assistance maintaining their independence, it is invaluable. Still, such information reveals that although there is some service provided, it is not systematic, leading many elders to have to rely on their family and neighbors to fill the gaps.

Indian Health Service. The Indian Health Service (IHS) operates a hospital in Pine Ridge and two health centers, in Kyle and Wanblee.

The 45 bed Pine Ridge Hospital, serving a Sioux Indian population of more than 17,000, is the largest in the Aberdeen Area. A 16 physician staff sees medical, obstetrical, pediatric, and surgical patients. The facility located in Pine Ridge, South Dakota, includes full service general surgery, an obstetrical ward, and dental. Kyle and Wanblee Health Centers and three health stations (Allen, Manderson, and Porcupine) operate within the Pine Ridge Service Unit. (IHS, 2010)

The Kyle health center is an outpatient facility that is smaller and provides services through a smaller number of physicians, nurses and medical professionals. The Wanblee clinic, “Wanblee Health Center is staffed by a pharmacist, dentist, clinic nurse, a physician's assistant, and physician consultants.” (ihs.gov)

The elders had a variety of views on the quality of the services provided by the IHS, their main complaint is that the physicians are not Lakota, and secondarily, not Native and are often rotating in and out as they fulfill their service in exchange for loan repayment or scholarship

requirements. The elders were unable to create relationships with a physician and often feel alienated and misunderstood by the medical professionals. One elder summed up the widely held views regarding the health care received in the following:

R: It's poor.

I: What does that mean?

R: Remember what I told you about sending us up there they find out how much it costs and they want us to pay for it.

I: When they send us up to?

R: Rapid or Sioux Falls or Denver or something and they want us to pay that bill. And it costs a lot of money, geez. That takes all of our - and then they put us here and by the time they send them off they die. They got that chopper but I don't know by the time they make it...they're dead. A lot of people have been suing Pine Ridge Hospital. They have been suing them because they keep their people until they die. Even if they go up there they just give us the generic stuff and when we come home we are supposed to have help and we don't get it. If we're lucky we get it. Like me see? I need to be cleaned up, the sweeping and washing dishes and whatever. When I wash that's when I fall, fall and hurt myself.

Not all of the elders were unhappy with the treatment and care they receive, but many had stories of being referred to Rapid City for health care that was beyond the scope of the services on the reservation and it is very taxing on families to arrange treatment more than a hundred miles away. The repayment of services often leaves families scrambling, as the healthcare is not always provided without charge, a commonly held belief about health care for Native people.

Community Action Program (CAP). Each district Community Action Program, or CAP office seems to have an elder fund, where they are able to provide assistance to the elders in support of their heating and electricity bills as well as transportation to medical appointments. Paying for their propane is a major stressor in many of the elders' lives and is therefore frequently mentioned in the context of elder care. As one elder noted:

I: You were telling me you need help with the propane bill?

E: I'm out of gas.

I: And they won't help you?

E: Huh uh! I went down there and that woman, down there, I went down there and she said, "[Elder's Name], you know what? After the worker went back there and she said "Tell [Elder's Name] I can't help her", "We help[ed] her before." The other lady, that's [Lady's name], she's a heart patient. She wants to help me with \$60, when we pay \$120 they bring gas, so half and half. Connie says half and half and you better do it before four [p.m] because some workers go back early. And here she, instead of coming here and

telling me in a nice way instead of going way back up there and telling the CAP office, “sorry we cannot help her with the elderly [funds].”

I: Do they only help you so many times a year?

E: Once, in an emergency. One time emergency, and the time that I needed help. They needed and her sister kind of got back to me, [Name of an elder] and said, “Look at my sister, it's not her money, but she is refusing elderlies.” That’s what she said. Her own sister said, “Instead of helping elderlies, she’s refusing them.” (Elder 11)

It is widely known on the reservation that there is corruption in the distribution of the resources. All too often, nepotism rules the day, so families related to the person controlling the money will receive the most benefits. The denial of helping the elders leaves them to rely on their own resourcefulness, often leading them to partake in risky ways of creating heat for their homes. When resources like propane or other delivery services come onto the reservation, it is unjustly expensive. The propane companies changed the requirements for delivery which creates another hardship for everyone, especially the elders who are on limited incomes. As one elder stated:

E: Yes! Last month I sat out here two and half months without propane and we used to be able to get \$50 worth and they jacked it up to \$120. And there are five orders in the community and that’s the only time they come.

I: You need propane to cook?

E: Yeah.

I: You used to buy it in \$50 chunks and then they moved it up to \$120

E: [\$]120 the only way they will bring it, plus there has to be five orders.

I: This is kind of nosey, but how much does it cost to heat your house in the winter?

E: Oh my gosh over [\$]300.

I: [\$]300/month

E: This house is old and it's four bedroom and full basement.

I: Do you use electric heaters too?

E: Yeah that’s why my electricity really goes up. (Elder 22)

Such inadequacies in delivery of basic goods reveal the lack of regulation of services by the state and the government. As a consequence, in order to make their small monthly incomes go as far as they can stretch them, a few Lakota elders will not sleep in their bedrooms, opting for the living room; one takes a small mattress and sleeps in the kitchen where it is warm. They often have to choose the lesser expensive option and forego comfort in order to stay warm in the long winters. As another elder stated:

I: Is [your income] enough to live on?

E: Not quite. If it wasn’t for the commodities, it would be pretty [inaudible] and then we get the heating energy. That helps a lot and that is enough to carry me over, but I try to be

saving that's why I close that [doorway] off. I'm not going to heat those two bedrooms. I do keep the heat on in the bathroom because I don't want the water to freeze. But the bedroom and the hallway and utility room -- I'm not going to heat those and when it feels nice, I open it. I take down those curtains. It really saves on energy. I sleep on the couch because I'm nice and warm. (Elder 6)

It is often hard to believe that such scant services for the elderly exist in a developed country like the United States; the conditions instead remind one of those existing in a Third World country.

Transportation Needs. The CAP²¹ office provides assistance to Lakota elders for transportation to medical appointments when they are in Rapid City, as the CHRs do not transport to there. Still, they only provide assistance to individuals only a certain number of times per year. In talking about assistance with having her yard mowed, one elder mentioned that when she needed to have the yard mowed, she needed assistance to help pay for the gas that goes into the lawn mower. She stated:

I: And then earlier you told me they charge you ten bucks for it.

E: Mm hmmm for that tractor for us to put gas in there. I said "Gee, [name of treasurer] is the one that is taking care of our money, why can't she take care of it. She's got the money."

I: What'd they say?

E: They said they help me with medical last month, so I have to wait three months before they can give me help.

I: How much did they give you, if you don't mind if I ask?

E: For what?

I: For the medical.

E: \$40 or \$30. Depending on the, that's supposed to take us up there and back and with my son's big car – no way! It's a Tahoe and it uses gas. That's all they give us. They give us a purchase order to get gas and that's it. (Elder 16)

In relation to the transportation needs of the elders, there is a general sense that the CAP offices are not providing as much as they can, that the funds are being diverted, and that nepotism is a guiding principle in distributing the funds. There is a tension between what the Lakota elders or other individuals are responsible for providing for themselves and what the community should provide in assistance to them. One elder who is concerned about the welfare mentality that has taken hold among the younger generations, encourages the tribe to take care of the elders based on cultural principles, stating, "Why not? Back in the old days, back in the old days, the tribe cared for the elders anyways." (Elder 12). The reality is that there seems to be

²¹ Community Action Program, as mentioned previously.

very limited resources to care for the elders. It is sad to note that the old Lakota ways of caring for the elders is diminished through the intervention of modern practices advocated by the state and federal government, but what has replaced the old ways is woefully inadequate in taking care of the needs of the elders.

In relation to transportation needs of the elders, the inadequate services lead to many practices that are dangerous to the well-being of elders. A general warning on the reservation was not to pick up anyone who was hitchhiking. However, one elder offered insight on her criterion for helping hitchhikers with rides as follows:

I: They say not to pick up hitchhikers.

E: Well if you know them, it's alright. If I know them, I give them a ride. Now these younger ones, I don't know them so I don't even give them a ride. Before I used to know all of them. When I was working, I knew all of them and used to take them, but now I don't know them. I don't know some of them; a lot of different people moved in here and ever since they put this trailer court, people, they all moved, strange people moved, so I don't even know them now! Or different kids. (Elder 9)

The elders worry about those who hitchhike because there have been many deaths as people were hurt when they were hit while walking alongside the roads. Two elders told me about how they worry for an elder woman who lives way out in the country on the reservation and she is often seen walking or hitchhiking late at night. They stated:

[Elder woman's name], she's the one that was hitchhiking all over. If you notice her, she's going to walk somewhere, even though, late like this – to Rapid or Rapid, or south Rapid, they seen her in Hot Springs, they seen her late at night coming back from Pine Ridge, they seen her in Martin the road goes through over there and they call it Bear Creek Canyon, they seen her late at night walking back this way and again Batesland this way old road they call it 18. They seen her over there. (Elder 11)

The two elders were very concerned about this elder and attempted to intervene on her behalf, but she had autonomy and despite their care and concern, she continued to hitchhike. In lieu of hitchhiking, the elders resort to walking, even in their own districts, where everyone knows them. As one noted:

[An elder and friend] She'll sit in the corner and just sit there and when I get done she'll say, "Are you going home? Walk me home." I always take her home and after that I hitchhike back or she'll say, "I'm going to come with you." So last time we walked and geez! It was getting late.

I: You ladies and your canes walking up that gravel road?

E: Yeah! We didn't have no flashlight and dressed in dark and we were kind of scared. When the cars were coming, we were way over there in the ditch. The dogs were barking

- it didn't bother us; it was the cars. Sometimes those young kids are crazy and we always try to make it back before. If it's too dark I say, "I'll sleep here and tomorrow. I'll get a ride in the van or somebody would take me back." So she always takes me to Angels [gas station] and she tells them, "She wants to go up North" or she calls the police for me, "She needs a ride [name of road she lives on]" and they pick me up and bring me back. She calls as soon as I get in she calls. "Did you make it home?" (Elder 16)

Hence, given the very limited assistance in transportation that the Lakota elders receive, the elders become their own great resource. The elder women look out for one another and will go to great lengths to ensure each other's safety and well-being. As many are widowed or divorced the women accompany each other and check-in on each other. Without formal resources, these women demonstrate great strength, tenacity and resourcefulness in order to meet their needs.

Elder Meal Sites. The elders also use formal resources such as the congregate meal sites on the reservation. Each district provides meals for the elders at 11:30am, five days a week, except on tribal holidays. Each site has a head cook and a few assistants that are placed there as TANF²² workers, or through the elder program, Green Thumb²³. The sites differ by district where some sites have a building allocated to senior services and others use the community action program, or CAP office, or double wide trailers as the meal site. The meal is available for dining in, carry out, and in some districts they deliver to homes. The following newspaper article provides information on how these meal sites operate:

From her centrally located service facility in Manderson, OST²⁴ Meals for the Elderly Coordinator Fern Apple can reach out to all nine districts, including Porcupine, and oversees a yearly budget of \$178,000 in federal Title VI grant money that must stretch across seven feeding sites on the Pine Ridge Reservation.

Last year [2008] the program prepared over 216,000 congregate or on-site, and home delivered meals. She is in the process of opening another location at Red Shirt. Two other sites at Lacreek and Medicine Root Districts receive funding through the state under Title III. Title VI and III funds are grants used in service programs for older American Indians. Ms. Apple is pleased with the additional resources the program receives from such sources as National Relief Charities through their AIRC Food service

²² Temporary Assistance to Needy Families, a federal assistance program.

²³ Green Thumb is now Experience Works. "Experience Works is a national, charitable, community-based organization that helps older adults get the training they need to find good jobs in their communities." (experienceworks.org) This organization funds the foster grandparent program that several of the elder women in this study participate. They assist in classrooms and schools on the reservation, using the Lakota language and culture while working with the children.

²⁴ OST is an abbreviation for Oglala Sioux Tribe.

(www.nrcprograms.org), whose goal is to "help Native American people improve the quality of their lives by providing opportunities for them to bring about positive changes in their communities." (Lakota Country Times 9/29/2009)

The Elder Representative in the district of Wanblee, offered insights into the business aspect of the senior center as follows:

Elders can come you know and then we have uh, what's allocated from the tribe. We pay our grocery bill here it comes to almost about close to \$2,000 groceries high, really high here but you know Fern Apple, she really supplies us with the meat. We have freezers that we keep our meat in.

The allocation from the tribe involves \$3700 issued quarterly from the Prairie Wind Casino revenues to be applied to expenses such as propane, electricity, and some groceries (Lakota Country Times 5/20/2009). Such resources are significant but the distribution is not well-regulated.

The Lakota elders still appreciate the opportunity to visit and enjoy a free or low-cost meal. When you enter the meal sites, you will find the men sitting on one side, the women on the other and conversations are held in Lakota. The elders sign in on a sheet as they enter the room, and depending on the meal site, the elders self-service their drink of fruit juice, coffee, milk or water. They find their seats and the meals are either delivered to them or they pick them up at the kitchen window, or serving line when the food is ready. As one elder described the process:

E: Yeah I eat over there [Oglala meal site].

I: How often do you do that?

E: Every day at noon.

I: Oh you do?

E: Yeah! We all do. They used to deliver it to us, but the van gave out. The van they were using gave out. So we have to go get it yourself. A lot of them get it.

I: Do you like the meals?

E: Yeah I really like the meals. They have a new cook there and she makes biscuits.

I: Like what did you have today?

E: Here it was spinach and uh...wieners or something like that and uh...uh...what did she? Oh she made a cake with white frosting and on the side was string beans and what else did she cook there? And fried spuds. I really like fried spuds.

I: [Elder 7], the day we went around to meet people. It smelled really good.

E: Yeah I really like her cooking; before it was always soup and first I don't like soup, but when you eat it every day you get tired of it.

I: They always think you elders like soup.

E: I do, but sometimes I like to eat mash potatoes and stuff like that I like to eat different every day. She needs to cook something different than soup every day. (Elder 9)

There is some dissatisfaction with the quality and content of the meals provided and the level of content varies by who is doing the cooking and the quality of the ingredients that are used. There seems to be a general suspicion that the meat and other quality ingredients are not available

Elders from another district shared the following:

They said that they bring food, but they don't know what happened to the food. What happened to the sausage and the hamburger and what happened to the meat, how come we are eating potatoes and gravy. It gives us diarrhea. They said they don't know. They said I can't, um, I, uh, I told [Program Director from the state] and she said that the state - it's from the state and uh and the food is coming and they are the ones that bring it down like that and that's how come they said that Kyle elderly meal. That's all they do, that's all we eat is potatoes and gravy and soon we got tired of it, that's all we eat, gravy gravy gravy. (Elder 11)

Another elder from this site corroborated the missing meat from the senior meal program. There were claims of this in other districts as well. She stated:

She feeds us food for the dogs. It's the left overs -left over stuff. When they get all the meat, that lady said that there was -when was it? May or March when I talked to her and she said, "Have you guys been eating soup because I've been getting a lot of meat for [the cook] to make some and I said, "No" and she came down, she checked it and there was \$149 worth of meat missing from the senior citizen's [meal site]. I think both [the cooks] took it whenever they wanted to cook for their families and they come and get it and nobody can do anything about it. (Elder 16)

Hence, once again, there is lack of accountability regarding the distribution of resources to the Lakota elders as corruption seems to occur frequently. Views differ among the elders regarding their satisfaction with the food. According to my observations, the elders often eat what is served to them; I heard little or no complaints during the meals times and the elders only shared their opinions when solicited. One stated the following:

Some of them, sometimes it's good and sometimes it's not. The one time they brought some to the house and I was just shocked. They had chicken and I just got this little part right here, not even the [wide] piece, just the little fat and the wing part right here. I was thinking I didn't get any meat. I got it wasn't even we were always taught you get a half cup of potatoes and half a cup of peas, carrots, or whatever and if they were diabetic, what they could have for bread. I was, they were saying they really eat good down there that day they brought it to me it was like 'oh.'

One day Aunt [name] said, "Come and eat with me." They were having beans and you could count the beans in the white water; they really need a cook and I think they cook all that stuff and take it home. They give them a lot of money for the food and stuff. I know one time we went with this lady and she got good meat and they made their own bread

and it was worth eating. I don't if they don't know how to cook or they don't want to cook. (Elder 4)

I spoke with the cooking staff, inquiring about how to please the meal site participants. The staff expressed some frustration because they had conducted a survey and adjusted the menu only to find out that the elders were unhappy with the changes and therefore threw out the food without eating it. The elders I spoke with wanted food that they ate when they were young: good meat, vegetables, homemade bread and sometimes treats like *wojapi*, which is like fruit pudding, or pie filling but less sweet. Hence once again there was a disconnect in that what the staff probably provided for the elders did not at all take into account the Lakota way of cooking and preparing food, leading to general dissatisfaction of both the providers as well as the consumers.

For the La Creek and Medicine Root (Kyle) meal sites, the menu is determined by the state nutritionist. I spoke with Donna Knoll, the Program Director, who said there was resistance by the state to incorporate culturally sensitive elements into the meal plan. She was working on ways to get them to change. She cited prejudice and fears of non-Indian people regarding traveling on the reservation. This exclusionary, discriminatory mentality inhibits the services provided to the Lakota elders; it also undermines the intercultural work relationship. Knoll also felt that the meal sites failed to follow the meal plans, altering them without explanation. She especially worried for the diabetics, as the meal is balanced in a way that is safe for those with chronic diseases. (Field notes)

There are also significant barriers that Lakota elders encounter in receiving the meals. The elders who have access to transportation or live within walking distance are able to access the meals. Some districts provide delivery and transportation to the site for elders living in certain areas. The Kyle site had both services, but because of budget restraints limited delivery to three days per week. In addition, they no longer transported elders to the Center. I noted that toward the end of the summer of 2009, they had totally ceased the delivery of meals. In addition, the delivery van was driven by an elder in the community. The Porcupine district secured a grant for their elderly services van. Wanblee Senior Services also has a van that delivers meals. As one elder stated:

E: ...We get a pretty good meal and they deliver that every day.

I: Who delivers it?

E: We have a van.

I: And a man or a woman delivers it?

E: We have uh, volunteers.

I: Oh volunteers, who coordinates that?

E: Well, this one here, his name is uh, [Name]. He's been volunteering three months because his mother lives out to...Lakota Homes so you know in order to get his meal to his mother, he comes and delivers all that and takes his mother his meal. We're doing alright.

Once again, it appears that the delivery of meals is not systematically done, but instead often maintained by volunteers in a casual manner. Despite having a van to deliver the meals, many people living farther away from the senior centers struggle to receive delivery services. Some elders live on dirt roads and depending on the weather, the roads and lanes leading up to their houses wash out or are too muddy to travel. As one elder noted:

They don't bring them into town. They only bring certain ones their meals. I live way out here. When I worked there, I told Fern "the majority of elders live way out in the country way past 7 Mile Corner and then going towards Kadoka there are some elderlies out there and out towards there are elderlies." (Elder 22)

There is often concern for those elders who are left out of the meal delivery service due to such obstacles, but with limited resources, it is difficult to find a way to get the meals to them. Access to the resources is a major issue on the reservation with some folks always feeling left out of the loop. Often groups come through the reservation in the summer, or donations for the elders are delivered to the senior center/elder meal site, CAP offices, or churches and they distribute the goods to the community on a first come, first serve basis. One elder described it as follows:

E:...Like me, I don't know what comes in; one time they told me a truck came in and brought a lot of frozen meat. Frozen meat and here the grandparents were just greedy.

I: That's one of our major problems.

E: Just like one time remember at the senior citizen? This woman, she took three of her daughters plus her kids and she keeps this old man and they used to all get it and this time they must have told her something because they told her we only brought enough stuff for 25-30 elders and after this it's only going to be those 60 and up. So this woman didn't like it because she's really greedy. That old man stayed there, but he couldn't get anything because he stays at this old woman's house.

It is hard to know what people do with the extra goods they take; it is often murmured and speculated that they give it to their younger family members who are also in need. There is often a scramble for the goods that are delivered. While I was conducting research, I saw a variety of church groups pass through the reservation. In particular, I was able to witness one Christian

group from Oklahoma pass out goods and provide healing services and pray. They had set up a baby pool for baptisms outside the senior center. In the dining room, they had a program of praying and testimony to healing from their prayers before passing out the goods to the elders. One elder attended this event and shared the following:

I: Did you get stuff?

E: I liked the laundry stuff. I like that. But the chicken was really greasy. It was precooked. That was the only kind of meat we got, I got.

I: I think that was all there was.

E: My niece called me and asked if got this little thing that had sliced ham in there.

I: She only had a few of those. It was like lunch meat. She only had a few.

E: I didn't get one.

I: They didn't get everything because I was on the one side.

E: I was sitting here [gestures] and my niece was there [gestures], but she was going that way so I didn't because I didn't have that much to carry out.

I: Some of them had boxes and boxes.

E: Cereal. I didn't get no crackers. But I whatever, I'm glad I got laundry soap.

I: How do you feel about, are you Christian?

E: I'm traditional.

I: What do you think 'bout them coming and praying and wanting to heal people?

E: Well the baptizing is going too far. But that's just me. Like I don't know. I don't know. I don't think... (Elder 22)

The day this event occurred was a hot summer day in a room without air conditioning. The Lakota elders were grateful for the food and supplies that were offered, but it was a lot to endure on a hot summer day. Despite the overbearing nature of their presence and demeanor, the Christian groups do provide resources to the elders. They have each elder make a list of items they are in need of and when they return to Oklahoma, they try to fulfill the things on the list. The Elder Representative, in filling out her list, provided a list for the elders in their 90s, and not a list for herself. She was looking out for the elders who were unable to attend and need assistance.

Several church and other groups pass through and do service projects as well. On the day I was visiting with one elder, there was a group in her community. Access to these groups and the services they provide is through the district CAP offices. The groups paint houses, clean up yards, do repairs and volunteer with services. Throughout the summer, I saw the "church kids" at pow wows, elder meal sites and visiting sites like Wounded Knee. They stand out because they wear brightly colored t-shirts of the same color. One elder shared her impressions with me:

I: I saw honk for Jesus on this van [in the driveway].

E: Yeah, they are painting the house [we laugh]

I: How do you get connected to that?

E: I guess they go around doing that, but I wasn't down there for the last two years, but they go around doing that so I called the CAP office one time and said, "How does a person do to get their house painted?" And then they just sit there and they could call around and on the index thing they have your phone number and they never call when a truck comes and brings stuff down and I don't know about it and other ones don't know about it and it's just right there in the community. The mothers and their kids this one time there and they had a big tub of laundry of soap and you have to take a bucket or whatever so this same woman she had all her daughters take two buckets of each and I heard it when I went to the clinic. (Elder 22)

In contrast to the grabbing of the goods, or angling to get the most goods possible, I have seen elders take only what they need -- they were too gracious to take what they should. Once friends and family knew I was out in the districts with the elders, I was given harvests from the garden, chokecherries, wild plums and material for quilts to take to the elders. When I delivered them, however, the elders would only take a small amount and I had to say, "take more" or "there's plenty more so take some more." Chokecherries grow wild all around the reservation and off the reservation; some enterprising young people will pick them and sell them in gallon ice cream bucket containers for \$10. The elders were very excited and grateful to be given chokecherries. One elder filled a large bowl with the wild plums, stating that she had not seen or had them in a long time. She lives in a multigenerational household and she hid the plums in her room so the younger family members would not eat them. Every time I saw her afterwards, she thanked me for those plums and told me how good they were. Some elders are very grateful for the smallest kindnesses extended to them. Still, this incident reveals how much the elders appreciate food that is grown locally. Their food needs are not at all taken into consideration in delivering food to them. In addition, corruption in the delivery of the food services, the lack of accountability and the unpredictability of the service make even the provision of the basic need of elders very problematic.

Community Health Representative. Each district has a Community Health Representative, or CHR that provides a variety of services. The quality and the extent of the services once again vary by district. CHRs are "paraprofessional healthcare providers who conduct home visits, health education, promotion and prevention programs, transportation, and

advocate for the health needs of the community” (ihs.gov). Two elders in this study were CHRs in different districts for twenty years, but they are currently retired. Still, they provided insight into the role of CHR in their communities as follows:

E: I was a CHR for 20 years.

I: And how did you get into that?

E: Just by you know, my friend was, my cousins was working there and asked me if I wanted to work there...So we got, she was head of the what do you call it? She hired us and ever since then, I worked for her, and she retired, and then a couple years later I retired.

I: What do you do as a CHR?

E: They take care of the diabetics and the well-baby clinic, make sure they are ready for immunizations and at the church over there we give them a ride there. Or they call us and we take them. They told us to go visit the elderlies, to go way out in the country and visit them.

I: You did?

E: Uh huh. Yeah, we would pick up the patients and they are there for four or five hours then we go after them. It's a lot of travel. It's alright.

I: It's hard in the winter.

E: Yeah, it's really hard on cars. We had to use our own cars.

I: You had to use your own car?!

E: Yeah! One year I went through three cars and then I bought me a new one and it only lasted me one year, too much miles on the motor. I decided to retire. “I might as well retire,” I said, “gee.” It takes a lot of money to run it. We used to have government cars, but they don't do that anymore so we used our own cars. For a while we had a van and started driving that with the other CHRs.

I: How would you know where to go?

E: Oh, I know everybody here. I just go over there and visit the ones that are diabetics or the elderlies and the younger ones can take care of themselves but the elderlies...if they want to go [to the hospital in Pine Ridge] then I take them; some of them have appointments every Monday. They tell us they call us and tell us they want to go in. I like visiting a lot of them.

I: When you visited the elders what did you do with them?

E: Just talked to them; they just needed company, they live by themselves and just go there and visit them and talk to them. We have some girls from the area; they go there and they clean their houses and they eat with them. But that's a different program, but us we just handled the ones that are sick and the ones that became diabetic; if there is something wrong with one of them then we have to help them. Make sure they are alright. (Elder 9)

Once again, the service provided did not secure transportation, leading many to resort to using their cars to drive the hundreds of miles of roads on the reservation. In some communities, the

CHR also became a readily available community resource where people ran up to their door and asked for help. One elder stated:

Sometimes I used to wonder when I was a CHR, twenty-four hours a day. I looked for something enit. Fourth of July there was popping firecrackers. I said, "I'm really tired, I just came back from the hospital." Took a patient up there and left him. I said, "Tomorrow I have to go check him out and bring him back." Just as I laid down to sleep she said, "They shot somebody on the other side over there." There I go again. He was laying on the ground in back of the house. I thought I was just going to help him. He was alive! We road with him halfway to Martin and he said, "I don't think I'll make it." And he lived and he came back and he was [Name]. He came back, but he was in Denver for awhile, but he came back. I seen a lot of things happen here. I seen a little boy get run over right here just as you turn around. But now I don't think I can stand that...I'll probably start crying first before I start helping them.

The role of the CHR has woven its way through the stories shared by the Lakota elders. Often the elders focus on what the CHRs are not doing – they are often criticized for not doing their jobs to the fullest extent of their abilities. But in Wanblee, the CHR is often talked about respectfully and can be found fulfilling her duties. As one elder noted:

The CHR is good; she comes out here and visits me. She helps me out and she helps me out. Even if I am it's ok and sometimes she said she's going to be gone two weeks and here she brought me \$25 food thing but this store here is really high. (Elder 22).

The administration and accountability of the CHRs is imperative for providing good services. The CHRs themselves have to accept the position in their communities and take the responsibility seriously. As evidenced by the narratives of the elders stated above, such elders sacrifice their personal time for the benefit of the community:

I: They said there is one CHR out here now.

E: She don't even work. [laughs] She leaves them over there and they all have to call around and come back. My niece worked here before she just died about a year ago. She used to haul all the dialysis patients in, she waits over there and brings them all back. We have about four or five of them from here. She takes care of them, but we all do that. But we had a good boss, she was really strict with us, make sure we did, "You visit this one?" You know. She was always having us report; she would have to, she would go to a wake and ask, "Did you go back and visit her?" So we had to, the next day we'd have to go and check on the patient or the elderly or a sick person. Or make sure they had – oh we gave insulin you know? They had a fair here and I was going and my aunt she's diabetic, she wanted me to come with her. She gave me her needle and said, "Here, give my shot" and she pulled her dress up and I gave her a shot back there [laughs]. She's so crazy. "Here?" "Yeah," she said, "That's alright."

“I didn’t even go, but I carried my needles with me,” she said. Oh she makes me laugh. They’re really that crazy. (Elder 9)

Being left at the clinic in Pine Ridge by the CHR is a common story many elders tell. Then, often the elders have to scramble to find a ride, which often means they have to hire someone informally to take them:

I: Do you use other resources for elders like CHRs?

E: Every time I call the CHR, they took me but left me over there. I gotta have someone bring me back.

I: That sounds unreliable.

E: Um hmm.

I: Well how come they left you?

E: She said she forgot about me. (Elder 7)

When the elders are unable to find someone to take them back, they resort to hitchhiking or walking beside the roads home which can be anywhere from a few miles to more than a hundred miles depending on where they live on the reservation:

E: I don’t have a ride to go around. I like to hitchhike, but not this year.

I: When you said that you have to have gas money to get back from Pine Ridge. Now you have to pay people for a ride?

E: Mmm hmm.

I: Nobody will just do it?

E: Huh uh

I: How come?

E: I don’t know. They always want money, money, money always comes first. (Elder 7)

This is the tension that everyone of all ages is negotiating – the individualism versus the traditional teachings and customs related to caring for each other. The elders hitchhiking and being stranded away from home and having to hire someone to bring them home is a sad situation. The elders have very little income, some hanging nearly by a thread and will have to pay someone \$10 or more dollars to arrive home safely. Granted, the younger generations are struggling to survive as well, the generosity and kindness in some cases have given away to opportunity.

Lakota spiritual practices and ceremonies are actively participated in by all ages in the community. The elders are sharing with the younger generations the teachings and lessons of their grandparents, thus connecting them to the spiritual consciousness of Lakota life. The elders have, over their lifetimes, experienced a wide variety of situations that diminish their spirit and challenge their ability to remain spiritually whole. A great pressure on the Lakota spiritual ways

is modern living and technology. Social and cultural behaviors that nourish the spirit of the community, like caring for the elders, honoring their wisdom and teachings, are giving way to capitalism and the quest for material goods. The youth are fragmented from their Lakota consciousness, while the elders honoring their role of service to the community as leaders and teachers attempt to prevent the pressure from consuming the young adults and removing them completely from their traditional Lakota lifeways. This chapter has shown that the elders are very resilient and self-reliant. When faced with adversity they continue to work hard for themselves and their communities. They help each other and fill in the gaps where their familial or social resources end.

Chapter Six

Conclusion

The goal of this dissertation study was 1) to determine whether or not the Lakota elders' patterns of defining health, illness, and wellness mimic or differ from the Western world. Learning more about their experiences, such as understanding what they consider health to comprise of, when they seek help, and how they go about doing so would demonstrate how Lakota elders cope with health challenges. 2) To identify the health resources available to Native older adults, such as social support networks, and the effects of these resources on their health. Like the rest of American society, Lakota elders make up for their lack of health resources with social support networks that may affect elders' health. 3) To reveal the connection between the status of Lakota elders within the community and their health. Traditionally, Native communities have always respected and taken care of their elders. Yet over time this pattern of respect and care has started to decline, which may adversely affect elders' health condition.

This research advanced the knowledge of Native elders' health in several key ways. First, this study reclaims Lakota culture as an important lens for viewing health and health behavior. I developed the theory of Triple Consciousness of Native Americans which allows for the full consciousness of Native people to be considered, thus giving them agency and acknowledges the full aspects of their beings – the body, mind, and spirit. Additionally, I use the Life Course Perspective and the Social Construction of Illness to shed light on the life experiences of Lakota elders across the life span and how they shape the ways they experienced health, wellness and illness on the Pine Ridge Indian reservation. In the life histories of the Lakota elders, the elders revealed how they navigated life circumstances that impacted their physical, mental and spiritual health. Additionally, the ways they view health, wellness, and illness is holistic and encompasses the intersection of their mind, body and spirit. Second, I employed Indigenous Methodologies, thereby articulating what is meaningful and logical for Indigenous people and the ways they interact in the world. These methodologies allow for both the elders and I, as the researcher, to

develop relationships that acknowledge the Indigenous connections to their spirituality, ideas, wisdom, traditions and history of living on these lands for centuries. This methodology also gives agency to the elders, paying respect to their social and cultural positions allowing them to share their stories and wisdom as they see fit. In using the Conversational Method, the elders would often direct a story towards a question I asked them, thus operating within their cultural norms. Next, this work addressed several gaps in the literature about Native elders and health. Very little is known about this generation of elders and how they experienced illness largely without formal western healthcare in tandem with experiences of the assimilation strategies of the federal government. Finally, bringing to light their life histories, experiences and meaning around health, wellness and illness provides a rich foundation for developing programs and services that are tailored to their unique social and cultural position. Current resources partially address their physical needs, but fail to take into account their mental, emotional and spiritual needs. The elders revealed a strong sense of independence and their greatest resource was the social support of other elders and their families. These positive informal structures could be augmented to relieve the burden from elders who struggle in impoverished circumstances.

This concluding chapter provides a summary of the findings of the three empirical chapters. I follow with a discussion of the future work and close the chapter by discussing the broader sociological and social work implications, specifically related to intervention.

Summary of Findings

The findings of this dissertation emerged out of the three empirical chapters that focused on the three components that came together to determine the health of Lakota elders: physical body, mental health and community spirit.

The first empirical chapter articulated the physical health of Lakota elders, taking their narratives through their childhood, adulthood into old age. The elders shared stories of their lives, their childhoods of surviving in their familial plots of land by gathering and raising their own fruits, vegetables and livestock. Some families tried to eke out a living by being a ranch hand or farm worker for the white landowners near the reservation. In spite of the inherent hardship during their childhood, their narratives were positive because they had agency over their own lives. Yet Lakota families were irrevocably changed when the American government forced them onto reservation lands, forced the children to attend boarding school where they

were culturally oppressed, experiencing violence and loss of agency. This adversity and ensuing fragmentation emerged as a collective trauma that may not have physically harmed them, but certainly negatively impacted their mental and spiritual health. Their ensuing adulthood experience was further negatively shaped as they were faced with limited formalized healthcare and government food programs that were not based on traditional Lakota diets, or foods that contribute to a healthy lifestyle. As a consequence, the Lakota elders are struggling with chronic diseases in a context where the medical treatments are complicated and their access to healthcare difficult.

The second empirical chapter on the mental health of Native American elders demonstrated that the strains on the mental well being of the elderly Lakota people are the result of their boarding school experiences, the grief and loss of their mothers, siblings and family members, illnesses in their families, caring for grandchildren and great-grandchildren, and especially the loss of the respect for elders. Their mental well-being is supported and fostered by the younger generations that live according to their traditional values of respect and reverence, through their own participation in traditional medicine. What restores the mental well being of the elders is seeing the younger generation thrive and succeed. Yet the gradual loss of the Lakota ways of living and values has led the youth and younger generations to be left to figure out how to live. When they adopt the white ways of living, they remain unsatisfied, and they still have identity crises because they are not fully accepted by the white people and feel discrimination. It is apt to conclude the chapter with the narration of the elder I cited immediately above because she notes the following: finding ways to incorporate Lakota values and supporting the youth in learning and participating in the ways that they have practiced for generations will draw on their talents and innate abilities, and build their self-esteem. As they grow stronger, so will the community. And as the community grows stronger, the mental well being of elders will improve as well.

The third empirical chapter on community spirit articulated the spiritual aspects of the Lakota elders, where they have been diminished and important aspects of their lives that uplift and sustain them. Lakota spiritual practices and ceremonies are actively participated in by all ages in the community. The elders are sharing with the younger generations the teachings and lessons of their grandparents, thus connecting them to the spiritual consciousness of Lakota life. The elders have, over their lifetimes, experienced a wide variety of situations that diminish their

spirit and challenge their ability to remain spiritually whole. A great pressure on the Lakota spiritual ways is modern living and technology. Social and cultural behaviors that nourish the spirit of the community, like caring for the elders, honoring their wisdom and teachings, are giving way to capitalism and the quest for material goods. The youth are fragmented from their Lakota consciousness, while the elders honoring their role of service to the community as leaders and teachers attempt to prevent the pressure from consuming the young adults and removing them completely from their traditional Lakota lifeways. This chapter has shown that the elders are very resilient and self-reliant. When faced with adversity they continue to work hard for themselves and their communities. They help each other and fill in the gaps where their familial or social resources end.

In summary then, the analysis of the three health components of Native American elders reveal that they have had to survive through multiple challenges in terms of physical health, mental well-being and community spirit. In spite of many adversities, there are insights into the strength and perseverance of the elders that need to be preserved and enhanced to ensure especially the well-being of the succeeding generations of Native Americans. And I discuss these policy implications next.

Policy Implications – Considerations for Intervention Research

This research required that I build relationships with the Lakota elders. Some of those relationships resulted in participation in the recorded conversations and their wisdom and experiences were shared in this dissertation. In order to build these relationships all of the elders asked what the end result would be, I always shared that I would be writing the dissertation, which completed the requirements of the doctoral program but more importantly I wanted to share their experiences with the world. I intended to gather their experiences and move them into interventions that would hopefully meet their needs. They always said, “I hope you do.” This is not an easy task considering the social and political context in which they live. However, they offered rich experiences and recommendations for interventions and programs that could positively impact their lives.

At the Individual Level. On the individual level, the elders experience great grief and loss across their lifespan often experiencing the loss of a sibling, parent or grandparent, spouse, children, and important community members. Many of the elders openly wept in recounting

these losses or would articulate the wounds that persisted into the present. In speaking with the mental health specialists at the Indian Health Service (IHS), they shared the inadequacy of offering assistance to the elders. They felt that the elders would not seek help, so targeting services towards elders was an area where they could improve and also models of care in working with Native elders and their mental health needs was greatly needed. A model of care should be developed to adequately address the specialized grief and loss needs of the elders across their lives. Relieving the weight of grief and loss is imperative for their overall well-being.

The elders have experienced a variety of trauma over their lives, beginning with boarding school and continuing through their marriages, job experiences and struggling financially in their older adult years. Maria Yellow Horse Brave Heart has developed a model of addressing the trauma of boarding schools and historical trauma which has provided some Native people with relief from the affects of boarding school. A model of addressing trauma and its affects could be tailored towards elders and encompass more diverse experiences with trauma.

In the process of meeting and developing relationships with the Lakota elders, I met elders who are currently in recovery and I also met elders who were actively experiencing issues with substance abuse, predominantly alcohol. There are Alcoholics Anonymous meetings held on the reservation and referrals from the IHS to substance abuse treatment programs on the reservation and in Rapid City and other off-reservation locations. Native people as a community are a youth culture with the majority of the population under the age of 25, many of the efforts are directed towards younger populations. The medical community that interacts with older adults should be screening for alcohol and other substance abuse issues in older adults with prevention and other programs being tailored to providing treatment and support to older adults.

At the Communal Level. On the community level, the elders shared their early years on their family homesteads, growing fresh vegetables in their gardens. Many of the elders try to maintain a garden until they are no longer physically able. There is a great need for fresh foods and vegetables as Native communities are ravaged by diabetes, heart disease and cancer. By addressing these health disparities through the growing of whole foods could have a dramatic impact on the health of the community. The elders have knowledge about successfully growing food on the reservation. Each community district on the reservation has a summer youth program. A partnership could be developed where the summer youth learn from the elders and

help them maintain their gardens in the summer. Funding would probably have to be secured and staff hired to oversee the workings of the program but has the potential to positively benefit both the elders and the youth. A community garden, which has been attempted, could be evaluated as an intervention for providing fresh vegetables to the community, where the community members could participate in growing the vegetables. Another solution may be selling the vegetables to the community as a Community Supported Agriculture (CSA) where families can buy shares, which help support the running of the gardens and in return receive weekly harvests.

Church groups often enter the reservation for their spring break and for weeks during the summer and volunteer painting houses and participating in other activities. Community members welcome the help but I did hear some criticisms of such programs as there is a shortage of work on the reservation and a surplus of human capital. In an effort towards building skills and self-sufficiency a better option might be for the church groups to support the community in providing the supplies and the community utilizing these to provide home improvements in their own homes and communities, thereby increasing the community capacity of self-sufficiency.

Many of the elders expressed a desire for a community space where they can spend time together quilting or sewing. They enjoy reminiscing and spending time together, with several expressing the desire for peer companionship. With the great distances separating communities they often do not have a way to spend time participating together outside of formal gatherings like ceremonies, church activities and family gatherings. Two of the districts have working vans which transport the elders to activities around the reservation and to nearby attractions at other reservations – like the community pow wow at Rosebud or to the casino. The elders enjoy these outings and participating together. Seeking funding that would allow the vans in every community district to be operational and maintained could augment the elders' social activities. Directing resources towards the elders by providing a space for them to congregate and enjoy the activities they desire will positively benefit them.

Many of the Lakota elders speak Lakota as their first language, have limited formal education and struggle with the medical model and the interventions prescribed to them. When they discussed the IHS, they often expressed frustration with the system and the many appointments, the paperwork and often they were left feeling they did not fully understand the treatment regime or their diagnosis. Given the relationships with physicians in the IHS are unstable, with doctors moving in and out of the community, there is little continuity or

relationship building. It would be imperative to develop a position of Advocate for the elders to help them navigate the system and work with them as they move through their medical interventions, spending time needed to providing understanding and continuity. Also, there are public health nurses who visit the home and each district has a community health representative, but further assistance is needed for the elders in their homes, such as home health care providing services like light housekeeping, meal preparation, cutting the grass, taking them to run errands, or doing the errands for them. A few elders receive this service but many more are in need and a more comprehensive service that is marketed to all of the elders on the reservation could help them maintain their independence in their homes.

Future Directions

My reflections on this research process have generated several thoughts in relation to possible future directions. I focus on three particular directions, first in terms of what additional studies I could undertake with the Lakota elders, second the research I could commence on other Native tribes living in reservations or urban centers in the United States, and third the comparative research I could engage with other Native tribes and Indigenous people living in Canada, South America, New Zealand and Australia.

Lakota Elders. First, I realized that this study could have been strengthened by a more representative sample, especially in relation to the representativeness of gender composition. As Lakota elder women comprised the majority of the participants of this study, I could in the future collect the life narratives of a larger number of men with the intent to analyze more closely the gender differences in relation to health, thereby enriching the insights and experiences of health, wellness, and illness of all Lakota elders men and women alike. These in-group gender differences may bring to light aspects of aging that have not previously been uncovered.

Additionally, there are aspects of the female elders' experiences that I did not explore fully. The elder women mainly shared either their early or late life experiences, not articulating the middle years of their lives as much. I could therefore specifically and more comprehensively explore their marital experiences and the process of raising their own children; their middle life years could provide additional depth into their experiences of health, wellness and illness that shape their older adult years. For example, several of the women experienced multiple marriages and very briefly alluded to tumultuous or difficult marriage situations which may have

complicated their grief and losses. Additionally, a more explicit exploration into the cultural space is necessary – the elders lived in a time and place of historical significance that dramatically impacted their cultural and spiritual practices. Native ceremonies and practices were outlawed until the late 1970s; also the Pine Ridge Indian Reservation was the site of the American Indian Movement takeover of Wounded Knee in the early 1970s. This period of time was very tumultuous dividing the Lakota people socially, politically and culturally. Some would argue that these pivotal oppressive historical moments have left a lasting traumatic mark. The elders did not discuss these experiences in depth, with the exception of one male elder who only briefly described these times on the reservation as very divisive and hurtful to many of the people living there. I also did not ask about these moments explicitly because I was attempting to capture their lifespan experiences and allowed the elders to share what they wished related to the questions. Also, the elders lived at Pine Ridge and were enrolled members of the tribe, however, the nuances in cultural identity was not developed further. Several of the elders had parents who were non-Native, or had marital partners who were non-Native, the ways in which this impacted their identity and experiences was not explored but often alluded to. There are social and cultural constructions around being full blood, mixed blood, or even “half breed” and the ways in which this enhanced or inhibited their opportunities and social interactions. In the future, I would explore these topics more fully, as the initial conversations with them were an excellent starting point and I build upon these initial conversations to further expand on important topics of their lifespan.

Other Native Tribes and Elders. This dissertation study focused on the Lakota elders from the Pine Ridge Indian Reservation. I would like to expand to other Indian people in other tribes. A comparison of elders across tribes is important in order to identify the similarities and differences of the experiences of the federal assimilation tactics, geographical and cultural differences that influence the shaping of health, wellness and illness across the lifespan of Native elders living today. Very little is known about urban Native elders, with the majority of Native people living in urban settings, many elders have lived in cities as a result of the federal relocation program and on their own volition for seeking job opportunities. The ways in which these elders have navigated a multicultural space, with intra-cultural experiences has yet to be explored. My next study entails participating with Native elders living in Detroit to uncover their experiences with health, wellness, and illness.

International Comparisons. An international comparison could be particularly compelling, as the Indigenous people of Canada, Australia, and New Zealand had similar colonizing experiences and scholarship across international boundaries could provide a wealth of insights regarding the similarities and differences of health, wellness and illness across the lifespan of Indigenous people living today. Also, comparisons of elders living in Indigenous populations of Central and South America could be particularly compelling and has not previously been fully articulated. I have lived in Peru, one summer during my doctoral program and the parallels between the lives of the Lakota elders and the Indigenous Peruvians was striking. In many ways, the rural Peruvians live very much like the Lakota elders lived when they were children – self-sufficient, working together to grow food and care for animals, and living in small homes. Further research should explore the cross-cultural similarities and differences.

Closing Thoughts

It is important for the research to look beyond the financial and structural factors that impede the health and well-being of Lakota elders access to health care and take a more culturally elder centered focused approach to better understanding their unique health needs. Work should continue to extrapolate the elders' ideas about health, wellness and illness, help seeking and treatment models that consider the physical, mental and spiritual aspects of Native elders' well-being. Recognizing these socio-cultural factors not only give a more complete picture of the elements of the Native elder point of view, but their experiences in the current health system and the potential to tailor interventions that respect their cultural position, as well as their well-being.

Appendices

Appendix A

Interview Protocol

Life Story:

1. Please tell me about yourself.
 - Where and when were you born?
 - Where did you grow up?
 - Who raised you?
 - What were they like?
 - What was it like where you grew up?
 - How many brothers and sisters did you have?
 - Where did you go to school?
 - What kinds of work have you done?
 - Where have you lived?

Historical Experience of Illness:

- 1) What is your earliest memory of illness?
 - How old were you?
 - How would you describe what illness is?
 - Have you had any experience with a life threatening illness?
 - What was your experience with this life threatening illness?
 - How did you address your needs related to the illness?
 - Have you had any experience with a chronic illness?
 - What was your experience with this chronic illness?
 - How did you address your needs related to the illness?
 - When I mention illness what comes to mind?
 - What are the boundaries of disease?

- 2) Native people experience high rates of illness, what do you think we need to heal ourselves?
 - When you think the healing stopped?
 - Have you been healed?
 - Do your children experience healing?
 - Have you ever heard of anyone being healed?

- Does the mind ever heal?
- Does the spirit ever heal?
- Does the body ever heal?
- How much did the white man contribute to illness?
- How much can be healed by white man's medicine?
- What remains?
- Can anything be done to heal Native people?

Health:

- 3) What are your overall experiences with your health?
 - How do you define health? Or healthy?
 - What are steps you take to maintain your health?
 - How do you define wellness?
 - How do you explain the cause of illness?
 - How do you explain the course of illness?
 - How do you account for illness?
 - What illnesses do you experience and what do you think causes them?
 - How much is health linked to the land?

Social Support:

- 4) What resources are you employing now, related to your health?
 - Do you use the IHS?
 - Do you use traditional medicine?
 - Are you visited by a PHN?

- 5) Who helps you access these resources or help you maintain the life you want to live?
 - Why do you use these resources?
 - How do you employ these resources?
 - Does a CHR assist you accessing resources?

Culture:

- 6) What are the cultural norms you learned related to caring for elders?
 - How do you feel you are treated?
 - Do you feel you are treated differently than when you were younger? In what way?
 - What are the ways in which younger people in your community care for elders?
 - How do they care for elders?
 - How do you think they should care for elders?
 - Why do you think they should care for elders in this way?

Reflection:

- 7) Please reflect on the conversation we just had, how did it feel to answer these questions or think about these concepts?
- Why did you choose to participate in the interview?
 - What does it mean that you talked about these topics?
 - What does it mean that you talked to me about these topics?

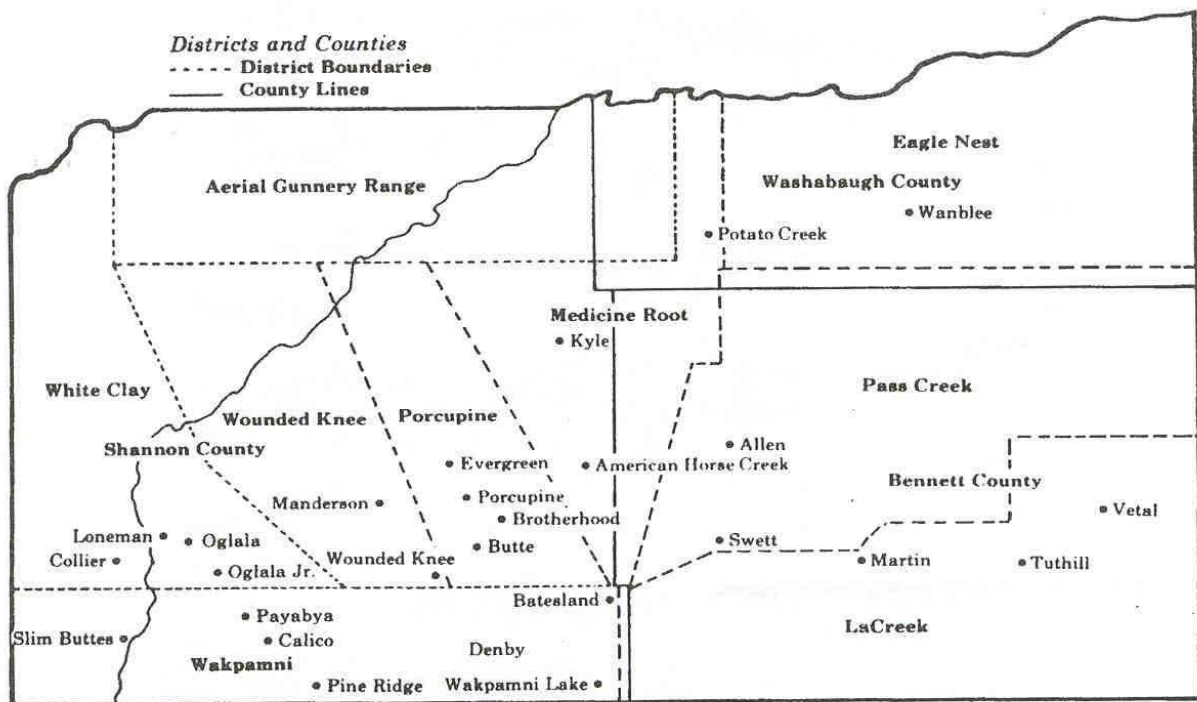
Appendix B
Community Assessment Protocol

- 1) What resources does this agency/hospital/program provide for Native elders on the reservation?
- 2) How many elders utilize these resources?
- 3) What are barriers for their participation in these programs?
- 4) How are these programs funded?
- 5) Are there any services that your agency would like to provide?
- 6) Are there any services that should be provided by other agencies that are not yet provided?
- 7) What are barriers to providing these services?
- 8) Does your agency/hospital/program collaborate with other programs to provide services? If so, how? How often? If not, why not? Would you like to collaborate with others?

Appendix C

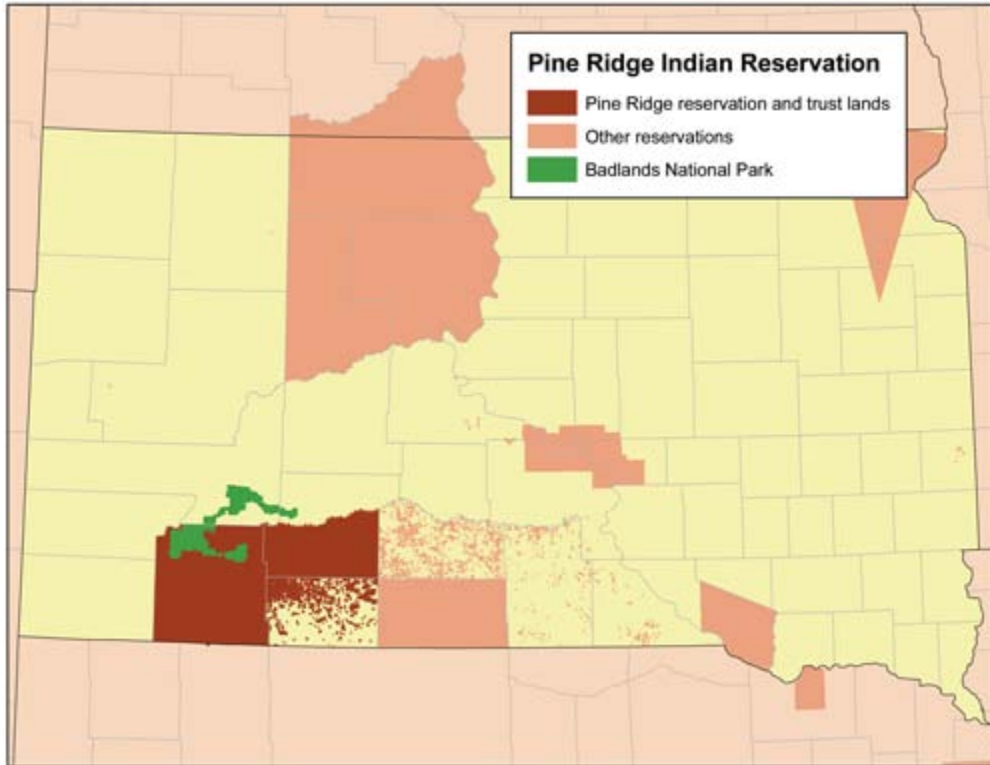
Maps of Pine Ridge Indian Reservation

Districts and Counties¹



¹ Referenced in Chapman, C., Conti, K., Frank, D., & Gansen, A. (2003). Pine Ridge Indian Reservation South Dakota. Community mini-plan. Full citation in Chapter II.

Map of South Dakota with Pine Ridge Indian Reservation²



² Retrieved from http://commons.wikimedia.org/wiki/Category:Pine_Ridge_Indian_Reservation

APPENDIX D

Photo of Wounded Knee Mass Grave and Cemetery³



³ Retrived from <http://www.getintravel.com/the-ghost-dance-at-wounded-knee-south-dakota-united-states/wounded-knee-cemetery-in-south-dakota-united-states/>

View of Cemetary with Wounded Knee Battle Field in the Distance⁴



⁴ Retrived from <http://carbonsabbath.org/uncategorized/history-of-an-unseen-face-part-2-of-4/>

Wounded Knee Memorial⁵



⁵ Retrived from <http://www.southdakota.com/wounded-knee-museum/395>