

THESIS

“INDIANS DON’T GET TRANSPLANTS”: DIALYSIS PATIENT EXPERIENCE AND POLITICAL
ECONOMIC BARRIERS TO TRANSPLANTATION ON THE PINE RIDGE INDIAN
RESERVATION

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ABSTRACT

“INDIANS DON’T GET TRANSPLANTS”: DIALYSIS PATIENT EXPERIENCE AND POLITICAL ECONOMIC BARRIERS TO TRANSPLANTATION ON THE PINE RIDGE INDIAN RESERVATION

The Oglala Lakota people of the Pine Ridge Indian Reservation have been plagued with poor kidney health due to political economic factors such as poverty, discrimination, unemployment, and limited food access. This poor health, exemplified in high rates of end-stage renal disease (ESRD), has created a population of patients that face daily challenges associated with dialysis treatment. Many of these patients would prefer kidney transplantation as treatment for their ESRD; however, a multitude of structural, institutional, educational, and biological barriers create obstacles that most find too difficult to overcome. This thesis explores the lived realities of dialysis patients on the Pine Ridge Indian Reservation and the structural challenges these patients face in accessing kidney transplantation. With dialysis patients often overlooked in terms of research and healthcare initiatives, this research provides the platform for patients to tell their stories, share their experiences, and advocate for their right to health and dignity. This applied anthropological research seeks to tackle the real-world issues of transplantation access among the Oglala Lakota population living on Pine Ridge. Therefore, the goal of this research is to both identify existing barriers as well as posit solutions that will help with the mediation of these barriers to improve access to kidney transplantation. Drawing on ethnographic methods such as participant observation and semi-structured interviews, this research attempts to provide an insider’s perspective to dialysis challenges and the experiences of patients suffering from end-stage renal disease.

This research focuses on three primary areas of interest. The first seeks to illuminate the dialysis patient experience, daily activities and limitations, and emotional responses to an end-stage renal disease diagnosis. This line of research serves as a window into the lives of dialysis patients, providing an *emic* or insider’s perspective into the difficulties and challenges these individuals face. The second primary area

of interest examines systems of belief and support present on the reservation represented by traditional Lakota belief systems and Christianity. Each of these systems functions to support patients during periods of hardship, but also plays an influencing role in healthcare decision-making. The third research focus explores the myriad barriers that inhibit access to kidney transplantation among the Oglala Lakota people. The distal and proximal barriers imposed on patients can be categorized as structural, institutional, educational, or biological, affecting patients in different areas and at different times in their lives.

Using critical medical anthropology and structural vulnerability as the theoretical basis for data interpretation, the different structural levels of the healthcare system are examined. Each of these levels provides explanatory power regarding the regulation, influences, and pressures applied by the larger system on the individual. The critical medical anthropology approach also demonstrates a clear mismatch between the ideal transplantation process and the real-world capabilities of Oglala Lakota patients. To mediate identified barriers and align these mismatched systems, I provide specific recommendations for policy and practice that can be implemented to improve patient health and facilitate access to transplantation for those who seek it.

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LIST OF ACRONYMS

CKD: Chronic Kidney Disease

CMA: Critical Medical Anthropology

ESRD: End-stage Renal Disease

HLA: Human Leukocyte Antigen

IHS: Indian Health Service

OST: Oglala Sioux Tribe

UNOS: United Network for Organ Sharing

CHAPTER ONE

Introduction

1.1 “Indians don’t get transplants”

Staring out the window of the Toyota Tacoma, I watched as pine forests, perched atop rolling hills and gullies, gave way to prairie and eventually the sharp points of the Badlands bluffs. Driving along the main road, one of the few to be paved, we sped through this vast expanse of land; a land we call the Pine Ridge Indian Reservation and a land the Oglala Lakota call home.

We slowly turned into Gerald’s driveway, a wheelchair ramp hugging the side of his house, paint peeling, one window broken and boarded. We let ourselves inside, calling up the half flight of stairs to announce our presence. Gerald greeted us at the top, a middle-aged man, overweight, and wheelchair bound. Gerald had been diagnosed with end-stage renal failure four years ago, the result of uncontrolled diabetes which had plagued him for a decade or more. A former Vietnam vet, Gerald had lost more physically from diabetes than he had from the war. A sliver of a titanium bar was barely visible between the end of his pant leg and sneaker where his right ankle should have been.

Sitting on an eclectic array of lawn chairs and novelty seats (one shaped like a hand with the seat nestled in the palm and the fingers serving as the back rest) we chatted, laughed, and snacked on a bag of lays potato chips. As our conversation shifted from his family to his health, his demeanor changed. Stiff and frustrated, he told us that “stupid dialysis” made him tired all the time, sometimes sleeping the rest of the day after a treatment. Naively I asked “have you ever thought about getting a kidney transplant? That way you wouldn’t have to stay on dialysis.” Gerald looked up and stared at me for a full minute before responding “Indians don’t get transplants.” I expected to find anger or annoyance accompany this blunt statement, but all I could see was sadness and resignation written across his face.

It was only later that I found out that Gerald had twice been listed for a kidney transplant and had twice received the call for an available organ. The first time he didn’t have gas money to get to Sioux

Falls. The second time his car was broken and couldn't find a ride. Out of frustration, he pulled his name from the wait list, resigned to a lifetime of dialysis instead. Less than a year later, I heard through a friend that Gerald had passed away.

1.2 Introduction to Research

American Indian and Alaska Native populations in the United States have, in recent years, been plagued with increased incidence and prevalence of end-stage renal disease (ESRD) largely due to higher rates of diabetes found on reservations nationwide. On the Pine Ridge Indian Reservation, located in the southwestern corner of South Dakota, discrimination, extreme poverty, rampant unemployment, limited access to healthy foods, and other factors have led the Oglala Lakota population to have one of the highest rates of ESRD and the lowest life expectancies in the United States (Narva 2008). Previous research has shown that kidney transplantation as a treatment for ESRD in lieu of long-term dialysis provides both increased life expectancy and improved quality of life (Esposito et al. 2017; Laupacis et al. 1996; Port et al. 1993; Wolfe et al. 1999). Despite these benefits however, the percentage of American Indian individuals receiving a kidney transplant is lower than that of every other ethnic demographic in the United States despite having the highest prevalence of ESRD (Narva 2002, 2003; Yeates and Tonelli 2006).

To explore these disconcerting trends, ethnographic methods were employed to examine three primary areas of interest: the lived experiences of dialysis patients, the systems of belief on the reservation, and the political economic barriers that inhibit access to kidney transplantation. Living on the reservation and embedding myself within the daily lives of dialysis patients, I gained an intimate view into the challenges faced by this population on Pine Ridge. Based on previous research, I developed a semi-structured interview protocol that focuses on my three primary areas of interest; however, the trajectory and topics of the interviews were largely determined by participants. In conducting this research, I felt it was of the utmost importance that patients had the ability and outlet to share their stories;

in this manner this research is guided *by* patients and developed specifically *for* patients with the goal of improving patient experience and access to care on the reservation.

The first primary area of interest is based on the unique experiences of dialysis patients. Understanding how patients perceive of dialysis treatment and knowing the ways in which lives and livelihood are limited, helps to illuminate desires for alternative treatments, namely transplantation. The challenges posed by the strict and physically taxing dialysis treatments often negatively impact the social, emotional, spiritual, and physical wellbeing of patients.

The second area of interest driving this research, systems of belief, has been included to study cultural norms and traditional conceptions of health, illness, and the body. These belief systems have the potential to shape patient perceptions of transplantation and therefore help to explain the disparities present among these populations. Through my exploration into this area of research, it became apparent that differing systems of belief, traditional Lakota belief systems and Christianity, operate to both support patients as well as shape patient healthcare decision making.

The third area of interest encompasses the applied aspects of this research by identifying the myriad barriers that inhibit or prevent patients from accessing kidney transplantation. Unlike previous research that focuses primarily on the distal barriers (those that occur once a patient is listed with a transplant center) this research seeks to outline the barriers that reduce patient agency, inhibit capabilities, shape decision making, and contribute to poor health on the Pine Ridge Indian Reservation. The identification of these barriers illuminates areas of improvement and the failures of the larger healthcare system to adequately care for minority, heterodox populations.

While this research will contribute to the existing literature examining access to kidney transplantation among marginalized populations, it also has significance beyond academia. This applied research seeks to explore the healthcare systems and structures utilized by Oglala Lakota dialysis patients to identify gaps in ideology, access, and practice. By acknowledging and identifying these gaps, they can be mediated and bridged improving both healthcare access and patient health outcomes. Results from this research will be shared with the dialysis centers on the reservation, tribal officials, and presented to the

Oglala Sioux Tribe Research Review Board, in the hopes that my recommendations will be included in future initiatives to improve the lived experiences of dialysis patients through better health and access to care.

1.3 Thesis Outline

Following this introduction, Chapter 2 provides a detailed background of existing literature that outlines the transplantation disparities mentioned above. This chapter begins with a discussion of the theoretical orientations that have shaped this research and guided the interpretation of collected data. This section is followed by a comparison of health outcomes between dialysis and kidney transplantation as a treatment for end-stage renal disease as well as inequities and disparities in the distribution and allocation of available organs among minority populations. I conclude this chapter by highlighting previously identified barriers to transplantation which have largely focused on limiting factors such as transportation, geographically remote location, and financial instability that occur during the latter stages of the transplantation process.

Chapter 3 details the methods utilized in this research. I provide a justification for the importance of this research on Pine Ridge, describe the sample population and setting, and outline the specific qualitative ethnographic methods used to compile and analyze data.

Chapter 4 focuses on the dialysis patient experience including perceptions of dialysis treatment and transplantation. Here patients outline the ways in which dialysis imposes limitations on their daily lives and prevents them from living their desired lifestyles. This chapter also explores patients' emotional responses to dialysis and the changes to these responses as patients process and come to terms with their new health reality.

Addressed in Chapter 5 are the systems of belief that operate on the reservation which provide support for patients through the challenges of their diagnosis and shape healthcare decision making. The two primary systems of belief on the reservation are traditional Lakota belief systems and Christianity.

These two systems are bridged by conceptions of family, friends, and community that permeate the values of most on Pine Ridge.

Chapter 6 outlines the multitude of barriers that contribute to poor health on the reservation and inhibit patients from accessing kidney transplantation as a treatment for end-stage renal disease. Here I first describe a necessary change in focus from the previously identified distal barriers to the proximal barriers, those that shape poor health and limit adequate health maintenance throughout the lives of patients on the reservation. These proximal barriers have been categorized as structural barriers, institutional barriers, educational barriers, and biological barriers.

Using the theoretical orientations described in Chapter 2, Chapter 7 serves to orient this location-specific data within the larger healthcare system. Examining the different levels described by the critical medical anthropology approach, it becomes clear that Oglala Lakota populations are further marginalized by the overarching systems and institutions that impose nationwide standards, procedures, assumptions, and regulations.

I conclude this thesis in Chapter 8 with a synthesized discussion of my results. Here I also include specific recommendations for possible ways to mediate some of the identified barriers, improving both health and healthcare access for Oglala Lakota patients living on Pine Ridge. I end this chapter by positing areas for future research to expand the limited literature that examines issues of native healthcare access in the United States.

CHAPTER TWO

Literature Review

In this chapter, I will discuss the theoretical orientations that provide the foundation for this research as well as information essential to understanding the complex interplay between the development of poor health, limited access to healthcare, and challenges in access to kidney transplantation on the Pine Ridge Indian Reservation. Compiling and combining literature that spans the diverse disciplines of anthropology, sociology, economics, history, and medicine, this literature review provides a comprehensive examination of existing research. In order to adequately understand issues of poor health on Pine Ridge, specifically focusing on the development of end-stage renal disease (ESRD), dialysis treatment, and kidney transplantation, it's important to examine more broadly the political, economic, and historical contexts in which patients are developing poor health. The discussion of poor health on the reservation is followed by literature supporting a medical preference for transplantation as a treatment for ESRD compared to dialysis. However, despite this medical preference, previous studies have set a precedence for the possibility of cultural incompatibility with the biomedical transplantation procedure which may or may not contribute to additional factors that explain the significant disparities in kidney transplantation distribution among minority populations.

2.1 Theoretical Approach

In attempting to identify the barriers individuals face in accessing kidney transplantation, theoretical contributions from medical anthropology provide the basis for interpretation, analysis and discussion. The field of medical anthropology is broad, encompassing a multitude of different theoretical orientations that cover a wide range of topics regarding human health, traditional medicine, cultural determinants of health, and health systems (both western and non-western) to name a few. According to Baer and colleagues (Baer et al. 2013:5) health can be defined as “access to and control over the basic material and nonmaterial resources that sustain and promote life at a high level of individual and group

satisfaction.” The concept of health is extremely dynamic in relation to individuals and populations and is influenced by a combination of cultural factors such as perceptions and experiences of health with the more concrete material factors such as access to health resources (Baer et al. 2013). While this research asks questions of personal experience, traditional systems of knowledge and spirituality, and opinions of transplantation, in its essence this research is an examination of a health system and individual patient positionality within that system.

The following subsections will explore two theoretical approaches within the field of medical anthropology and the associated literature from each. The first of these sections discusses the political economy-oriented approach called critical medical anthropology (CMA). This theoretical orientation examines health care systems and the complex connections and relationships that exist at differing levels and scales within a given system. Following the section on critical medical anthropology is a discussion on structural vulnerability that emphasizes the vulnerabilities individuals embody as a result of their social, political, economic, and culturally hierarchical positions. These theoretical lenses will both expose and clarify root causes of ill health on the Pine Ridge Indian Reservation while simultaneously examining the complex relationships, pressures, and influences that exist within this health care system.

2.1.1 Critical Medical Anthropology

The anthropological study of human health moves beyond limitations of individual biology and instead examines the role of culture and society in determining health outcomes. Drawing on political economy, the Critical Medical Anthropology (CMA) approach described by Hans Baer, Merrill Singer, and Ida Susser identifies larger social structures, political power dynamics, and economic inequalities that influence health. Unlike other perspectives in medical anthropology, CMA approaches health and disease, not as natural phenomena, but instead as intimately entwined with cultural, social, political, and economic realities within a given population (Baer et al. 2013). CMA is often used for research working with disadvantaged populations, especially indigenous populations whose historical interactions with capitalist and large-scale institutions have left them in positions of decreased power, marginalized locations, and

situations of poverty (Baer et al. 2013). By examining the ways in which “social inequalities find direct expression in the shape and appearance of the human body” this theoretical orientation uncovers the cultural and social structural root causes of physical illness (Baer et al. 2013: 56).

Holistically concerned with health, critical medical anthropology seeks to understand the ‘bigger picture’ of health phenomena by identifying and understanding the complex relationships between multiple health conditions, “sufferer and community understandings of illness... and the social, political, and economic conditions that may have contributed to the development of ill health” (Baer et al. 2013: 15). To gain this holistic perspective, CMA examines different levels of interaction between agents within a political economic system (Baer et al. 2013). Therefore, questions regarding access, barriers, and gaps in healthcare systems are frequently and effectively understood by means of a critical medical anthropology perspective because of its in-depth examinations of different structural levels within a given system. These structural levels include the macrosocial, intermediate, microsocial, and individual levels; each providing an additional layer of explanatory power through which entire health systems can be better understood. For this research, I am adapting this multi-scalar framework to better examine the specific health care system at play regarding access to kidney transplantation on the Pine Ridge Indian Reservation.

The most expansive macrosocial level examines and represents broad scale systems and institutions and their interactions with political and class structures (Singer 1995). This level usually examines the global capitalist system which relies on power inequalities, profit, and economic gain at a structural level. Another frequent topic of study within this level is the relationship between biomedical systems and alternative medical systems; a relationship often characterized by biomedical dominance (Singer and Baer 1995). In terms of the kidney transplantation health system, the macrosocial level is represented by the United Network for Organ Sharing (UNOS) and other regional organ procurement organizations which represent the dominant medical ideologies of biomedicine. Dictated by nationwide policies and influences, these organizational structures that comprise the macrosocial level work to

benefit those who specifically fit within the norms of biomedicine creating disadvantages for people who adhere to alternative heterodox medical systems (Baer et al. 2013).

The intermediate level is traditionally concerned with the interactions and relationships found within health care facilities including hospitals, clinics, and physician offices (Singer and Baer 1995). Regarding this research, this level is being modified to examine the interactions and conformity of specific hospitals and transplant centers to the larger macrosocial system of organ allocation. The need for hospitals and transplant centers to conform to the policies of the nationwide organ transplantation system limits the capabilities of these slightly smaller entities to best care for patients within their regional jurisdiction.

The microsocial level examines the physician-patient interaction. This level looks at the larger influences placed upon physicians and examines the power dynamics “as exercised both *during* and *through* the interaction” between a doctor and their patient (Singer and Baer 1995:71). At this level, the physician has the power to stress or diminish patients lived social experiences (such as poverty, unemployment and discrimination) and its impact on health. Also at this microsocial level is the “community level of popular and folk beliefs and actions” (Singer 1995:81). This level of examination highlights culturally specific beliefs and opinions, differences in cultural norms, cross-cultural miscommunications, and the influence of power dynamics on individual health.

Lastly, the individual level gives voice to the lived experiences of people (Baer et al. 2013). This is particularly important on Pine Ridge where patients often feel their experiences are being diminished to numbers within a system; a statistic that highlights the hardships of reservation life. The CMA approach to the individual level instead “seeks to elucidate the nature of the sufferer experience, symptom expression and behavior, and the transformation of sufferer into patient and the patient into the depersonalized site of an isolatable, treatable disease” (Singer and Baer 1995:73). Through this lens, it is not the numbers and statistics that are valuable, but instead individual stories and experiences that shape their relationship to, and perceptions of, their health as well as understanding the process of societal structures that work to diminish these experiences to tangible quantitative data.

One key aspect of critical medical anthropology is the recognition of the western biases often injected into research projects. Incorporated into this theoretical approach is the goal of working with communities to identify their specific needs and understand where their investments lie regarding research (Singer 1995). Too often, research projects are driven by external perceptions of what is needed within a population. I have deemed this research on the Pine Ridge Indian Reservation to be culturally significant due to the sheer number of individuals on dialysis on the reservation and most importantly because of patient buy-in, encouragement, and validation. These individuals wanted the opportunity to tell their stories, discuss their experiences, expose their dissatisfactions with their health and the larger health care system, and assist in finding solutions that can improve current and future patient health.

2.1.2 Structural Vulnerability

Complementing the critical medical anthropology theoretical framework, the concept of structural vulnerability draws on political economy, social inequality, and historical contexts to examine how the positionality of individuals within a social and structural hierarchy influences their state of health and well-being (Quesada et al. 2011). While CMA primarily focuses on the structure and levels of interaction within a health system, structural vulnerability works to explain conditions of human health in the context of political and economic pressures as well as societal influences and cultural norms. The concept of structural vulnerability is based on the concept of structural violence, first coined by the sociologist Johan Galtung. In its original conception, structural violence describes “the indirect violence built into repressive social orders creating enormous differences between potential and actual human self-realization” (Galtung 1975:173). This definition was then adapted within the field of medical anthropology to draw attention to social disparities and inequalities as well as to “identify socially structured patterns of distress and disease across population groups” (Quesada et al. 2011).

To further broaden the application of this idea, anthropologists James Quesada, Laurie Hart, and Philippe Bourgois choose to utilize the “more neutral and inclusive term” *vulnerability* to expand the breadth of structural violence beyond political economy to also include the “cultural and idiosyncratic

sources of physical and psychodynamic distress” (Quesada et al. 2011:341). Structural vulnerability refers to the cumulative embodied forces based on one’s positioning within a hierarchical social and political network that limit agency and capabilities while also directly influencing and impacting the development of ill health (Quesada et al. 2011). This approach can be used to identify the “clinically invisible” barriers of care access, medication and treatment adherence, and patient health understanding that are often “misattributed to the self-destructive will of the patient” (Quesada et al. 2011:351). Structural vulnerability shares the goals of critical medical anthropology which work to bring anthropological insights beyond the confines of academia and implement them in a practical sense within larger health care systems to improve patient treatment and health. The very existence of structural vulnerability has real and devastating consequences among marginalized and minority populations; Quesada and colleagues (2011) capture this idea poignantly claiming that structural vulnerability leads to “shorter lives [that are] subject to a disproportionate load of intimate suffering” (351). Identifying how the dialysis patient population on Pine Ridge is subjected to structural vulnerability, and understanding the many social, political, economic, and cultural factors at play may serve to improve physician-patient relationships and provide a more nuanced ability to understand root causes of ill health on the reservation.

2.2 An Introduction to Pine Ridge

The Pine Ridge Indian Reservation, like all tribal reservations in the United States, is home to a beautiful and unique culture. Nestled within the Great Plains region, Pine Ridge is bordered by the densely forested and sacred Black Hills to the west, the starkly beautiful buttes of the Badlands to the north, the Rosebud Reservation to the East, and the Nebraska state border abutting it to the South. The colonization of the Lakota by the United States government can be characterized by war, economic marginalization, forced acculturation, broken treaties, and a devastating loss of life. This colonial history has created many lasting legacies and historical traumas, the scars of which are readily visible on the reservation today. However, despite this history and in the face of ongoing hardship, the Oglala Lakota

people who call Pine Ridge their home have maintained and fostered a vibrant and resilient community on the reservation.

The Oglala Lakota are one of seven sub-tribes that comprise the broader Lakota cultural and linguistic group often referred to as the Great Sioux Nation. The terms Sioux and Lakota are often used interchangeably to describe the native peoples of the Great Plains Region that extend beyond the Pine Ridge Reservation and include the Rosebud, Cheyenne River, Lower Brule, and Standing Rock reservations. The name “Sioux”, meaning “snake” or “little snake” was given to these peoples by the white colonizers at the time of contact. Although the official tribal name remains Oglala Sioux, the people of Pine Ridge prefer to call themselves Lakota and therefore will be referred to as such in this research.

After the official formation of the Pine Ridge Indian Reservation in 1889 and throughout the twentieth century, the United States government focused on civilizing the Lakota people by dismantling the traditional economic systems of exchange and implementing a capitalist system (Pickering 2004). The Lakota were overseen by white administrators in all walks of life from farm owners and school teachers to employers. Traditional lifestyles, conceptions of work, religious and spiritual beliefs, and education were condemned and forcibly replaced by westernized ideologies; those who pushed back were killed (Pickering 2004). One of the most effective means of cultural imperialism enacted by the United States government was the creation of Indian Boarding Schools run by the Bureau of Indian Affairs (BIA). These schools were implemented across the United States and modeled after the Carlisle Indian School in Carlisle Pennsylvania whose goal, motto, and mantra were to “kill the Indian, save the man” (Bess 2000; Hoerig 2002).

In the continued attempt to exercise control over the political and economic resources of the tribe, the United States government kept Pine Ridge deliberately isolated from any urban ties to prevent the flow of resources onto the reservation (Pickering 2001). The subsequent shortage of resources and marginalization has created the foundation upon which the Pine Ridge economic system now rests; one that is characterized by an absence of industry, struggling local economies, and an 80-90 percent unemployment rate (Strickland 2016; Friends of Pine Ridge 2016). The epidemic of unemployment is a

large contributor to the suffocating poverty that afflicts a majority of the 28,000 people (Sweet Grass LLC 2017) to whom Pine Ridge is home.

In addition to the destruction and suppression of the Lakota economic system, the legacies of colonization have also had detrimental impacts on the health of the Oglala Lakota people. As part of the government's control of resources on the reservation in the mid-1900s, a rationing system was implemented which introduced the Lakota people to sugar, lard, salt, and flour along with other American surplus foods (Pickering 2004). These products, while previously unfamiliar to the Lakota people, have since become staples of American Indian cooking, especially in the form of Indian fry bread. These systematic alterations to traditional subsistence and diet, when paired with economic marginalization and the creation of food deserts, are largely to blame for the current obesity, diabetes, and cardiovascular disease epidemics found on the reservation. These poor health trends are not unique to Pine Ridge but are found nationwide among American Indian populations. Today native peoples are among the least healthy populations in the United States suffering from high rates of diabetes, cardiovascular disease, and drug and alcohol addiction. These ailments, historically rare among American Indian populations, have reached catastrophic levels (Weidman 2012). On Pine Ridge, diabetes rates are eight times that of the national average with close to 40 percent of the total population (60 percent of adults) being diagnosed (Friends of Pine Ridge 2016). These high rates of diabetes have been linked to the correspondingly high rates of end-stage renal disease or chronic kidney disease on the reservation; approximately 3.5 times higher than the national average (Narva 2002).

2.3 Treatments for End-Stage Renal Disease

End-stage renal disease (ESRD), also known as end-stage kidney disease, is a chronic disease resulting from the gradual loss of kidney function. The kidneys act as a natural filter that remove waste and other toxic substances from the blood stream and body, excreting them as urine. When the kidneys become damaged, they are no longer able to efficiently or effectively filter out waste material allowing these toxins to become more concentrated within the bloodstream. Without treatment, ESRD is fatal. The

leading causes of ESRD are Type 1 and Type 2 diabetes, high blood pressure, inflammation of the kidney's filtration units and tubules, and frequent or prolonged obstruction of the urinary tract. ESRD can be devastating, often presenting with nausea, vomiting, loss of appetite, fatigue and weakness, sleeping problems, alterations in normal urination patterns, decreased mental acuity, swelling of the feet and ankles, and a buildup of fluid in the lining around the heart (CDC 2001; Mayo Clinic 2017).

Treatment for ESRD requires either mechanical filtration of the blood stream through hemodialysis or peritoneal dialysis, or the implantation of a 'used' filtration system by means of kidney transplantation. Comparisons in patient outcomes between these two treatment methods have shown that kidney transplantation is associated with lower long-term health risks than dialysis treatments (Port et al. 1993; Wolfe et al. 1999). Kidney transplantation can occur in one of two forms: living donor kidney transplantation or cadaveric kidney transplant. Living donor kidney transplantation confers improved outcomes than transplantation of cadaver kidneys; however, risks to donor health, need for organ compatibility between donor and recipient, donor health status, and financial burden of recovery make live donor kidney transplantation a less common option (Wolfe et al. 1999). With compounding health conditions common on the Pine Ridge Indian Reservation and limited financial resources, live donor transplantation is extremely uncommon. Therefore, the following discussion will be focused on cadaveric renal transplantation; transplantation from a deceased or braindead organ donor.

When measuring and comparing health outcomes, frequently cited are mortality, relative risk, and overall quality of life as health indicators. Early studies examining the mortality rates of dialysis and transplantation used as comparative samples those who received transplants and those being treated with dialysis. These studies concluded that transplantation conferred lower mortality compared to dialysis treatments. However, this approach ignores the selective forces that determine candidacy for transplantation; patients whose health conditions had significantly deteriorated or those above the age of 65 were prevented from receiving transplantation while those who were healthier and younger were selected for transplantation (Port et al. 1993; Wolfe et al. 1999). Conducted in the 1980s, these studies have since been denounced as biased due the selective advantage of the healthier individuals for

transplantation (Hutchinson et al. 1984; Port et al. 1983; Weller et al. 1982). In a series of landmark studies, Port (1993), Wolfe (1999) and colleagues addressed these former biases and compared mortality rates between dialysis treatment and kidney transplantation by limiting their participant population to those eligible for transplantation. All study participants were wait-listed for kidney transplantation (and therefore had similar health characteristics) and outcomes were compared between those who had received a transplant and those who remained on the waiting list (Port et al. 1993; Wolfe et al. 1999).

Results from these studies show that even after eliminating selection biases, kidney transplantation decreases long-term health risks in patients with ESRD. These results have been replicated in several countries outside of the United States including the United Kingdom, Germany, and Canada (Oniscu et al. 2005; Rabbat et al. 2000; Schnuelle et al. 1998). Following renal transplantation, mortality risk is higher than that seen in dialysis patients due to risks associated with undergoing a major surgical procedure such as risk of infection, taking high doses of immunosuppressant medications to prevent organ rejection, and the chance of a non-functioning renal allograft (donor organ) (Port et al. 1993; Wolfe et al. 1999). The risk of death due to these factors decreases the longer the time after transplantation and becomes equal to that of dialysis patients at approximately 110 days post-surgery (Port et al. 1993; Wolfe et al. 1999). Patients surviving past this point in time had a 68 percent lower risk of death than wait-listed dialysis patients (Port et al. 1993; Schnuelle et al. 1998; Wolfe et al. 1999). The long-term benefits associated with kidney transplantation were shown to double life expectancy: 5-10 years on average for those patients on dialysis waiting for transplantation compared to a life expectancy of 15-20 years for those who were able to receive a kidney transplant (Oniscu et al. 2005; Wolfe et al. 1999). For younger patients, those aged 20-39 years, the projected life expectancy was up to 17 years longer than those who remained on the transplant waiting list (Wolfe et al. 1999).

Across all patients undergoing transplantation, there was a lower long-term risk of death regardless of age group or original condition leading to the development of ESRD (Oniscu et al. 2005; Rabbat et al. 2000). These survival benefits were even seen among high risk patients (Oniscu et al. 2005). Particularly significant were the long-term survival benefits for individuals for whom diabetes was the

root cause of their ESRD (Port et al. 1993; Rabbat et al. 2000; Wolfe et al. 1999). Patients with diabetes were projected to gain approximately 11 years of life after transplantation compared with the 8-year average gained by those whose ESRD was caused by other health conditions such as high blood pressure or chronic obstruction of the urinary tract (Wolfe et al. 1999). Using mortality as a health indicator, it is strongly supported that kidney transplantation increases life expectancy and decreases one's overall risk of death (Port et al. 1993; Rabbat et al. 2000; Schnuelle et al. 1998; Wolfe et al. 1999).

In addition to long-term survival, it is important to account for the quality of the extended life-years associated with kidney transplantation (Port et al. 1993). Health-related quality of life, defined as “a person's sense of well-being and ability to function productively in daily life” (Avramovic and Stefanovic 2012:581), is an important measure in gauging the physical, social, and mental well-being of an individual or population. As with mortality, the period directly following transplantation surgery is associated with significant restrictions and limitations to one's physical, social, and emotional life (Esposito et al. 2017). Hospitalization and restrictions such as wearing a face mask, limited contact with animals, and frequent hand washing, were shown to decrease quality of life (Esposito et al. 2017). However, after this initial period of decreased quality of life, significant improvements were observed in patient's cognitive, physical, and sexual function as well as in mental and emotional well-being (Esposito et al. 2017; Kostro et al. 2016).

Patients receiving dialysis utilize one of two treatment options: peritoneal dialysis or hemodialysis. Peritoneal dialysis works by absorbing waste products from the body through a catheter inserted into the abdomen. While peritoneal dialysis offers better health outcomes and a more flexible lifestyle and diet (Mayo Clinic 2018), this option is uncommon on Pine Ridge. Instead most patients receive hemodialysis which uses either a chest catheter or a vascular access fistula in the arm to mechanically remove, clean, and return the patient's blood. Dialysis patients tend to experience severe disability and challenging symptoms such as muscle and joint aches, dry and itchy skin, gastrointestinal pain and discomfort, difficulty concentrating, shortness of breath, cramps, dizziness, and decreased sexual function (Laupacis et al. 1996). These symptoms often lead to high rates of unemployment, depression,

pain, poor sleep quality, malnutrition, inflammation and anemia (Esposito et al. 2017). Each of these symptoms and their related outcomes has been shown to improve after renal transplantation (Kostro et al. 2016; Laupacis et al. 1996). Employment rates increased from 30% employed before transplantation to 45% post renal transplantation. For individuals with functioning transplanted organs after two years (eliminating those with complications in the first two years after surgery) employment rates increased to 51% (Laupacis et al. 1996). As with mortality rates, the health-related quality of life benefits experienced by diabetic patients was particularly significant (Esposito et al. 2017; Laupacis et al. 1996). While transplantation does not restore a patient's health to that of the general population, it does offer patients increased life expectancy and improved quality of life compared to treatment through long-term dialysis (Avramovic and Stefanovic 2012; Esposito et al. 2017; Griva et al. 2013; Kostro et al. 2016).

2.4 Disparities in Kidney Transplantation

Cadaver renal transplantation is controlled and distributed in the United States through the United Network for Organ Sharing (UNOS), meaning patients must join the kidney waitlist and remain on dialysis until a matched organ becomes available. Cadaver organs are allocated using blood type, height, weight and the human leukocyte antigen (HLA- a key factor in transplantation graft survival) to the next patient on the waiting list within the given region who matches these same biomarkers (UNOS 2017; Wu et al. 2017). Although frequently referred to colloquially as a wait-list, UNOS describes their system for organ matching as a “pool of candidates who are waiting for organ transplants” (UNOS 2017). This computer matching system then “generates a ranked list of transplant candidates who are suitable to receive each organ” based on wait time, donor/recipient immune system compatibility, prior living donor, distance from donor hospital, survival benefit, and pediatric status in addition to the previously mentioned biological factors (UNOS 2017). Significant improvements in “immunosuppressive therapy, organ preservation, and recipient selection by HLA matching have resulted in increased graft survival” and corresponding positive health outcomes among transplant patients (Schnuelle et al. 1998: 2135).

With sharp increases in the number of individuals in the developed world suffering from ESRD, the United States and other westernized nations face a serious shortage in available organs as the rates of organ donors has not significantly changed in recent decades (Alexander and Sehgal 1998; Jha et al. 2017; Wu et al. 2017). Recent estimates show that the number of patients currently listed for renal cadaver transplants in the United States has doubled in the last decade reaching a current high of around 100,000 patients. With an average wait time of about four and a half years on the kidney transplant list, almost 5,000 patients die each year while waiting for a kidney to become available (Wu et al. 2017).

In addition to the risk of death while waiting for an organ match due to complications with ESRD, wait time while on dialysis is strongly correlated with post-transplant health outcomes (Meier-Kriesche et al. 2000). The longer a patient spends on dialysis the more risk they face in terms of graft deterioration and mortality after transplantation (Meier-Kriesche et al. 2000; Wu et al. 2017). The poor nutrition, chronic inflammation, and altered immunologic function experienced by those on dialysis may predispose patients to decreased tolerance of immunosuppressive therapies and anti-rejection medications after transplantation (Meier-Kriesche et al. 2000). Age is also considered a risk factor for successful transplantation with older individuals tending to have worse health outcomes after transplantation (although still improved from conditions on dialysis) than their younger counterparts. Therefore, extensive delay in waiting for transplantation creates added risk based on age demographics alone (Esposito et al. 2017; Wu et al. 2017).

In the United States, UNOS claims their organ matching and allocation system is based “only [on] medical and logistical factors... Personal or social characteristics such as celebrity status, income, or insurance coverage play no role in transplant priority” (UNOS 2017). Although this ‘blind’ system appears to provide equal opportunity to waiting transplant recipients, significant disparities exist in the allocations of organs based on ethnicity (Alexander and Sehgal 1998; Cao et al. 2016; Davison and Jhangri 2014; Epstein et al. 2000; McPherson et al. 2017; Mucsi et al. 2017; Kucirka et al. 2011; Rubin and Weir 2015; Wu et al. 2017; Yeates et al. 2009). The biomarkers and blood types necessary for appropriate renal allograft survival create a biological disadvantage among minority populations. This is

largely because deceased donor kidneys are primarily harvested from donors within the white majority population (Yeates et al. 2009). While cultural distinctions of race are often invisible in a person's biology, according to Nadene, a study participant, specific HLA types are more common among certain minority populations making a match with a white donor more difficult. Although disparities still exist, changes to the UNOS allocation system in 2014 reduced biological disparities by placing an increased priority on "highly sensitized patients and patients with rare HLA types" commonly found among minority patients (Cao et al. 2016; Wu et al. 2017:1288). More significant and difficult to address and quantify are the ethnic disparities caused by discrimination, likelihood of referral, and remote geographic location (McPherson et al. 2017; Rubin and Weir 2015).

Discrimination, institutional biases, or racism in areas of the United States puts minority groups at a disadvantage in relation to their ability to access kidney transplantation (Yeates et al. 2009). Compared to their white counterparts, minority populations such as Blacks, Hispanics, and American Indians all have been shown to have a higher prevalence of ESRD; yet despite having higher rates of ESRD, minority populations have a lower prevalence of kidney transplantation (Alexander and Sehgal 1998; Avanian et al. 1999; Cao et al. 2016; Epstein et al. 2000; Kucirka et al. 2011; Mucsi et al. 2017; Wu et al. 2017; Yeates et al. 2009). A significant factor in one's ability to obtain a successful kidney transplant is the timely referral to the UNOS transplant waiting list. It has been shown that minority populations have lower rates of transplant referral from one's physician and longer duration of dialysis treatments than their white counterparts (Kucirka et al. 2011; Yeates et al. 2009). As previously mentioned, the more time spent on dialysis, possibly due to delayed referral and the difficulties associated with finding an organ match, the worse health outcomes individuals tend to experience; therefore, individuals with delayed referral may no longer be eligible for transplantation due to deteriorated health conditions (Alexander and Sehgal 1998; Wu et al. 2017).

In addition, social determinants persist beyond the realm of the renal transplantation health system (Yeates et al. 2009). Poverty and low levels of educational attainment reduce the likelihood of kidney transplantation due to a limited ability to consume health care information and results in reduced

engagement in one's own health situation (Yeates et al. 2009). Additionally, socioeconomic status (closely linked to one's insurance status), patient preferences, lack of knowledge regarding transplantation, and past experiences with discrimination in the healthcare system all act as contributing factors in creating health disparities in access to kidney transplantation (Cao et al. 2016; Mucsi et al. 2017).

Geographical remoteness has also been linked to decreased accessibility of kidney transplantation (Anderson et al. 2009; Yeates et al. 2009). UNOS operates 58 donor service areas which are grouped into 11 regions. Due to the limited lifespan of a preserved organ (kidneys can be preserved for 24-36 hours), recipients for kidney transplantation within a given region are only able to be matched with a donor from the same region (UNOS 2017). This system leads to many geographic inequalities because organ accessibility is directly linked to regional populations and donor rates within a given region (Cao et al. 2016; Wu et al. 2017). Based on this relationship, patients listed in a region with high numbers of waitlisted patients, but low rates of organ availability, would result in a longer wait time. Issues of remote locations involve additional barriers related to distance, financial stability, and access to appropriate healthcare. Increased distance to healthcare facilities or transplant centers require ownership or access to a car or alternative transportation and a corresponding financial ability to pay for gas and an overnight stay (Anderson et al. 2009; Bello et al. 2012). Populations in remote areas were "less likely to receive appropriate specialist care" and "distance was viewed as a deterrent to initiating renal transplantation" (Bello et al. 2012: 2852).

2.5 Barriers to Kidney Transplantation among Native Populations

Of importance, yet understudied, are disparities in access to kidney transplantation among indigenous populations of the developed world and American Indian populations in the United States specifically (Davison and Jhangri 2014; Mucsi et al. 2017; Yeates et al. 2009). Rates of diabetes, heart disease, hypertension and obesity, previously rare among American Indian populations, have greatly increased in recent decades (Weidman 2012). Poverty, unemployment, and the adoption of modern diets

and lifestyles have led to the development of these diseases of modernity. Those living on reservations in the United States are often geographically marginalized which in some instances may lead to a lack of opportunity and limited access to adequate health care facilities (Weidman 2012).

The epidemic of metabolic diseases which plague American Indian populations were, at one time, thought to be due to genetic differences- the result of fewer generations to genetically adapt to modern environments (See “thrifty genotype hypothesis” James Neel 1962). This paradigm has since largely been abandoned and instead now focuses on the cultural “embodiment of the chronicities of modernity” (Weidman 2010, 2012). This theory focuses on the social and cultural factors which influence daily life, leading to the three main risk factors which result in the development of metabolic disorders: decreased physical activity, overnutrition, and chronic stress (Weidman 2012). The United States reservation system, which allotted areas of land for tribal groups across the country, confined native populations physically, psychologically, politically, and economically. The institutions and legacies of past colonial relationships create “structural violence” through land appropriation, powerlessness, and economic isolation (Weidman 2012). The introduction of a western diet and lifestyle, an obesogenic environment, has led many to develop metabolic disorders, especially diabetes. Diabetes, difficult to control due to the persisting structural violence suffocating native populations, has led to particularly high rates of ESRD on reservations nationwide. While many attribute the current poor health of native populations to individual behaviors, choices, and biology, the chronicities of modernity (the obesogenic environments in which we live) instead focus on identifying social circumstances that allow these diseases to proliferate (Weidman 2012).

In the United States, American Indian populations experience rates of ESRD which are up to four times that of white populations (Blagg et al. 1992; Yeates 2003). This trend can be seen in other developed nations such as Australia, Canada, and New Zealand where local indigenous or aboriginal populations suffer significantly higher rates of ESRD (Davison and Jhangri 2014; Yeates et al. 2009). In addition to high rates of ESRD, American Indian populations have the lowest prevalence of kidney transplantation among minority groups in the United States (Anderson et al. 2009; Narva 2002, 2003;

Yeates and Tonelli 2006). These low rates of transplantation have been attributed to many social factors such as language barriers, home sanitation, remote living locations, perceived lack of motivation (as perceived by health care practitioners), patient preferences, health practitioners' attitudes, and a lack of culturally appropriate patient education programs (Anderson et al. 2009; Yeates et al. 2009). In addition, lack of education and unfamiliarity with the long-term benefits of kidney transplantation leads patients to feel conflicted towards or wary of renal replacement surgery because of its associated short-term risks (Davison and Jhangri 2014; McPherson et al. 2017).

Remote locations of reservations in the United States have created difficulties in accessing healthcare facilities and transplant centers (Cao et al. 2016; Condiff 2009). The Pine Ridge Indian Reservation is situated in a particularly remote area of the country. Despite having a clustered population with high rates of ESRD on and around the Pine Ridge reservation, including Rapid City, South Dakota, a 'hot-spot' for high ESRD, there is a lack of health care facilities and a complete absence of transplantation centers. While transplant teams do travel and see patients in clinic in Rapid City, the nearest transplant centers (with surgical transplantation permissions and capabilities) are in Sioux Falls, SD, Denver, CO, and Omaha, NE (5.5 hours, 6 hours, and 7 hours away respectively) (Cao et al. 2016). Small population and comparatively low numbers of donors make the availability of organs that much more limited within this mid-western region (Cao et al. 2016).

While information regarding cultural beliefs, opinions, and knowledge of transplantation on the Pine Ridge Indian Reservation has not yet been studied, previous research has been conducted among other native populations in the United States, Canada, and Mexico. The results of these studies indicate that cultural beliefs, opinions, and spirituality *may* deter individuals from seeking transplantation as a treatment option for ESRD (Anderson et al. 2009; Blagg et al. 1992; Condiff 2009; Crowley 1999; Davison and Jhangri 2014). In 1999, Megan Crowley examined the cultural views on organ transplantation in Mexico. She found that popular beliefs in Mexico focused on the sacred integrity of the body (Crowley 1999). These cultural views and meaning of the body contrasted starkly with the

“mechanistic view of the body in which organs are simply interchangeable parts to be replaced as needed” (Crowley 1999:130).

Another study conducted by Davison and Jhangri examined traditional beliefs regarding organ donation and transplantation among Canadian First Nation members. It was commonly stated that “the dead must be left in peace” and that it is important for one to “enter the spirit world with an intact body” (Davison and Jhangri 2014: 782). While these beliefs were commonly held and may have been a deterrent for some individuals, only 18.7% of participants in that study reported that these views influenced their opinions about organ donation or transplantation (Davison and Jhangri 2014). Among Pacific Northwest tribal groups in the United States, similar views were held regarding the importance of one’s body remaining whole; this is viewed as contributing to the low rates of organ donation and a general lack of interest in organ transplantation in this region (Blagg et al. 1992).

Due to many social, economic, political, and historical factors, the Oglala Lakota people have extremely high rates of diabetes and correspondingly high rates of ESRD. However, because the people of Pine Ridge are both geographically marginalized and an ethnic minority, this population faces significant barriers resulting in low numbers of kidney transplantation. If desired, transplantation as treatment for end-stage renal disease could be the difference between life and death; therefore, the identification of barriers and gaps in the health care system is essential to providing the best possible health outcomes for those suffering from ESRD. These contrasting trends highlighted by existing literature demonstrate a need for further examination. Specific research methods, discussed in the following chapter, are used to elucidate many of the issues involved in kidney transplantation access.

CHAPTER THREE

Research Methods

This research draws on ethnographic and qualitative data collected through semi-structured interviews and participant observation that was conducted on the Pine Ridge Indian Reservation in June and July of 2018. Although this research examines the health care system that operates on Pine Ridge, the primary focus is on the role of the individual in relation to the different levels (macrosocial, intermediate, microsocial, individual) that comprise the system as a whole (Baer et al. 2013). Oglala Lakota individuals often feel powerless within the predominantly white, hegemonic health system; therefore, this research works to uncover these marginalized discourses by presenting individual stories and experiences. In conducting this research, *a priori* knowledge, gained from existing literature, helped to generate research questions and drive the preliminary directions of this project. As research continued, I relied on “grounded theory” (Glaser and Strauss 1967) to capture the nuances of emerging themes that uncover the emic, or insider, perspective.

This chapter outlines the methodological processes that were utilized in conducting this research. I begin with a statement on the justification for this topic as an appropriate and necessary area for research on the Pine Ridge Indian Reservation. The following sections address the sampling methods used to recruit research participants and provides additional detail of the population based on collected demographic information. Subsequently, I introduce the settings for this research to provide additional context for the interpretation of results. Lastly, I highlight the specific methods used to collect data and discuss the utility of MAXQDA as a means of analyzing this data.

3.1 Justification for the Pursuit of Research on Pine Ridge

According to some tribal members, local community development corporations, and researchers who had previously conducted work on the reservation, the population of Pine Ridge is the *most* researched reservation in the United States. While I was unable to find published or reported information to support

this claim, evidence that Pine Ridge is heavily researched can be seen through the sheer volume of published studies focusing on Pine Ridge, the vast quantity of ongoing research projects monitored by the Oglala Sioux Tribe Research Review Board (OST RRB), and the exacerbated sighs of some tribal members that communicate an equivalent of rolled eyes that essentially say “this again?” Conducting research on an Indian Reservation necessitates certain precautions not found among other potentially vulnerable populations. Past colonial abuses have left communities “deeply suspicious of outsiders in general and researchers in particular” (Gone 2006:338). Instead of “objectifying...people for the purposes of research” it is vital that communities participate in and approve of the research process as well as have a voice in the outcomes and distributions of results (Gone 2006:339). This departs from traditional western and institutional approaches towards research that promote the idea that collected research belongs to the researcher and is theirs to share at will; instead, research conducted on sovereign reservations belongs to the people and should be modified and shared as they see fit (Harding et al. 2012).

The idea for this research originated during the summer of 2017 when conducting a housing market survey for a consulting organization working alongside Thunder Valley Community Development Corporation (TVCDC). Spending three non-consecutive weeks on the reservation, I spoke with many individuals about the quality of their homes and what types of housing they would like to see built on the reservation. I was surprised to find how often these conversations transitioned to topics of health and more specifically, issues with diabetes and dialysis. Gerald’s statement “Indian’s don’t get transplants” as discussed in the introduction, brought the scope of this research into perspective. Over the remainder of my time on the reservation in the summer of 2017 I spoke with Oglala Lakota friends about this potential research idea and was surprised by the overwhelming support and encouragement for the pursuit of this research topic. With rampant diabetes and high rates of end-stage renal disease on the reservation, this issue of access to kidney transplantation held significant weight to everyone I spoke with. This was clearly an issue that people wanted to address and a topic that had never been studied before on this reservation; and as I later discovered through my own research, had never been studied on any reservation.

With support for this research topic, my only remaining hesitations in conducting this research were based on the color of my white skin and my status as “wašiču”. Wašiču, the Lakota word meaning ‘other’ or ‘outsider’, historically also means “the one who takes the best meat” referring to the ways in which white colonizers would steal precious resources from the Lakota people. Expressing concerns regarding my wašiču status among this group of Lakota friends, two things became clear: the first was that being wašiču may present challenges in developing trust among patients. The second being that my wašiču status may actually yield more honest responses; I was told that Oglala Lakota patients do not often openly discuss their hardships and suffering to other native individuals. Therefore, my status as an outsider guarantees anonymity and my position as separate from the deeply interconnected kinships on the reservation allowed me to see each patient as an individual instead of part of a specific family or community. Confident in these justifications, I received approval from both the Colorado State University Institutional Review Board and the Oglala Sioux Tribe Research Review Board to move forward with this research project.

3.2 Sampling

Based on recommendations from the Oglala Sioux Tribe Research Review Board, a convenience sample was utilized to gather research participants on the Pine Ridge Indian Reservation. I gained permissions from the two dialysis centers that operate on the reservation to set up tables, provide snacks and research pamphlets (see Appendix II), and talk with patients in the waiting room. I was present at each dialysis center for a minimum of six consecutive days (patients receive treatment on either a Monday/Wednesday/Friday or a Tuesday/Thursday/Saturday schedule) and stayed for all patient shifts (two shifts at Sharps Corner and 3 shifts at Pine Ridge Village) which provided exposure to every patient currently receiving dialysis on the reservation: approximately 112 patients. All patients had the opportunity to participate in this research project and therefore the participant sample reflects those who expressed interest *and* followed through with scheduling or setting aside time for interview. At the Sharps Corner dialysis center, the on-site social worker helped to identify interested participants. Additionally,

one kidney transplant recipient was identified through word-of-mouth. As part of this research project I also interviewed health educators working on the reservation. These individuals were contacted directly through their place of work. In order to gain a more holistic view of the healthcare system that operates on Pine Ridge, I had hoped to conduct interviews with individuals working at transplant facilities, statewide non-governmental organizations (NGOs) working in kidney health, and the regional organ procurement organizations operating in South Dakota. Despite obtaining many potential contacts and persistent efforts, I was unable to conduct interviews with these additional populations. All participant names have been replaced with pseudonyms and identifying characteristics removed to ensure anonymity.

Regarding the interpretation of results, it is important to acknowledge three primary sampling biases that are present. First, because of the nature of this research and its focus on kidney transplantation, there may be a potential sampling bias in that those patients who are more open to the idea of kidney transplantation, or have discussed this option previously with doctors, are more interested in participating. Those individuals who may hold more traditional Lakota beliefs about the body and therefore do not support transplantation may be less likely to participate. This may bias the representativeness of my sample in terms of those who participate in and subscribe to Lakota belief systems; however, the primary goal of this research is to minimize barriers to transplantation *for those who want it* which acknowledges that this avenue for treatment may not be the most desired for everyone. A second bias which may or may not influence results but should be acknowledged is that those patients whose dialysis run times were later in the day had more time in the waiting room to talk with me. While later run times do not stand as a proxy for things like gender, quality of health, age, or any other variable that was readily visible, my participant sample is primarily comprised of individuals in these second or third shifts. Lastly, patients who were overall healthier (ambulatory, younger, more energetic) were more likely to talk with me in the waiting room while those patients in very poor health usually slept or did not engage while waiting for an open chair or their ride to pick them up. Therefore, it is likely that my sample population may not be completely representative in terms of their current quality of health status and may lean towards those who are healthier. While this is important to recognize, it is unlikely that those individuals who are

suffering from very poor health and did not engage would qualify as candidates for transplantation. While every patient has a unique and valuable story to tell regarding their health and healthcare experiences, I do not believe that these sampling biases significantly reduce the reliability or value in the results outlined in the following chapters.

3.3 Participant Characteristics

The total participant sample for this research is 12 individuals (n=12). Of these 12, ten participants make up the patient sample: nine dialysis patients and one kidney transplant recipient. Three of these research participants are health educators (kidney transplant recipient is also an educator) currently working on the reservation in areas related to kidney health. The small sample size of this research project may be the combined result of poor patient health (and therefore lack of desires to set aside scheduled time for interview), limited schedule flexibility, or because of a “reluctance to engage in a proposed research project” due to past colonial histories or exertions of white power over native individuals living on reservations (Harding et al. 2012:6). While this is a small participant sample size it captures a large percentage of the total population currently on dialysis. Through semi-structured interviews with patients I was able to achieve a high degree of data saturation and a wealth of individual experiences that are rich in depth and content. The following provides some key demographic information collected during dialysis patient interviews and provides a cumulative picture of this sample population.

Of the ten patient interviews conducted, nine were with dialysis patients living and seeking treatment on the Pine Ridge Indian Reservation. These participants varied in age with the youngest participant being 32 and the oldest being 74. The average age for dialysis patient participants was 55.5 years old. Both male (n=4) and female (n=5) participants were represented with the majority having lived on the reservation for their entire lives. Only one of the dialysis patients was employed at the time of interview; likely the combined result of extremely high unemployment and the very rigid and time-consuming dialysis schedule. The amount of time spent on the dialysis machine varies depending on patient labs; however, the average run time among research participants was about 3 hours and 12

minutes which brings the average weekly run time to 9 hours and 36 minutes. These times do not include wait time before and after treatment or transportation time to get to the dialysis center. Of the patients included in this study, the number of years spent on dialysis varied greatly; some patients had been recently diagnosed and therefore had been on dialysis for less than a year while others had been on dialysis for many years (range <1- 12 years on dialysis).

As previously mentioned, high rates of diabetes on the reservation strongly correlate with high prevalence of end-stage renal disease. Seven out of the nine dialysis patients have comorbid diagnoses of diabetes and four patients have been diagnosed with and are treated for high blood pressure or other cardiovascular related health issues. Three patients, at the time of interview, were listed for kidney transplantation; 2 had been listed for transplant but were never active on the list and have since been removed, and the remaining four have never listed or are unable to list for kidney transplantation. All patients interviewed were covered by Medicare for their dialysis treatments and a combination of Medicare and Medicaid for other health needs. Most participants described their income status as “poor” or “low” with many receiving monthly support through disability, unemployment, and social security.

3.4 Setting

This research took place within what I am calling primary and secondary settings. The primary settings, the settings where the bulk of my information was obtained and the majority of my participant observation was conducted, was within the two dialysis centers located on the Pine Ridge Indian Reservation. One of the dialysis centers is located in Pine Ridge Village, a community along the southern border of the reservation. This dialysis center has 12 stations and treats approximately 72 patients. The larger of the two dialysis units, the Pine Ridge unit primarily services individuals from the Pine Ridge Village, Wakpamni, and Oglala districts. The other dialysis center, located at Sharps corner, also has 12 stations and treats approximately 40 patients and services the districts of Wounded Knee, Porcupine, Medicine Root, and Pass Creek with some coming as far as the village of Wanblee in Eagle Nest district about an hour away.

The waiting room of these dialysis centers was the primary field site for research. At times empty, apart from me and a large bowl of snacks, the waiting rooms were usually a busy place of transition for patients and their family members. Patients were either dropped off or picked up individually by friends or family or arriving and departing in waves with the free tribal funded transport shuttle. Depending on the day or hour, the waiting room could be alive with chatter and friendly banter, or silent as people sat sleeping or watching the small tv which would undoubtedly be playing “The Price is Right” or “Let’s Make a Deal”. Memos and reminders plastered the walls, informing patients of changes to tribal assistance programs or giving tips on how to stay cool on a hot day without drinking too much water (a big no-no on dialysis). Here I became a part of everyday interactions between patients, unit staff, family, friends and support systems.

While these waiting rooms constitute the primary setting, it is impossible to study issues of health care access regarding kidney transplantation or even dialysis patient experience without acknowledging the impacts of and relationship to the larger reservation as a whole. The reservation, the secondary setting for this research, is sparsely populated with concentrations of houses in what are typically referred to as villages or communities. Split into nine distinct districts- Pine Ridge, Oglala, Wakpamni, Porcupine, Wounded Knee, Medicine Root, Eagle Nest, Pass Creek and La Creek- the reservation encompasses an area of land comparable to the state of Connecticut. The large size of the reservation means people often have to travel great distances to shop, go to school, or receive medical attention. With only one main grocery store on the reservation, located in Pine Ridge Village, the majority of people on the reservation live in food deserts with limited access to healthy foods. Most of the roads on the reservation are graded gravel or dirt roads with only the major roadways that pass through and across the reservation being paved. During times of rain, many roads become impassable except to four-wheel drive vehicles and horses. Understanding these characteristics of Pine Ridge and its spatial distribution, helps to provide the context for interpreting and mediating space-based challenges that inhibit access to adequate healthcare.

3.5 Participant Observation

For this research I relied on participant observation, one of the foundational methods of anthropology (Musante 2015). Participant observation allowed me to gain an in-depth understanding of dialysis patients, their relationships to and constraints within the healthcare system, and the broader political and economic structures that exist on the reservation. Participant observation is a method whereby the researcher not only observes but takes part in the daily activities of research participants (Musante 2015). While I am unable to experience the physical treatment of dialysis, I was able to be with patients before, after and during treatment as well as see the impacts of dialysis on lifestyles away from the dialysis centers. I visited houses or nursing home facilities, shared meals, gave rides, and played bingo with some my research participants to really see and experience the lives they lead. My daily presence in the dialysis centers allowed for the development of rapport with research participants and dialysis patients. Those who were initially wary of my presence became more open and comfortable the more time I spent with them. These relationships only continued to strengthen after demonstrating my familiarity with the area and local lingo and sharing relatable stories (like the time I took my 1998 Honda Accord off-roading down a field because the driveway was impassible with mud). Over the course of five consecutive weeks living on the reservation, I conducted approximately 150 hours of participant observation in the dialysis centers.

Apart from participant observation in the dialysis centers I also conducted participant observation outside of the dialysis centers, experiencing life on the reservation. I lived in Wounded Knee, shopped at the local grocery store, waited in line for gas at Common Cents, attended several tribal events such as the Veterans Pow Wow in Pine Ridge Village, and participated in *Inipi*, the purifying sweat lodge ceremony. While I can never claim to fully understand what it is like to be a tribal member living on the reservation, by utilizing participant observation, I have gained a more nuanced understanding of the myriad social, cultural, political, and economic complexities that influence life on the reservation. Participant

observation works to enhance the quality of collected data while also providing the larger context for interpreting data collected through complementary research methods.

3.6 Semi-Structured Interviews, Data Analysis and the Applicability of Research Methods

In order to understand dialysis experiences, thoughts and opinions regarding transplantation, and barriers in accessing transplantation, I conducted semi-structured interviews among my two participant populations: dialysis patients and health educators on the reservation. Semi-structured interviews provide the structure to elicit specific types of information while at the same time allowing for flexibility from both the respondent and researcher. The two interview protocols for each of the participant groups can be found in Appendix I. Twelve interviews were conducted over the course of five weeks on the reservation. Interviews lasted between 30 minutes to 2 ½ hours, the duration being determined by the participant. Interviews were conducted in private at a location of the participant's choosing. At the Sharps Corner dialysis center, I was given access to a private room in the building so interviews could be conducted while patients waited for their treatment time or the arrival of their ride.

All interviews were audio-recorded, transcribed, and coded using the qualitative data analysis software MAXQDA. Qualitative data were coded using deductive themes identified during literature review and participant observation such as transportation, geographic marginalization, and financial insecurity. In addition, codes were inductively generated based on emerging themes elicited from the semi-structured interviews. These codes were generated through the identification of tacit themes, those not explicitly discussed but readily apparent. Examples of these inductively generated themes are hesitations in 'asking', emotional response to dialysis, and systems of support. The coding process, facilitated by the MAXQDA software, acts as a means of generating grounded theory through the identification of unanticipated themes, as well as an organizational tool which can be used for data interpretation and the formation of results.

The methods utilized in this study allow for the holistic examination of access to kidney transplantation on the Pine Ridge Indian Reservation. Among cultural anthropologists, these methods are

well-established and central to the pursuit and generation of ethnographic and qualitative data. Drawing on both participant observation and semi-structured interviews, this research delves into the personal experiences, beliefs, opinions and knowledge of study participants and situates these within the broader cultural context of life on the reservation. These methods promote culturally sensitive and culturally appropriate research that values the impacts and influences of culture on the physical and emotional well-being of patients. Interviews and participant observation highlight the myriad forces that impede kidney transplantation in American Indian populations and are further bolstered by the emic understandings and perspectives gleaned from study participants. By identifying these forces and understanding the different societal structures that create them, we can acknowledge their impact and work to develop programs and policies to rectify these issues.

CHAPTER FOUR

“Dialysis is the Pits”: Dialysis experiences and the desire for transplantation

Walking into the dialysis center I am greeted by a rush of cool air, a needed respite from the searing heat and humidity which had persisted for most of June. A poster on the waiting room wall echoed my thoughts exactly claiming “It is now that time of the year when the heat tries to beat you down” followed by tips for patients to stay cool on these hot summer days. Despite the suffocating heat outside, many patients sitting in the waiting room were bundled up in jackets and wrapped in blankets. Some days the waiting room would be quiet save for the low murmur of the tv. Patients would sit with their eyes closed, either sleeping or resting (I could never tell). Other days, the waiting room was alive with chatter and laughter as patients would greet their friends, joke with the techs, and banter with me asking “back again?” to which I would teasingly respond with the same question knowing full well they had to be there.

Inside the treatment room there is a constant groaning buzz from the dialysis machines which is frequently punctuated by the harsh beeping sounds and flashing red light of a machine that is, according to one nurse, “having issues”. Yet patients seem unfazed by the low cacophony of sound which I could only describe as anxiety-inducing. Most sleep, wrapped in their colorful blankets decorated with Lakota design elements. Those who do not sleep usually watch tv on individual screens which pull down from electronic arms in front of each patient’s chair. A smaller portion spend their time reading, often from the bible. Regardless of how patients choose to pass the time, they all seem able to tune out these now familiar sounds that permeate their lives.

This chapter seeks to uncover Lakota dialysis patient experiences and understand how these experiences shape individual desires to access kidney transplantation. Many dialysis patients refrain from sharing their experiences on dialysis with friends and family so as not to burden others with ongoing challenges or appear weak. This chapter acts as a platform through which these often-suppressed experiences can be shared, and both the positives and negatives of treatment can be brought to the

forefront of dialysis discourse. To begin, this chapter introduces the two dominant paradigms which very broadly capture patient perceptions of dialysis treatment. This sub-section is followed by a discussion of daily life on dialysis and some of the limitations that impede one's desired lifestyle. Lastly, this chapter will explore the emotional progression experienced by patients beginning with their renal failure diagnosis and their transition to dialysis treatment.

4.1 Patient Perception Paradigms

Every dialysis patient has his or her own unique set of experiences associated with life on dialysis. How these patients view or perceive this treatment reflects the culmination of both positive and negative aspects of this dialysis lifestyle. Throughout the course of research through both formal semi-structured interviews as well as casual conversations with dialysis patients, every patient fell into one of two categories regarding their overarching perceptions of dialysis. One of these patient groups had positive perceptions of dialysis which were predominantly characterized by attitudes of gratefulness. The other perception paradigm is comprised of patients who have a negative perception of dialysis driven by resentment over the limitations this treatment imposes upon desired lifestyles. While all patients fit in one of these two categories, all expressed both positive and negative aspects of dialysis treatments with their overarching perceptions shaped by that which individuals valued most.

Patients who subscribe to the positive perception paradigm are generally older and often have comorbid health conditions that further limit their day-to-day activities. Among this group, individuals highly value their health and life longevity. They are grateful for their dialysis treatments because they know that it is keeping them alive and therefore look forward to treatments for the health benefits it brings. JoAnne, a dialysis patient, views dialysis as her "life's work". She says, "the only reason I'm living is those three days a week I spend four hours a day in that chair getting my blood exchanged and cleaned and giving it back to me." For many of these patients, the start of dialysis and the regulating of glucose, phosphorous, potassium, and blood pressure meant significant improvement in their health which enabled patients to be more present in other aspects of their lives. Some patients who fit within this

positive paradigm may have transitioned from a negative perspective of dialysis to this more positive perspective because of the extended duration of their dialysis treatment. Many expressed the difficulties associated with first being diagnosed, but after years of treatment, it becomes less difficult. John said that dialysis was hard when he first began treatment, experiencing shortness of breath and periods of pain; however, he now says “It’s not hard for me. After I’ve been comin’ for nine years, it doesn’t bother me.” After years of treatment with many of the same patients, friendships develop with those on the same dialysis rotation. Instead of being just a treatment, dialysis becomes an opportunity to see and talk with friends as well as an activity to occupy one’s time.

The negative perception paradigm is primarily comprised of individuals who feel their desired lifestyles are significantly limited by ongoing dialysis treatments. Most of these individuals are younger (<55), were recently diagnosed (<2 years on dialysis) and have young children or dependents. While some patients feel better after starting dialysis, others feel significantly worse as their old “normal” is drastically altered. While some patients feel better with the normalization of blood pressure and blood glucose levels, other patients experience pain, shortness of breath, lightheadedness, fatigue, and weakness as their bodies adjust to a healthier state. When asked about her dialysis experience, Valerie said “I did the dialysis for some time, then it seemed like when I did do it I was getting sicker and sicker.” Despite all patients acknowledging that dialysis did provide needed treatment, many feel the negative “side effects” often outweighed the benefits.

Dialysis significantly limits and impacts the desired lifestyles of many patients. The transition to three treatments per week, changes to diet and water intake, and the lack of control over one’s time and lifestyle is extremely difficult to become accustomed to. Linda says that “just being on dialysis is the pits. I don’t want to be on dialysis. Nobody does. I wouldn’t wish dialysis on anybody... not my worst enemy.” Significant life changes are not uncommon on the reservation; unemployment is rampant, poor health widespread, and premature death due to drugs, alcohol, and car accidents are sadly frequent. The tenacity and resilience of the Lakota people in dealing with and adapting to these life changes is remarkable. And yet, for many, the diagnosis of end-stage renal disease and the beginning of dialysis

treatment is a life change many cannot get used to. Randall compared the challenges of dialysis with the deaths of his father and sisters in a car accident, both leading to severe depression and anxiety. Gloria overcame difficulties with being a diabetic, adjusted to life in a wheel chair after the amputation of her leg due to medical malpractice but about dialysis she says, “this life...I can’t get used to it.” Regardless of which perspective patient’s take, negative aspects of dialysis predominately originate in the limitations imposed by dialysis treatments. These daily activities and limitations will be further explored in the following section.

Irrespective of their overarching paradigm, every patient I interviewed or casually spoke with about transplantation would choose transplantation as a treatment for their end-stage renal disease over long-term dialysis. While many patients I spoke with were not candidates for transplantation, the option or opportunity for a kidney transplant was clearly the preferred treatment option for patients. For those who have negative perceptions of dialysis, the desires for transplantation are clearer due to ongoing dissatisfactions with current treatment. Many of the challenges and lifestyle constraints which patients resent are eliminated with treatment via transplantation. For those who view dialysis in a positive light, the increased life expectancy, improved health outcomes, and time and lifestyle freedoms conferred through transplantation provide a better, brighter, and healthier future.

4.2 Daily Activities and Limitations of Dialysis Patients

Unlike much of the United States where “time is money”, on the Pine Ridge Indian Reservation, it is very common to hear people refer to the pace of life as running on “Indian time.” Life moves at a slower, relaxed pace. Instead of time being dictated by profit, responsibilities, workload, or schedule, “Indian time” allows for people on the reservation to spend their time on those things they most value: family and *tiospaye* (friends and relations), community, spirituality, pow wow, radio, art, music, and nature to name a few. Dialysis treatments, as part of the larger biomedical system, maintain a strict schedule that contrasts with Lakota lifestyle norms. Dialysis patients must receive their hemodialysis treatments three times a week on either a Monday/Wednesday/Friday or Tuesday/Thursday/Saturday

schedule. The treatment duration, or run times as they are casually called, can last anywhere from two to four hours. Patients are treated in groups of 12, the number of chairs at each of the dialysis centers on the reservation. The Sharps Corner dialysis center runs two shifts, one in the early morning and the other around mid-day. The Pine Ridge dialysis center runs three shifts to accommodate the larger population in the area. Patients treated in the second or third shifts arrive later in the day but must wait for a chair to become available as the earlier shift finishes their runs.

For many patients, dialysis is a physically taxing process. After completing their runs, patients often feel fatigued or experience some degree of muscle cramping. On non-treatment days, some patients are able to maintain some semblance of their normal lives, but many experience persisting fatigue and therefore need to sleep much of the day. Describing the “hard schedule” of dialysis, Beverly is so tired after her dialysis treatment that she is unable to cook or eat dinner and goes straight to sleep when she returns home. She then “wakes up late at night and... ends up staying up” leading her to sleep much of the following day. When Beverly began dialysis, she says

I was just sleeping. I mean that, I remember two days, I slept for two days. I remember I sat down on the couch, I just do myself back and I just laid there and I slept. Try to get up and move, try to wash dishes, try to sweep, try to do this in the house, I couldn't do nothing. Nothing.

Based on the quality of health, desired lifestyles, external or family pressures, and social networks, each patient has different capabilities and responsibilities which are reflected in their daily activities. Some patients are healthier or more mobile and this is reflected by the activities in which they participate. However, regardless of individual capability, all patients identified limitations that are imposed by the frequency and regularity of dialysis treatments.

One of the most frequently identified limitations of dialysis is the intensive time commitment that comes with this mode of treatment. As mentioned previously, patients receive dialysis treatment three times a week with an average run time of 3 hours and 12 minutes per session. This run time does not include getting hooked up to and taken off the hemodialysis machine, time spent in the waiting room and transportation time to get to and from the dialysis center. For Linda, the total time commitment for a single day at dialysis is a minimum of six hours which is not unusual for dialysis patients. Patients feel

that the total time spent on dialysis takes away from time that could be spent with family and friends which is needed to bolster one's intrinsic happiness. Valerie says the strict dialysis schedule means "you can't really do anything... By the time there is no appointments then it's like, there's nothing, it's a clean up day or whatever... We hardly have any family time." The dialysis treatment process is time consuming, life-saving, but also freedom inhibiting. This is felt by the patients but also readily known and acknowledged by those individuals working at the dialysis centers. One of the dialysis educators I interviewed linked this lack of freedom with instances of poor adherence to treatment which negatively impacts the long-term health of the patient.

In addition to the extensive time commitments associated with dialysis treatment, the variability in how patients feel after treatment and the rigidity of the schedule makes planning tough. Difficulties in planning for the immediate future could be as mundane as the ability or inability to clean one's house or as difficult as the ability or inability to provide support to a family member needing surgery. Beverly exemplifies both ends of this spectrum; she says about cleaning her house "I'll do it today. I don't get it done, I'll do it tomorrow. I don't get it done. So I can't really plan... I decided to take it day by day and there's some days, yes I do do it. I make a plan, I do follow it, but I can't every day." Her inability to clean her house some days pales in comparison to the emotional distress she feels at not being able to support her son during his own medical difficulties. With an upcoming surgery that will be planned last minute, Beverly is fearful she will not be able to go with her son to the hospital because it may overlap with her dialysis treatment. Some days after treatment, patients feel fine, while other days they may experience a multitude of symptoms. Randall has managed to maintain a flexible work schedule while on dialysis; however, he says "there's a time or two I went straight from [dialysis] to work and I regretted it... Sometimes I can feel the dialysis, sometimes I can't. Sometimes it creeps up on you." The apparent randomness of intensified symptoms after some, but not all, treatments make it extremely difficult for patients to plan chores, activities, and work schedules. The inconsistencies and dynamic nature of life on the reservation makes it difficult for dialysis patients, who are constrained by the inflexible dialysis schedule, to participate in social activities and provide support to loved ones.

Far and above the most frequently discussed limitation identified by dialysis patients was diet and fluid intake. Upon diagnosis of end-stage renal disease and the beginning of his dialysis treatment, Luther said the biggest lifestyle change he encountered was that he “had to watch the foods [he] eats...and has ta’ really watch [his] water intake.” Kidney failure results in the body’s inability to remove toxins, minerals, and water from the blood stream. In a healthy individual, these would be removed through the production of urine facilitated by the kidneys. In dialysis patients, the hemodialysis machines function as mechanical kidneys that filter the blood; it removes the toxins and excess water and minerals then funnels the blood back into the body. Because dialysis patients receive treatment every other day, patients are more susceptible to the excessive buildup of these undesirable toxins and therefore need to avoid them in the foods they consume. Despite feeling excessively thirsty, dialysis patients must be extremely careful about how much liquid they consume daily. Because many patients have significantly decreased urinary output, drinking too much water can dilute the blood leading to dangerously high blood pressure.

In addition to fluid intake, patients must avoid eating foods with certain minerals, specifically phosphorous, calcium and potassium. These essential minerals, without a filtration mechanism to control their quantities in the bloodstream, can be deadly. Excess phosphorous and calcium can lead to the development of calciphylaxis, a rare condition in which ulcerations form from the internal layers of the dermis and work their way to the skin’s exterior. Calciphylaxis become large gaping wounds which are extremely difficult to treat and often lead to infection and subsequent death. Potassium is another mineral that must be closely and carefully monitored in dialysis patients. To gauge the seriousness of diet in dialysis patients, I spoke with Nadene, a dialysis educator about potassium:

Researcher: If you were to eat six bananas...

Nadene: Oh you would definitely have a heart attack

Researcher: You would have a heart attack! Ok, so if you were to have only one banana?

Nadene: It depends, yes. Still maybe heart attack, yeah. Bananas are a huge no-no

The accumulation of potassium in the bloodstream puts patients at extremely high risk for heart related problems and therefore, foods containing potassium must be strictly avoided.

The strict dietary and fluid limitations are extremely difficult on patients. Dialysis often makes patients feel thirsty, especially as they approach the next treatment session. Even though their bodies are saturated with fluids, patients feel excessively thirsty and have a difficult time managing how much they drink. To stave off thirst, it is recommended that patients suck on ice chips or hard candies. Managing water intake during the summer months is especially challenging as patients work to find a balance: avoid dehydration but don't drink too much, all while trying to stay cool in the sweltering heat.

Managing diet while on dialysis is equally challenging. Many foods that patients have eaten their entire lives, foods they love, foods that hold a familial or cultural significance they can no longer eat. Bananas, tomatoes, beans, ground beef, turkey, sunflower seeds, dairy, and certain types of fish are just a few of the items that dialysis patients can no longer have. Long lists of "Foods to Avoid" hang in the waiting room, lists which often go unnoticed and unacknowledged. On dialysis, patients must learn to adjust their diet, alter their normal cooking routines, and avoid foods they love to eat. For several of the patient's I interviewed, the most challenging part of maintaining their diets on dialysis was seeing people who were consuming foods and beverages that they can no longer have. Randall says seeing people "sitting in front of me with orange juice, it's like a slap to the face... it's tempting. Yeah, it's really hard." For patients on dialysis, the time commitments, variability in health, and strict regulation of diet all contribute to the challenges and negative associations linked to this treatment method. While kidney transplantation comes with its own set of limitations, transplantation provides the freedom from the heavily scheduled and time-consuming dialysis runs, allows for increased consistency of health quality and reduces the food and liquid restrictions necessary while on dialysis. The increased freedoms from these limitations as well as the conferred health benefits associated with kidney transplantation largely explain the widespread preference for this treatment in lieu of long-term dialysis.

4.3 Emotional Response to Dialysis

When speaking with patients about their experiences on dialysis they would talk about the explicit limitations, lifestyles, and procedures that entail dialysis treatment; however, through these

discussions, tacit undertones were brought to the surface in the form of emotion. Although each patient has a unique story and experience when it comes to their relationship with treatment, there were general trends in how patients emotionally experienced and processed this transition to life on dialysis. These emotional responses were more readily apparent in newly diagnosed patients who have been on dialysis fewer than two years. However, among those patients who have been on dialysis for extended periods of time, when looking back on their diagnosis and start of dialysis, many recall having similar emotional responses. Widely experienced, patients describe the transitions from denial upon diagnosis to anger and fear at the start of treatment and then to resignation and depression as they accept this new dialysis reality.

While many patients experience some form of disbelief or denial upon diagnosis of end-stage renal disease, these emotions are most prominently felt by younger patients who conceptualize kidney failure as something that happens to older individuals. Having worked with many diverse dialysis patients, Nadene, a health educator at the dialysis center, claimed “it’s tougher with what I consider the younger ones, the ones that are, I’d have to say 40 and younger. They have the invincible attitude of ‘no, this isn’t happening, this isn’t how I planned my life to be.’” This is reflected in a conversation with Randall, the youngest patient in the sample who says “I felt bad. I don’t know, it’s a hard feeling to explain. Like, am I really here? I’m too young to be sitting here.” Many patients on the Pine Ridge Reservation do not receive frequent physical examinations and are therefore often unaware of their poor health conditions. For example, one patient recalled seeing a doctor for a toothache and being diagnosed with end-stage renal failure. These unanticipated diagnoses add to the shock, disbelief, and subsequent denial of the diagnosis. Valerie found out she had diabetes and was in kidney failure at the same time and says “I was in disbelief... I didn’t want to be diabetic and I was like, oh it can’t happen to me.” For some patients, this denial leads them to postpone treatment, ultimately worsening their health conditions. After being diagnosed with diabetes 20 years earlier, JoAnne was diagnosed with end-stage renal disease. She “was supposed to have started on dialysis... but put it off for about three years. [She] started getting sicker and sicker and [she] finally decided that [dialysis] was what [she] needed.” After the initial shock and denial of the diagnosis, patients start dialysis treatment and begin to process this new reality.

As patients are introduced to life on dialysis, they become exposed to the many limitations imposed by this treatment. For some, this major lifestyle transition is scary as they do not fully understand the purpose, reason, and necessity of dialysis. With lots of unanswered questions and unwanted procedures such as the implantation of a chest catheter to gain access to the bloodstream, patients become fearful of the perceived lack of control over their own bodies. Other patients respond to these life alterations with anger. The sudden limitations imposed on dialysis patients greatly impact how patients want to live their lives. When thinking about the things they can no longer do or foods they are no longer able to eat, patients sometimes become angry. For some, like Beverly, “it was like a silent different kind of anger that [she] had” when she thought about the lifestyle changes she needed to make. For others, the anger stems from issues of identity. Randall feels angry when he thinks of how dialysis has come to define who he is and limit his day to day activities. He says “when I first started getting out [after starting dialysis] I enjoyed it, but the part I hated was when it was time to come home, time to get ready for dialysis. I’d be doing good and all of a sudden I’d itch my chest and I’d remember I have this on [chest catheter].” As a patient, who besides having kidney failure, is young and in good health, Randall rejects this “sick” identity which he feels has been forced upon him. However, although he does not feel sick much of the time, he is constantly reminded of his circumstances when he feels the chest catheter through which he receives his hemodialysis.

As patients adjust to their new lives on dialysis, many experience bouts of depression and resignation as they come to terms with the permanence of their diagnosis. Having been on dialysis for 12 years, JoAnne has seen many patients experience the same depression she felt when she began her treatment. She says “when I am down in the dumps I always think every ache I have, every pain I have, every sickness I did to myself. And I’ve been told don’t think that way because you can come out of it.” Having experienced a “really, really, really deep trouble with depression... for the past five years” JoAnne understands the difficulties newly diagnosed patients face in coming to terms with this reality. She knows that patients “are gonna get down in the dumps when they get on dialysis” and even though “it makes you feel good... your mind is gonna be ‘what do I have to exist for?’” For some, depression clouds

their minds and makes the possibility for a brighter future seem impossible. On the reservation where suicide, alcoholism, and drug addiction rates are extremely high, patients suffering from dialysis-induced depression think about turning to these alternatives for relief. One patient said “you know, I could easily turn to drugs and alcohol and not face reality. Or I could easily just maybe, you know, take myself out.” Luckily this patient also acknowledges that these alternative actions would devastate his family and therefore would never act on these impulses. Many patients who are experiencing depression on dialysis find solace in the possibility of receiving a kidney transplant and escaping the suffocating regimented life on dialysis. However, the rarity of transplantation often dampens this optimism. Linda, who had been in the process of listing for a transplant, was removed because of health complications. She said “I want to get on that list again, but I don’t know what its going to take. Like, there’s not very many transplants. People come here and do this [dialysis] until they die from what I’ve seen.” Just as patients transition from the negative to positive perception paradigm when it comes to dialysis treatment, as patients spend more time on dialysis and come to terms with their new lifestyles, the depression felt at the outset of treatment usually begins to fade.

In an interview with Beverly, the concept of neglect played a significant role in the development of her emotional response to her diagnosis and the beginning of dialysis. While only mentioned explicitly by one participant, other patients identified aspects of neglect from the healthcare system as a contributing factor toward the development of their denial, anger, depression and resignation. After three years of dialysis treatment, Beverly looks back with hindsight at the way she was treated by health professionals:

When this was happening to me [falling ill with ESRD], I was trying to figure out what was going on with me. Why am I being... why was I being neglected? Why wasn't I being paid attention to? Why wasn't I being helped? Why was I being just pushed to a side and waiting for me to get so bad that I was ready to die before they did anything for me? The point is, they could have tried to do something a little more... but they didn't do it. I feel like, if I wasn't neglected, I wouldn't be in this position.

Feelings of neglect and resentment towards doctors heighten the emotional responses of patients on dialysis and make contentment more difficult to attain.

This chapter serves to highlight the individual experiences of dialysis patients on the Pine Ridge Indian Reservation. Acting as a platform to tell the stories of these patients, this chapter illuminates the perceptions of dialysis treatment as well as the challenges, limitations, and emotional responses dialysis evokes. It is vital to appreciate the diverse spectrum of patients, their beliefs, motivations, and desires for the future. By bringing these patients' stories into dialysis and transplantation discourses, we can better recognize the lifestyles they live, the limitations they face and the resulting emotional responses they embody. Exploring these multifaceted aspects of patient experience is vital to understanding issues of transplantation access and the challenges faced by those for whom transplantation is no longer an option. The heavy burden of dialysis treatment and challenges patients face create an immense need for systems of support as they continue with treatment and/or work towards receipt of kidney transplantation.

CHAPTER FIVE

“This is the body I was given, this is the body I’m taking”: Systems of belief and support

The women filed in first and took their seats uttering *mitakuye oyasin* (all my relations) upon entering. Then the men brought in the red-hot rocks, placing them in the central pit. Instantly the sweat lodge, the *inti*, began to bake the air around us, a dry hot heat that made the lips burn and the tongue feel cracked. The men took their seats, completing the circle around the glowing pit. The hide door was closed and we were engulfed in blackness except for the bright red that gleamed, burning the eyes from both heat and light. The first round of the *inipi* ceremony, the sweat, consisted of chanting. Not knowing the words, I hummed along to the beat and tone of the others. Water was poured over the rocks immediately filling the dome with a burning steam. Inhaling felt like drowning; the steam condensing on my body, mixing with my own sweat, and dripping, no, *pouring* down my face, neck, back, and legs. I used my towel, draped over my lap to wipe off my face and momentarily shield my eyes from the heat radiating off the rocks.

In the second round, each of us prayed, taking turns in a circle; some out loud, some in silence. Some prayed for strength; some prayed for health; some prayed for peace; some prayed for prosperity. Others prayed for luck or good fortune and still others prayed for love. *Mitakuye oyasin*, all my relations; not just friends or family, but every human, animal, plant, mineral, earth and spirit we have come to know. The second round concluded with a ladle of water passed around, each of us sipping the *pejuta* (medicine) followed by the sacred pipe. Round three, another round of singing and chanting. The rhythm and tune emanated from my body in a hum. The many voices blending together, becoming one, mine indistinguishable from the rest. It felt at that moment that we were all connected. Round four was more prayer, this time without an order; anyone could speak when the spirit moved them. *Mitakuye Oyasin*. The ceremony ended, and we filed out the narrow door, greeted by a rush of cool air and the delicious smells of a crockpot dinner despite the midnight hour. It is customary to share a meal after the *inipi* ceremony, cementing the bonds and sense of community forged in fire and sweat. We stood quietly in

line, grateful for the presence of those around us, intimately linked, without the need for words or small talk. With the food came casual conversation and laughter as we sat under the nearly round moon and splattering of stars in the South Dakota sky.

The *inipi* ceremony, the ritual of the sweat lodge, is one of the most frequently practiced ceremonies on Pine Ridge. Through this ritual the Lakota connect with the past while drawing on the spirit presence, embodied in the steam, to provide strength to tackle the hardships of daily life (Harrod 1999). This ceremony functions both to improve individual physical ailments while also demonstrating an “accelerat[ion] of group dynamics that contribute to multiple dimensions of well-being” (Waterfall et al. 2016:47). The *inipi* varies significantly depending on who is hosting the ceremony; therefore my account as described above cannot be taken as a generalization but instead acts as one individual’s experiences. Here I use this experience to demonstrate how systems of belief and support are closely linked through the reinforcement of social cohesion, spiritual connection, health, and the body.

This chapter discusses different systems of belief present on the reservation and explores how these systems provide support to dialysis patients as well as examines the ways in which they might influence patient decision making. The first section of this chapter will delve into traditional Lakota belief systems. Traditional belief systems among the Lakota move beyond what is often thought of as religion and instead encompasses a holistic life perspective that incorporates things like spirituality, traditional medicine, conceptions of time and space, family and community, and very broadly, human existence. The second section of this chapter will examine the role of Christianity on the reservation and its influences and support of individuals who subscribe to this religious system. Each of the belief systems discussed in these first two sections highlights the supportive role they play in the lives of dialysis patients. In addition, both systems of belief may significantly influence decision making regarding one’s health. The last section in this chapter will bridge the gap between these two distinct belief systems and discuss the importance of *tiospaye*, loosely translated as extended family, which is a vital source of support regardless of the belief system to which one belongs.

5.1 Traditional Lakota Belief Systems

The traditional Lakota belief system perceives the world as a balance between the physical body, the mind, and the spirit world (Bucko and Iron Cloud 2008; Snyder and Lundquist 2006). The religious, or supernatural elements of these belief systems, are inseparable from perceptions of health, and what is often referred to as traditional medicine (Johnston 2002). The word traditional often evokes images of the antiquated; however, in this context I use the term traditional to capture the culturally rich traditions of the Oglala Lakota people which exist in conjunction with biomedical practices. The use here of “traditional belief systems” is to demonstrate a cultural specificity of practice, belief, and ritual that is rooted in precolonial history. Tradition denotes a shared cultural meaning and world view that is often embodied in ceremony or ritual process and reinforces a shared identity among a given population (Harrod 1999). Lakota traditional belief systems are “grounded in social relations and a universal order” which looks past a strictly individualistic perspective and instead encompasses aspects of the individual such as health and conceptions of wellness as well as the larger social group and spirit realm (Johnston 2002: 198).

Focusing on conceptions of health within this belief system, the physical body is viewed as a singular piece among a complex interconnected system that reflects aspects of one’s social network, mental and physical state, and spiritual connectedness. This integrated approach towards health and healing lies central to, instead of distinct from, other aspects of Lakota life and culture (Simons 2002). In order to maintain balance and harmony, and subsequent holistic wellness, community relationships are nourished through ritual activities that draw on Lakota values of family and relatedness (Johnston 2002; Simons 2002). It is when the balance between the physical, emotional, and spiritual aspects is lost that people experience disease and illness, which may or may not manifest as physical symptoms (Simons 2002). Therefore, to treat or heal illness, intervention may occur at any or all of the aforementioned holistic levels: the individual, family, community, or spirit (Snyder and Lundquist 2006).

What constitutes health among the Lakota differs from conceptions of those within biomedicine. In addition to physical maladies and diseases of the body, illness can also manifest through misfortune,

social tumult and disconnection from the spiritual world (Bucko and Iron Cloud 2008; Kemnitzer 1976). Physical health may not be the goal of healing traditions among the Lakota. A person may be dying from illness or disease as conceived in biomedicine, but still be healed; in this instance healing takes place in the social, psychological, and spiritual realms leading to happiness and contentment regardless of the physical condition of the body. These traditional conceptions of health fit within Lakota conceptions of time which is viewed as “continuous, harmonious, and cyclical” (Voss et al. 1999: 233). In contrast to a western linear perception of time, Lakota conceptions of time are grounded in the repetitions of day to night, winter to summer, and birth to death (Catches 1999). These cyclical processes contribute to the balance and harmony of nature and highlight the role of the body as ephemeral, a physical representation of one’s spirit which is timeless. Therefore, each body and each life is viewed as a singular journey amid an eternity of spiritual wanderings (Simons 2002).

Based on empirical observations of the body, biomedicine is limited to the physical manifestations of disease. Largely developed with the purpose of treating symptoms of ill health and disease, biomedicine projects a mechanistic view of the body with each organ working as a part of a machine that can be fixed or replaced as necessary to keep the body functioning (Scheper-Hughes and Lock 1987). Therefore, according to this view, healing and medicine is used to maintain the mechanistic structures of the body, paying little attention to the larger whole (body) or context (physical and social environment) in which ailments occur. This empirical view, based in what is perceived to be rationality, science, reality, and fact, rejects issues of the mind and spirit (Scheper-Hughes and Lock 1987).

Whereas biomedicine focuses on individual treatments and individual health as separate from nature, traditional Lakota belief rejects individualism and instead posits that everything is intimately connected to everything else whether biologically, spiritually, or psychically (Iron Cloud and Bucko 2008; Voss et al. 1999). This interrelatedness, captured in the Lakota phrase *mitakuye oyasin*, all my relations, emphasizes the belief that no piece of the universe can exist or change in isolation (Simons 2002). “All my relations” not only refers to contemporary social relations but also encompasses spiritual

relations, psychological relations, plants, animals, and earth that currently exist or have ever existed (Lame Deer and Erdoes 1992).

For patients on dialysis, feelings of connectedness brought on by community and spirituality from within this traditional Lakota belief system provide support to patients in the face of ongoing hardship and physical malady. All Lakota ceremonies include aspects of healing; those most commonly practiced on the reservation include the *inipi* ceremony as described above and the sacred Sundance ceremony. Nadene, one of the educators at the dialysis center described conversations she had had with patients who sought traditional healing practices as a way of treating their end-stage renal disease. She says “when [the patient’s] body is starting to fail, they try sweats and different types of healing ceremonies.” Sometimes these healing ceremonies are conducted separately from the biomedical approach of hemodialysis treatment; at other times, patients pursue a medically plural approach receiving dialysis as well as participating in traditional healing ceremonies such as *inipi*.

While the dialysis patients interviewed did not themselves participate in these ceremonies, a few patients emphasized their beliefs in these ceremonies. Gloria says “I believe in the ceremonies. I have a cousin, her husband is a medicine man so they have sweats, they often pray for me. That’s probably one reason that I’m still alive...yeah, so I believe in those ceremonies a lot.” This example demonstrates the power of these ceremonies in both their healing properties as well as the strengthening of social and community ties through ongoing support and prayer. These ceremonies also connect patients to the spirit world which provides support and guidance in their daily lives. Gloria continued saying “when I first got my foot amputated, when I was in the hospital in Rapid [City]...at night I’d see people sittin’ on the edge of the bed and next day I called home n’ I told them about it. They had a ceremony so that’s the spirits that want to be with me. They said one of ‘em was my mom.” Her mother’s visit from the spirit world at a time of great need and significant life change gave Gloria the motivation and encouragement to move forward.

For some on the reservation, participation in powwow is a way to channel traditional lifestyles and beliefs. While not often thought of as being integrated within this belief system, the values it upholds

and sense of community it brings to individuals mirrors those of traditional ritual. Randall attends powwows as a means of escaping his current reality and connecting with those around him. He says “when you go powwow or do anything like that, it’s a whole different feeling. Its like there’s no worries in the world...it just draws your focus. When I go powwow, I feel good. I get to be around with my bros and sing a lot, just having a good time. Kind of just forget the daily struggles you go through.” The community, spirituality, and support provided by traditional Lakota belief systems help dialysis patients as they face the harsh realities and difficulties of life on dialysis.

While some patients, such as those mentioned above, embrace aspects of the traditional Lakota belief system such as support, others rely on this system of belief to shape the way they live in and perceive of the world around them. While none of the patients interviewed fully embraced this belief system, according to Nadene, a dialysis educator, some patients she has encountered have refused to pursue biomedical treatment because of their reliance on traditional medical practices. The conflicting ideologies of biomedicine and Lakota traditional beliefs come to a head regarding discussions of organ transplantation. According to Nadene, “there’s a lot of Native Americans that believe in the ‘this is the body I was given, this is the body I’m taking’” mentality. While biomedicine maintains a mechanistic view of the body, the Lakota beliefs reject this narrow view and instead conceive of the body as a sacred whole that functions in conjunction with other aspects of life. This sentiment was echoed by Julie, a diabetes educator on the reservation who says “being Native American, I think they’re kind of skittish about [transplantation] cause they just want to keep everything intact...its just out of the culture, you know.” Individuals who partake in the traditional belief system maintain desires to keep their bodies intact, therefore rejecting kidney transplantation as a treatment for end-stage renal disease. These beliefs not only apply to transplantation, but also apply to organ donation as this too goes against the idea of maintaining the sacred integrity of the body. These findings regarding traditional belief systems and views of organ donation support the findings from previous studies (Anderson et al. 2009; Blagg et al. 1992; Condiff 2009; Crowley 1999; Davison and Jhangri 2014) among Native American populations in the United States and Canada. While these beliefs were commonly acknowledged on the Pine Ridge

Indian Reservation, I did not come across any individuals who adamantly held to this traditional belief system and its views of the body. Instead, during an informal conversation with one of the dialysis center staff, I learned of a current dialysis patient, who is also a traditional Lakota medicine man, who is in the process of pursuing live donor kidney transplantation. While traditional Lakota beliefs may influence one's desires or rejection of transplantation, there is enormous variability in how these beliefs manifest making it altogether impossible to generalize.

5.2 Christianity

While the traditional Lakota systems of belief play a significant role in shaping world view, values, relatedness, and relationships on the reservation, Christianity dominates the religious norms. Christianity on Pine Ridge takes many different forms, some of which incorporate elements of Lakota spirituality. As can be found among Christian populations across the United States, on the Pine Ridge Indian Reservation there are varying degrees of religious practice and dedication. For some, Christianity is central to identity and for others it plays a supporting role. The supporting role of religion may take a sideline to other aspects of identity but is often relied on most when in need of physical, emotional, or spiritual support.

The history of Christianity on native reservations can be challenging to address because of the complicated interplay between its current day importance and its fraught relationship to violence, colonization, and forced acculturation. For many Oglala Lakota, the colonization of native peoples in the United States is nothing short of genocide. Widespread violence and the dismantling and rejection of traditional lifeways have led to severe historical traumas that continue to plague Native American populations to this day. This historical trauma is arguably most symbolized by the indiscriminate killing of 300 men, women, and children at the Massacre of Wounded Knee by the Seventh Cavalry of the United States army shortly after Christmas day in 1890. The grave site for those killed during the massacre is surrounded by wrought iron fencing protecting the stone monoliths etched with the names of those who perished. Atop the arched entrance to the grave site stands a cross and scrawled in black

sharpie on the painted white brick someone wrote “Fuck Historical Trauma, we Survived all and Every Act of Genocide” (Figure 1).



Figure 1. Wounded Knee Massacre Grave Site

To pacify and civilize the Lakota people (and other indigenous populations in the United States), the Bureau of Indian Affairs made it mandatory for all native children to attend Indian Boarding Schools. Modeled after the flagship Indian School in Carlisle, Pennsylvania founded in 1879 with the motto “kill the Indian, save the man”, these boarding schools persisted well into the twentieth century (Bess 2000; Hoerig 2002). These schools functioned as a way to “civilize” Native American children who were thought to be savage, pagan, and uncivilized. In addition to being beaten for speaking the Lakota language, forced to dress, eat, and act like the “white man”, and having their long hair cut short (Littlemoon 2009), Lakota children were also forced to attend church and practice Christianity. Vine Deloria Jr., a leading Native American scholar, activist, and teacher says in his landmark text *God is Red* (1973):

A substantial portion of every tribe remains solidly within the Christian tradition by having attended mission schools. They grew up in a period of time when any mention of tribal religious beliefs was forbidden, and they have been taught that Indian values and beliefs are superstitions and pagan beliefs that must be surrendered before they can be truly civilized (247)

The forced acculturation of the Lakota people led to a subsequent widespread adoption of Christianity on the reservation. While many embrace the Christian religion, others are conflicted by internal tensions that simultaneously pull towards their tribal values and those ‘white’ values forced upon them (Deloria 1973).

Similar to the ways in which traditional Lakota belief systems influenced patient's dialysis experiences and healthcare decision making on Pine Ridge, so too does Christianity. With hardship a regular feature of reservation life, the support provided by Christianity promotes individual resilience and perseverance. One dialysis patient, Randall, fully embraced Christianity after the deaths of his father and two of his sisters in a car accident. In total, he says "we lost five people in our community [that night], three of them was my family. My dad and my two older sisters. From that time until now, I guess that's when we really relied on Jesus and relied on God and relied on Christian life." This embrace of Christianity has helped Randall with his recent end-stage renal disease diagnosis and start of dialysis treatment. He says "when I first started coming here, I used to read [the bible] all the time. In the end it paid off." While he would sometimes question "what did I do to deserve this? I guess it's in God's hands" his confidence in Christianity and God allows him to know he will "bounce back from this, just having the time and the patience to continue with [his] treatment." Many of the participants interviewed for this research identified as Christian. And while many did not identify Christianity as a central feature in their lives, they gained comfort and support in knowing that their family, friends, and church were praying for them and their health.

For some patients, their dedication and pursuit of Christianity influences their health and healthcare decision making. Nadene, a dialysis educator, has worked with patients who choose not to seek dialysis treatment because of their beliefs in God and Christianity. She says some patients don't want to "mess with, not do anything that God didn't intend to happen...A lot of 'em see it as 'okay well this is my journey in life and this is what I gotta do. This is my, you know, my suffrage for my people." Among the participants I spoke with, only Valerie shared this viewpoint. Her religious beliefs led to her to stop seeking dialysis treatment for a time. She "just figured, if God wants me dead he'll take me. If God's gonna take you, he'll take you." After having moved away and discontinued treatment, Valerie felt that she needed to come back and continue with dialysis for her family and children.

5.3 *Tiospaye*

When talking about systems of support on the reservation, it is impossible to ignore the vital role of one's *tiospaye*. While the *tiospaye* is highly valued among traditional Lakota belief systems, this concept surpasses a single system of belief and permeates all aspects of life on the Pine Ridge Indian Reservation. The *tiospaye* is loosely translated to mean "extended family" but includes so much more than what this would normally entail among western, non-native populations. According to Ella Deloria, an anthropologist, linguist, novelist and aunt to the aforementioned Vine Deloria Jr., the *tiospaye* holds people together "in a great relationship that [is] theoretically all-inclusive and co-extensive" within a tribal domain (Deloria 1944: 23-25). Anyone born within the domain can become part of the *tiospaye*. In a study conducted by Diane Josephson (2000), she asked native participants to define what constitutes one's *tiospaye*, one's family. These are a few of the collected responses: "All humans are my family, everyone is my sister or brother. For me family is friends and immediate family", "Family is like a circle. When something happens it disrupts the family, but at the same time it brings the family closer", "When individuals experience problems they come back to the family for support" (Josephson 2000: 300). Instead of being limited to what western populations view as their nuclear or blood family, the concept of *tiospaye* describes a diverse group of people that have the same intimacy, importance, love, and beliefs generally attributed to family regardless of blood relatedness, physical distance, or time spent together.

Participants of this research expressed the importance of *tiospaye* in providing love and support throughout the hardships of dialysis. Encouragement from family, friends, church and village (neighborhood) communities, and powwow singing groups all constitute support from one's *tiospaye*. During periods of depression while on dialysis, Randall leans on this broadly defined familial support "bouncing back with everyone's encouragement" and maintaining positivity "through everybody sticking together." Currently living in a nursing home, JoAnne says of her biological son, "He's been my anchor, my root." When talking about his *tiospaye* Randall introduced me to the Lakota word '*takini*' which he defined as strength. In researching this term further, it literally means "to die and come back" but is most

commonly translated as “survivor” (Brings Plenty 2013). This sacred word, *takini*, is most often used to describe the persisting survival of Lakota people and culture after the Massacre at Wounded Knee despite ongoing and imposing historical traumas (Brave Heart 2000; Brings Plenty 2013). Not to detract from the sacredness of this word in the context of Wounded Knee, I thought this term *takini* beautifully captures the dialysis patient experience. Developing disease largely as a result of persisting structural inequalities, historical traumas, discrimination, and marginalization (some of which are discussed in the following chapter), dialysis patients are literally and figuratively dying as they experience the hardships, pain, and isolation that often comes with this treatment. However, with the *tiospaye*, a powerful source of strength and resilience, these patients overcome the many challenges they face and come back stronger; they survive.

CHAPTER SIX

“Just keep swimming”: Barriers to accessing kidney transplantation

Making the turn onto route 87 from Rushville, Nebraska, I know I am in the home stretch; the last leg of the drive up to Pine Ridge. Surrounded by agricultural fields growing corn and wheat, the flat highway soon gives way to gently rolling hills and eventually the steeper pine-ridged bluffs which give the town and reservation its name. A small cluster of buildings lie on the Nebraska-South Dakota state border, the unincorporated town of White Clay. Now a ghost town save for a small grocery, a mission headquarters, and a large Family Dollar, White Clay used to be comprised of multiple bars, liquor stores and saloons. These heavily frequented establishments were the combined result of a reservation-wide ban on alcohol and the high rates of alcoholism among the Oglala Lakota people. After several years of protest, the sale of alcohol in White Clay was prohibited.

A faded green sign that says “Entering Pine Ridge Indian Reservation” greets visitors and residents alike as they continue driving the two miles into Pine Ridge Village. My first stop on the reservation is usually at Big Bats convenience for gas. I know if I fill up here, I can avoid the long lines at the gas pumps closer to where I stay at the Common Cents convenience in Sharps Corner. While pumping gas, I am approached by a young man who asks for seven dollars to pay for gas money. I hand him five crumpled one-dollar bills, all I have in my pockets, and then head across the street to Sioux Nation, the largest grocery store on the reservation. The produce section is small but has more variety than arguably any other grocery on the reservation offering things like avocado, jalapenos, raspberries, strawberries, and kale. Despite visiting Sioux Nation many times, while I load my cart, I am shocked at the sky-high prices of many of the foods, significantly more expensive than prices in my local grocery in Fort Collins, Colorado. Entire aisles are dedicated to soft drinks and simple syrups, frozen and canned vegetables are more prevalent than fresh, and the meat section is dominated by ground beef, beef franks, bacon, and steak.

Staying in the village of Wounded Knee, I drive east out of Pine Ridge Village, past the Indian Health Service (IHS) hospital and health complex on route 18. Many people on the reservation live in mobile homes, which whiz by as I continue along the highway. Parked next to these homes, there are often two or three cars, propped up on concrete blocks or with noticeably flat tires. These “parts cars” are stripped as needed when a family’s functioning vehicle needs some maintenance. After a couple miles I turn north onto Bigfoot trail, the vast expanse of the reservation opening up as I climb the hill; the many shades of green, slightly muted by the haze which hangs in the humid air. Despite the immense beauty of the reservation and the people who call it home, life on Pine Ridge can be exceedingly difficult. Dialysis patients living on the reservation continue to hope for and work towards transplantation while the world in which they live throws hurdles, barriers, and blockades before every step. Nadene says “it *is* tough. There are lots a challenges...sometimes there’s people on the waiting list for quite a long time and it’s tough. I tell ‘em don’t give up. And then I have to quote the *Finding Nemo*, ‘just keep swimming...’ You know it gets frustrating, just take a breath and keep going with it because there’s something out there for you.”

This chapter is the culmination of all collected data and emphasizes the myriad barriers that limit or prevent access to kidney transplantation on the Pine Ridge Indian Reservation. While different patients are more (or less) susceptible to any specific barrier, these barriers have a compounding effect that severely inhibit individual capabilities of accessing transplantation. This chapter begins with a section discussing the distribution of what I am calling distal and proximal barriers and how these impact the likelihood of transplantation. Conversations about specific barriers start with previously identified distal barriers that support existing studies among poor and geographically remote populations. Next, this chapter will address different categories of proximal barriers that have a less direct, but equally impactful connection to kidney transplantation. The first category consists of barriers to live donor transplantation, the preferred option for kidney transplantation. This section is followed by structural barriers; barriers which are the result of colonization, economic marginalization, poverty, and historical trauma. The following section emphasizes institutional barriers, those that stem from interactions with the healthcare

system including misdiagnoses, miscommunication and lack of trust of physicians, and difficulties in maneuvering the healthcare system. Next are educational barriers which highlight the lack of widespread education, by no means the fault of the individual patients, regarding patient health and the larger healthcare system. Lastly, this chapter will address biological barriers that further limit access to transplantation among this participant population.

6.1 A Change of Focus

Based on my initial conversation with Gerald (Chapter 1) and literature review of previously conducted research examining access to kidney transplantation, I anticipated that the vast majority of barriers would be experienced right before surgical transplantation. As mentioned in the introductory chapter, Gerald had been placed on the transplant list and had twice received calls that a kidney match was available if he could make it to Sioux Falls, South Dakota (a five and a half hour drive from his house). A lack of money to pay for gas and lack of transportation prohibited his receipt of each organ. Existing literature highlights financial instability, geographic remoteness, cultural norms and beliefs, and discrimination within the healthcare system as primary barriers that limit access to transplantation (Alexander and Sehgal 1998; Anderson et al. 2009; Avanian et al. 1999; Bello et al. 2012; Cao et al. 2016; Condiff 2009; Crowley 1999; Davison and Jhangri 2014; Epstein et al. 2000; Kucirka et al. 2011; Mucsi et al. 2017; Wu et al. 2017; Yeates et al. 2009). Most of these barriers exist towards the later end of the transplantation process which was therefore where I expected to find the most inhibitive barriers. While this research does support previously identified barriers, as will be discussed in the following section, most of the barriers identified by patients and through grounded theory exist much earlier in the transplantation process.

In order to conceptualize when these barriers impact patients, I have built a simplified timeline showing disease progression and transplantation process; barriers that occur closer towards surgical transplantation are what I am calling distal barriers while those that occur in the earlier stages of the timeline, I am calling proximal barriers (see Figure 2). As mentioned above, most studies concentrate on

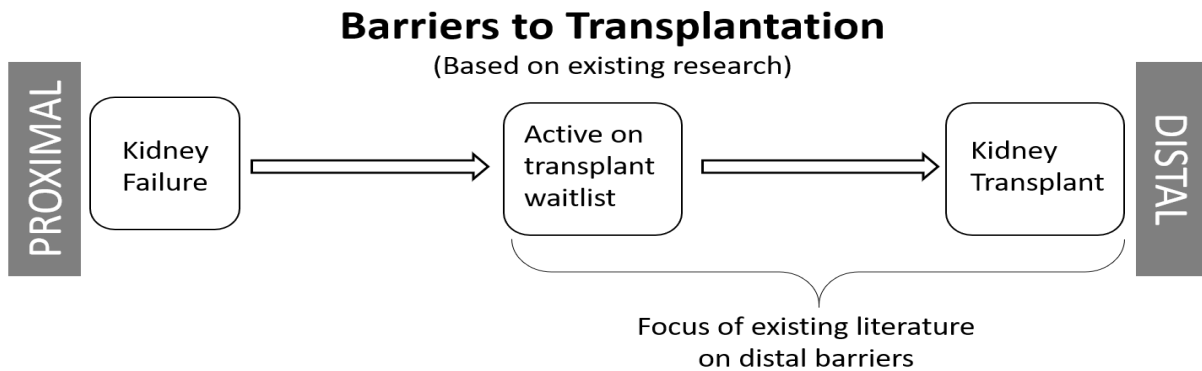


Figure 2. Barriers to Transplantation- focus on distal barriers

those barriers that affect patients on the distal end of the transplantation timeline. These primarily limit patients during the period between activation on the transplant waitlist and the surgical transplantation itself. Figure 2 acts as a visualization of this simplified timeline, highlighting the areas of concern for most research conducted on this topic of transplantation access. However, over the course of this research, I have found that proximal barriers were much more common and played a larger role in determining individual likelihood for receiving a kidney transplant. These proximal barriers have been separated into four primary categories: structural barriers, educational barriers, institutional barriers, and biological barriers. Modifying the timeline above to include the proximal barrier categories gleaned from this research and including birth as a life event, I created Figure 3 to highlight the distribution and

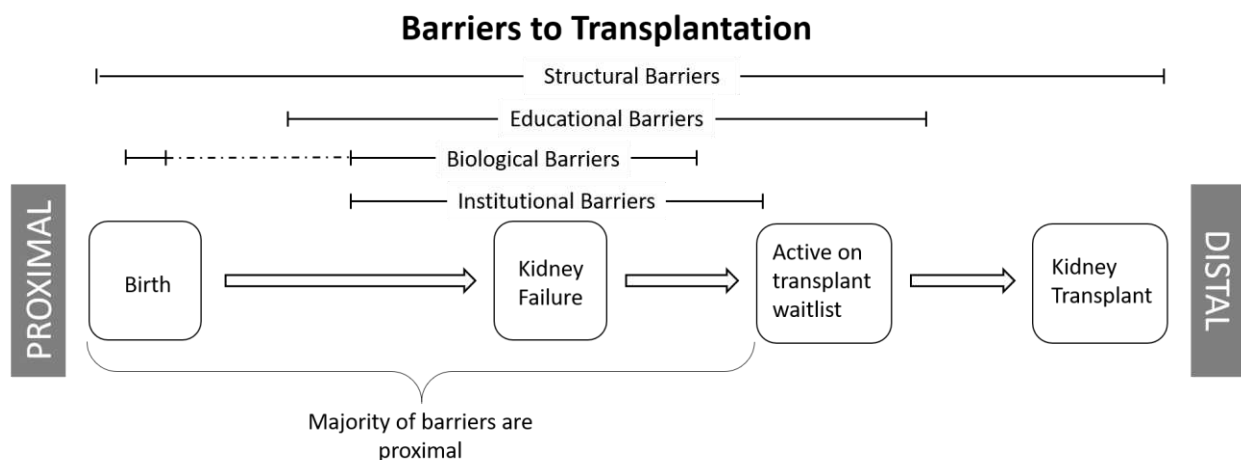


Figure 3. Barriers to transplantation- overlapping and compounding barriers

compounding nature of these proximal barriers. While this may seem a strange choice for inclusion, there are significant forces acting on Oglala Lakota individuals throughout the course of their lives that impact the development of poor health, kidney failure, and a subsequent inability to access transplantation. Each category of barriers includes an estimated time range indicating when, throughout the lives of patients, these barriers are most inhibitive. After adding these different categories of barriers, Figure 3 clearly highlights the concentration of barriers present at the proximal end of this timeline. This model also demonstrates the overlapping and compounding effects of these barriers which simultaneously act on Oglala Lakota individuals.

6.2 Support for Previously Identified Distal Barriers

While most of the barriers identified throughout the course of this research are proximal barriers, those taking place towards the beginning of the transplantation process, findings also support distal barriers identified by previous research studies. These distal barriers limit the capabilities of those patients on the transplant wait list to receive an available, matched organ as was the case with Gerald. These patients have overcome, or because of unique circumstances were not exposed to, the proximal barriers encountered throughout the earlier stages of the transplantation process. These later stage challenges are largely the result of the protracted time frame between the donor match and the physical surgery (24-36 hours organ viability). As John, a dialysis patient, says, “well it’s a short notice. To get a call like that... you got to, get up and go. You have to have everything, money and all that. Money to go right away.” The most frequently identified distal barriers revolve around the related issues of distance and transportation as well as money and financial insecurity.

6.2.1 Transportation and Distance

The Pine Ridge Indian Reservation is located approximately 5.5 hours from Sioux Falls, South Dakota, the location of the nearest transplant center. Other transplant centers located in Denver, CO and Omaha, NE are 6 and 7 hours away respectively. For many patients, this long travel distance is extremely

taxing and they become reliant on their support systems for assistance with the drive. For Beverly, when she sees doctors in Sioux Falls she says “my son takes me, but that’s like a five hour drive.” With her son being her primary support system, he is usually the one who drives Beverly to her appointments; however, a recent cancer diagnosis has made extended driving excursions difficult for him as well. Luther echoes this sentiment saying “I have family drive me [to appointments] but sometimes I have trouble finding a ride.” The lack of healthcare services offered on the reservation poses challenges to patients in terms of distance. From a distal barrier perspective, finding someone willing to drive the distance to Sioux Falls (or further) on such short notice is immensely challenging. Distance also acts as a proximal barrier as many patients see physicians in Rapid City for other health concerns, only an hour to an hour and half away from the reservation. According to Julie, a health educator on the reservation, “a lot of ‘em [patients] live in rural areas. Like our res is huge. It’s huge and I think a lot of ‘em have transportation issues and financial issues.” The distances calculated for these time estimates are from Pine Ridge Village, located on the southern border of the reservation. Those patients who live in more rural, remote sections of the reservation will face additional challenges in terms of driving time, road maintenance, and accessibility.

In addition to issues of distance, patients often lack consistent access to a functioning vehicle. While it is common to see multiple cars parked in front of homes on the reservation, many of these vehicles are used as “parts cars” and cannot be driven. Instead they mirror the process of cadaver transplantation; old, broken down cars ‘donate’ their functioning parts to replace malfunctioning machinery in an operational vehicle. Alice, another educator reinforces the transportation challenges brought up by Julie saying “A lot of people don’t have transportation” on the reservation. A lack of access to a functioning vehicle provides significant challenges at the distal end of the transplantation process when time is of the utmost importance.

6.2.2 Financial Insecurity

Financial insecurity poses significant challenges for individuals on the reservation with regard to health and healthcare. Issues of financial insecurity on the reservation act as a structural barrier which influences and impacts patients at all stages of the transplantation process (as demonstrated in Figure 3.). The structural barrier of financial insecurity will be discussed in subsequent sections as a proximal barrier; here, however, a lack of funding will be discussed specifically in the role of a distal barrier. Building on the issues of transportation and distance, lack of financial security impacts a patient's ability to pay for gas money. Even if patients have access to a functioning vehicle, many are not able to afford the necessary gas money on such short notice to make the long trip. Because many patients are not driving themselves, money is needed to pay for the lodging of family or friends who are called upon for transportation. When asked what types of challenges patients face in getting a transplant, Luther said "Gas money... and probably findin' a place to stay at Sioux Falls." John says "people don't have that much money to go. Who are going that far [to Sioux Falls]."

To support Oglala Lakota individuals on the reservation, the tribe will provide financial assistance to patients for travel to doctor's appointments on and off the reservation. Submitting a medical travel request will provide patients with money for gas, and if needed, money for food and lodging depending on the length of the trip. While this program provides much needed financial support to patients on the reservation, there can be lengthy processing time for the funds to become available. Requests usually need to be processed days in advance, and even rush funding takes some time. Nadene, a dialysis educator, says that if a patient were to receive the call for organ availability during the day, patients would be able to receive funding in time. However, accounts from other participants demonstrate significant delays in receiving the funding support. If a call comes "in the middle of the night...and if [a patient] didn't have gas" Nadene says "they're kinda out of luck." This added financial barrier means that upon receiving a call that an organ is available, the patient must have the support system in place to

guarantee a ride, must have access to a functioning vehicle, and must have the necessary funds to pay for the gas to get from point A to point B.

6.3 Barriers to Live Donor Transplantation

When it comes to kidney transplantation, live donor transplantation is the preferred treatment option. In addition to improved health outcomes that reduce the likelihood of surgical complications and organ rejection, live donor transplantation comes with certainties; it lets patients bypass the long wait times associated with cadaveric transplantation and allows them the convenience of scheduling when the surgery will take place. Patients know that an organ is guaranteed upon the identification and willingness of a donor match. While less common on Pine Ridge, live donor transplantation is still pursued as the first step in the process towards transplantation.

6.3.1 Family Member Health

Nationally, most live donor recipients receive their organ(s) from family members because of desires to donate and genetic similarities. On Pine Ridge, high rates of diabetes, cardiovascular disease, high blood pressure, alcoholism, and drug abuse are frighteningly common. Therefore, when examining family member health as a possibility for live donor transplantation, many are not candidates because of pre-existing health conditions that disqualify them as donors. Many of the structural factors (discussed in the following section) that have led to patient's kidney failure, also affect family members who may suffer from the same or similar health related issues. Diabetes is one of the leading causes of end-stage renal failure on Pine Ridge, and while having diabetes does not disqualify a patient from receiving a live donor transplant, a diabetes diagnosis *does* disqualify an individual as the organ donor. Therefore, if a dialysis patient has many family members who are diabetic, it significantly reduces one's options for a potential donor match. Regarding family member health, Nadene says "finding donors [is hard], and there are some that, when they go to be tested, find out that they are also in [kidney failure]." When asked about the possibility of live donor transplantation, Valerie, a dialysis patient, says "most of [my family]

are diabetic too. Kind of going downhill. No good kidneys in my family yet.” For those who want to be tested to see if they are a good match for a family member or loved one, it is quite common that upon testing they find out they are not candidates. Not because they are not a good biological match but because they too are suffering from undiagnosed diabetes, high blood pressure, cardiovascular problems, or are even in kidney failure themselves.

Some patients have broached the subject of live organ donation with their children. However, with such high rates of diabetes and end-stage renal disease on the reservation, these family members are concerned about the impacts donation will have on their own health. John asked his children if they would donate, but they were all too scared of the negative consequences for their own health. As it turns out, they are already diabetic so they wouldn’t be considered candidates for donation anyways. Fears of poor health repercussions or the future need for both kidneys may deter individuals on Pine Ridge from volunteering their organ for donation.

6.3.2 Ideas About the Body and Low Rates of Organ Donation

Another factor reducing the availability of live donors on Pine Ridge may be the result of traditional beliefs about the body. Among the Lakota people, there is an important perception of the body and its relationship to the world in which it exists. According to Nadene, many Lakota people subscribe to the “this is the body I was given, this is the body I’m taking” mentality. There is great importance in having a whole, complete, and intact body upon death. Therefore, this belief system may prevent some individuals from offering to become a live donor for transplantation. The traditional Lakota belief systems, ideas of the body, and how it relates to and interacts with biomedical organ transplantation is discussed at length in Chapter 5.

6.3.3 Hesitations in “Asking”

So far in this section on barriers to live donor transplantation, I have discussed situations in which potential live donors may not be able to or may choose not to donate a kidney for live donor

transplantation. However, in many instances, patients will forgo asking family or friends to donate their kidneys, therefore eliminating any possibility of live donor transplantation. While all patients were open to the idea of live donor transplantation, most were unwilling or expressed great discomfort in asking others to get tested for a potential match. Feelings of guilt and burden paired with common misconceptions regarding live donor transplantation led patients to have hesitations in “asking” for someone’s organ. Despite the likelihood that their children would want to donate their kidneys, dialysis patients Luther and Linda do not want to burden their children. Luther feels that if he were to ask, his children would feel obligated to donate regardless of their individual desires to do so. Linda says “I didn’t ask any of my kids... I think they’d be willing to, I don’t know if I want to put them through that.” Others feel uncomfortable asking for such an immense and life altering ‘favor’; “it’s a tough question, to ask somebody for a kidney...I don’t know, I wouldn’t feel too comfortable just asking somebody, ‘hey, let me have your kidney’” (Randall).

Much of the discomfort fueling patient hesitations in asking about live donor transplantation comes from misconceptions about what kidney donation entails for the donor. While donating a kidney is major surgery which comes with possible complications, a kidney donor faces very few long-term negative consequences and can maintain a normal lifestyle (with the exception of contact sports). Although she never asked her children to donate, Linda says “any of my kids probably would [donate]. A couple ones said they would like to, [but] how would they function with one kidney if, you know, they might get sick.” Many patients are justified in fearing that family members may eventually become diabetic or go into kidney failure and would therefore need both of their kidney’s. Randall says “I don’t want anyone to go through this, I lived it from that time until now. I don’t know, I’m barely hanging on myself. I don’t know if I want to put any family or friends through what I’m going through because this is hard.” Believing kidney donation will lead to kidney failure, Randall’s misconceptions about live kidney donation prevent him from asking family members because he does not want to put any of his loved ones through the difficulties he has faced since starting dialysis. Lastly, individual sense of responsibility has prevented some patients from asking family for donation. Walter feels his current situation is the result of

past life choices which he does not want to impose on his children. He says “nah, let them keep their own [kidneys]. I can’t let them [donate]. Let ‘em live longer with two what they got...I brought ‘em to this earth. Let ‘em live their own way, and I’ll live mine.” The combined impacts of a lack of eligible or willing donors with dialysis patient hesitations may contribute to and help to explain the low rates of live donor transplantation present on the reservation.

6.4 Structural Barriers

For those living on the Pine Ridge Indian Reservation, the legacies of colonization and minority status within the white-dominated United States have created myriad structural pressures that influence agency, capability, health and well-being. Colonization and the formation of the reservation systems in the United States placed the Lakota people under the ‘protection’ of the United States government. As a means of exercising control over this native population, the Pine Ridge Indian Reservation was intentionally marginalized from existing economic systems. This marginalization paired with forced lifestyle changes led the Lakota people to become dependent on government rations and commodities such as flour, sugar, salt, and lard. These structures have led to poverty and financial insecurity (addressed above), challenges of food security and food sovereignty, and high rates of unemployment on the reservation. The implementation of Indian boarding schools on the reservation (discussed in further detail in Chapter 5) have legacies of historical trauma that continue to impact people today through high rates of domestic violence, suicide, and drug and alcohol abuse. Mentioned earlier, these structural factors are constantly present on the reservation, impacting and influencing people throughout the course of their lives. While these structural factors contribute to challenges regarding health and healthcare on the reservation in many ways, participants highlighted three specific barriers to transplantation directly linked to these omnipresent pressures: food access, unemployment and lack of stability, and drug and alcohol abuse.

6.4.1 Food Access

One of the most frequently identified barriers to accessing transplantation on the Pine Ridge Indian Reservation is food access. The issue of food access on the reservation encompasses food availability, food security, and food sovereignty. Food availability primarily addresses issues in the distribution of grocery stores and food deserts across the reservation while also examining available food options within these stores. Food security describes individual or family ability to purchase adequate quantities and nutritional quality of food. And lastly food sovereignty focuses on issues surrounding the lack of local food production and increased costs of imported food to the reservation. The structural barrier of food access impacts patients throughout the transplantation process from the development of poor health, diagnosis of end-stage renal disease, and poor health maintenance while on dialysis.

As mentioned in the introduction to this chapter, *Sioux Nation*, located in Pine Ridge Village, is the one primary grocery store on the reservation. Smaller convenience groceries can be found spread across the reservation in larger villages like Oglala, Manderson, Porcupine, Kyle, and Wanblee. These smaller groceries have fewer food options and significantly smaller produce sections, often carrying only apples, oranges, bananas, lettuce, and cucumbers. Julie addressed this issue of food availability saying “we only have certain grocery stores and then they only buy certain things. Like, I notice that [Sioux Nation] started getting organic things but it’s not like a whole aisle of organic things or much options around here.” The large expanse of the reservation coupled with few grocery stores means much of the reservation is considered a food desert. While the range of products offered in these groceries is increasing, the options are still severely limited. For dialysis patients, this can be extra difficult with such demanding food restrictions. On dialysis, Randall says we “can’t have regular milk. They said rice milk...around here, it’s hard to find rice milk on the res so you have to go to Rapid [Rapid City, SD] or Chadron [Nebraska] and load up as much as I could. It goes quick because it’s so little.” The food restrictions of diabetic and dialysis patients and the lack of availability of these foods on the reservation means patients must travel great distances to acquire these products.

With rampant poverty and high rates of unemployment on the reservation, people are limited by their financial insecurity regarding the foods they eat. The ongoing commodities paid for and provided by the United States government are affordable, but low in nutritional value. Nadene says “I know it sounds cheesy” but patients are “cut off from the leaner, healthier foods...that we were used to back in the roaming days... We’re supplemented with commodities which are full of very high sodium, cadmium, canned food. They do give buffalo meat but very little, their giving more trans fats.” Instead of supporting the people of Pine Ridge with healthy, nutritious, and affordable options, the provided commodities are full of trans fat and sodium. These unhealthy, yet affordable foods become staples for those living on the reservation, contributing to poor diet, diabetes, and eventually kidney failure. Fast food is another desirable option for families because of the low costs. In Pine Ridge Village, a Taco John’s and Subway dominate the main street. According to Linda, a dialysis patient, “everybody eats fast foods...there’s a lot of foods we eat are not good, like all the whites: sugar, flour, salt.” Here she emphasizes that the primary food consumption comes from either fast food, or the cheaper and nutrient poor commodities. These commodities, provided to reservations across the country, led to the development of cultural food staples such as fry bread. Despite being a treat that should only occasionally be enjoyed, I wholeheartedly agree with participants when they say it is “irresistible”.

With most foods on the reservation imported from companies and businesses off the reservation, the costs of food are higher than those found in surrounding urban and suburban areas. The issue of imported food is being addressed through local movements towards food sovereignty. These initiatives promote the local production of agricultural products with the long-term goal of decreased dependency on outside sources of food. With a dependency on imported foods and a corresponding increased travel distance, the shelf-life of foods is a concern therefore leading groceries to purchase more canned or frozen products. Nadene is concerned by this switch from fresh to processed foods saying “I don’t see a lot of vegetable uses as I used to. Like, you know, you had a fresh vegetable with dinner every night. Now it’s just easier to just go and get the can...Its just, there’s a lot of things that are more expensive on the reservation compared to off the reservation.” One agricultural product that is doing well on the

reservation is in the raising of buffalo (American bison). Among the Lakota, the buffalo holds significant cultural importance. The great spirit, *Wakan Tanka*, is often portrayed as a buffalo, it is and has been historically an important source of protein, the hunting of buffalo acts as a coming of age ritual, and among traditional Lakota families, one person is tasked with the role of buffalo caretaker. These buffalo caretakers will monitor and care for buffalo in the same way ranchers care for their cattle. However, despite the local production and availability of bison meat, the “fattier meats are less expensive than the leaner meats.” Nadene continues by asking “why is buffalo meat \$20 and you know, hamburger \$15? You know, of course you’re gonna go for what’s cheaper because you gotta gauge other things into your menu.” With increases in locally produced foods and a transition to food sovereignty, the hopes are to provide the Oglala Lakota people with healthier, cheaper, and more sustainably produced food resources.

6.4.2 Unemployment and Lack of Stability

With limited economic development on the reservation, the population of Pine Ridge suffers from extremely high rates of unemployment with estimates as high as 90%. This degree of unemployment has contributed to the widespread poverty and financial insecurity felt on the reservation. Because work opportunities are so difficult to come by, many Oglala Lakota individuals face a high degree of fluctuation and variability in their day-to-day lifestyles. Alice says, “a lot of people don’t have...jobs, or their moving from house to house with relatives or friends or something, so they don’t really have a stable home.” While many dialysis patients are unemployed, partly due to the demanding treatment schedule, widespread unemployment on the reservation creates issues of stability long before the end-stage renal disease diagnosis. This instability may strain support networks, limit interactions with health care providers, contribute to poor diet, and lead to drug or alcohol abuse, all of which are significant inhibitors to accessing kidney transplantation.

6.4.3 Drug and Alcohol abuse

Although drugs and alcohol are prohibited on the reservation, the population of Pine Ridge suffers from high rates of alcoholism and drug addiction. Associated with traumas of the boarding schools and a reflection of the ongoing hardships on the reservation, the perseverance of alcoholism and drug addiction lead to poor health outcomes and are a large contributor to the high rates of end-stage renal disease on the reservation. In addition to playing a large role in the development of disease, persisting consumption of alcohol and/or use of drugs like heroin, methamphetamine, and marijuana further degrade patient health while on dialysis. Toxicology screening, blood testing, and urinalysis are all conducted by transplant teams as part of their evaluative measures for candidacy on the transplant waiting list; the presence of any illicit substances or an increased blood alcohol content are immediate disqualifiers for transplant eligibility. Interview participants Nadene and Valerie each identified drug and alcohol abuse as significant barriers to transplantation. They highlighted the role these addictions play in the development of poor health on the reservation while also acknowledging their continued negative impact on the health of dialysis patients. Alice, a kidney transplant recipient, says she is not allowed to drink alcohol because it can counteract the anti-rejection medications she takes daily. One of the only other people she knew on the reservation to receive a kidney transplant had previous alcoholic tendencies which she reverted to after her transplantation resulting in death. High rates of drug and alcohol abuse on the reservation play a significant role in all stages of the transplantation process starting with the development of kidney failure and even affecting individuals after a transplant is received.

6.5 Institutional Barriers

Many of the barriers patients encounter in accessing kidney transplantation occur at the interface between patients and the larger healthcare system. These barriers, that I call institutional barriers, are the result of cultural differences, power differentials, miscommunications, and misdiagnoses that negatively impact patient health and limit their ability to pursue transplantation. A lack of regular physical examinations lead to a protracted timeline in providing patient care, generally leading to worsened health

outcomes. Miscommunications and cultural misunderstandings during interactions between patients and physicians leave patients feeling disempowered and uncertain about their healthcare. This often leads to a generalized lack of trust between patients and doctors; a lack of trust that is only exacerbated by frequent misdiagnoses and significant delays in referrals and treatment. With little experience maneuvering the healthcare system, many Oglala Lakota patients are unaware of the bureaucratic policies and procedures that run this biomedical system leaving them confused about how to pursue ‘next steps’ in their treatment process. The primary health system operating on the reservation is the Indian Health Service. Frequently expressed discontent with this service highlights the reduced quality of care and limited options for patients living on Pine Ridge.

6.5.1 Infrequency of Physical Examinations

Among the general populace of the United States, pressures abound to receive an annual check-up, also called a yearly physical examination. Whether or not individuals stick to this yearly schedule, it is common within the United States to see a doctor every few years. These physical exams play an important role in preventative medicine, identifying early signs and symptoms of disease. When caught early, these diseases can be better managed, and patients tend to have improved health outcomes. On Pine Ridge, according to research participants, people very rarely receive generalized physical examinations. Instead, people reserve visits to the doctor for specific ailments such as toothaches, infection, or other symptoms and illnesses. Because of the infrequency of regular physical exams, many patients visit the doctor for an unrelated illness and discover they are in kidney failure. Linda explains this infrequency in doctor’s visits saying “maybe [patients] don’t want to hear what’s wrong with them. So they ignore their own health...I think that they don’t want to be sick I guess.” Others said that they didn’t notice anything felt wrong because the accumulation of their symptoms felt like a ‘new normal’. Instead of catching early signs of illness, patients are being diagnosed with diabetes or even kidney failure without any prior knowledge or warning.

Patient's lack of regular physical exams significantly reduces the likelihood for transplantation in other ways apart from a decline in physical health. If kidney damage is caught early, it can be monitored, and patients can begin the listing process with a transplant center before starting dialysis. At this point, they are healthier, have fewer limitations, and will reduce the wait time for an organ. However, for "a lot of 'em, it's not caught 'til it's too late" (Nadene). Catching decreased kidney function early has significant implications for the approach to dialysis treatment. Instead of having an emergency chest catheter placed, patients who do not need to immediately begin dialysis can have surgery to have a vascular access point (also called a fistula) placed in their arm. According to Nadene, "if we can get the patient to get the vascular access placed before they start [dialysis], just by telling them this is inevitable, this is where you're gonna end up, it works out better. You know, labs are better, placement with the transplant team is better. But if its sudden onset or they had no communication with the nephrologist, they go for the access or for the catheter." Randall was one of these "sudden onset" patients who had a chest catheter placed and after 6 months of dialysis treatments had surgery to put in the vascular access. He says "I guess the fistula is better than the catheter, because the catheter is more likely...to get infected because it's connected to the heart. Directly to the heart, so I guess with the fistula I have a good point of getting my time reduced again [dialysis run time], and the blood gets cleaner through the fistula than the catheter." If patients are able to plan ahead because of prior knowledge of kidney damage, it not only improves health outcomes but reduces the run time on dialysis, results in better lab outcomes, allows for fewer limitations while on dialysis, and decreases risk to infection. All of these make a patient a better candidate for kidney transplantation.

6.5.2 Cross-cultural Miscommunication with Physicians

When Oglala Lakota patients see physicians to treat ailments (in lieu of or in conjunction with traditional Lakota medicine), many report feelings of discomfort as their culture interacts with that of the western biomedical system. Power dynamics play an important role in patient-doctor relationships (discussed further in Chapter 7). For many, the unequal distribution of power leads patients to feel like a

bystander to their own care. Feelings of inferiority may make patients reluctant to ask questions about diagnoses and treatment so as not to impose on the busy physicians. Differences in belief systems, conceptions of the body, and language provide additional barriers to effective cross-cultural communication in healthcare settings. Julie emphasizes these differences in cultural dynamics saying:

“I think it’s different for the medical professionals and the patients. Especially around here because it’s just two different worlds coming together to try to help and then trying to get help [patients and doctors]. It’s just foreign for the patient who needs the help. It’s just unknown territory that they’re not used to I guess. Same for the doctors and medical people too. It’s just unknown. They don’t know who to talk to or if they’re stepping over lines, or...language wise and everything.”

These cultural differences and miscommunications between the culturally Lakota patients and the western biomedical doctors create a tenuous foundation on which other challenges proliferate.

6.5.3 A Lack of Trust

When dealing with an issue as intimate and significant as health, it is important to trust those who are making healthcare decisions that directly impact patient’s physical, mental, and emotional health and overall well-being. While many patients expressed a generalized trust in the healthcare system, many emphasized situations and circumstances in which they lost trust in those who were attempting to provide care. Beverly, is one of the few patients who says that she really does not trust the healthcare system but feels reliant on it. This lack of trust stems from the lack of communication and clarity in speaking with doctors. Beverly feels like she is being intentionally marginalized from her own care and being neglected by doctors who are supposed to help. She says:

One of the things really got me upset too is that, when I walked in, the doctors would be there, the doctor up there, look at my paperwork and everything. ‘Oh your numbers are good. Your numbers...’ I was like a number person. I was like a number. I’m not a number. I’m a human being. Tell me what these numbers mean... [Doctors] need to be more specific and address you a little bit better. Then they ask you ‘you got questions for me?’, ‘oh not really...’ Boom, walk away. Tell me what’s wrong with me. Tell me what my chances are. Tell me something. Talk to me. I’m not a board to laying, I’m a human laying there, I’m still breathing... You got me on a machine, I’m still breathing. I’m breathing as long as I can, and I myself want to live and enjoy life.”

For Beverly, the quick dismissal and perceived lack of interest in explaining her lab results marginalizes her from her own healthcare. Although she says that her doctors usually ask if she has questions, she feels she doesn't even have enough information to know what to ask. The doctors take her lack of questions as an indication that she understands, when in fact it reflects the opposite.

For other patients, their lack of trust is generated by a lack of transparency regarding treatment. A few patients reported never receiving results from procedures, blood tests, and urinalysis. Especially when in positions of poor health, patients should be informed about risks, procedures, and treatment plans so they can be an active participant in their own health. While Randall was in the hospital, he was receiving information from doctors that his kidney function was low. Without knowing he was in kidney failure, he was told that he needed to have a catheter placed. He says, "at that time, I didn't know what it was, so I said alright." The following morning, he went down to surgery and doctors "gave [him] a shot, they didn't wait, they just cut [him] wide open." He thought "they were going to put [him] to sleep." Without knowing that the catheter entailed surgery and that he would be awake for the duration of the procedure, he was unable to make an informed decision. He says "After that, I was pissed, man. I was just mad at the world." Experiences like these emphasize the importance of communication in a medical setting to ease patients fears and concerns and allow them to make informed choices about how best to approach their care.

6.5.4 Misdiagnoses

Challenges with cross-cultural communication and in some cases malpractice, lead to disproportionately high instances of misdiagnoses on the reservation. These misdiagnoses further bolster the lack of support in the medical system and can have extreme consequences for patients. In talking with patients, some described receiving one diagnosis at one doctor's office and a different diagnosis somewhere else. On the reservation, the son of one participant was told his cancer was in remission and he should stop taking his medications; however, a separate visit to a physician's office in Rapid City shortly after said he still had lesions and he should continue with treatment. Beverly describes another

scenario where, after having her vascular access implanted in her arm, she told the doctor she was experiencing a freezing sensation. When she went to visit the doctor “they checked it out, they said there was nothing wrong.” However, after persisting symptoms she saw another doctor in Sioux Falls of which she says “they took me in for an angiogram. The following day they took me in for surgery...And so I had to go clear over [to Sioux Falls] to get a problem taken care of when Rapid City should have taken care of it if they’d checked me out correctly.” The issue she was experiencing was unrelated to the placement of the vascular access, but the doctors didn’t look further into what was causing her symptoms. While these scenarios are largely unrelated to issues of kidney health, these experiences fuel mistrust in the healthcare system and significantly impact other aspects of patient health that directly influence likelihood of transplantation.

In some instances, these misdiagnoses can have catastrophic consequences. Gloria has suffered from a string of misdiagnoses and malpractices that have significantly reduced her overall quality of health and likely will prevent her from being eligible for transplantation. After a bout with pneumonia, Gloria had an unexplained swelling in her leg. At the hospital, doctors cut into her leg thinking it would relieve the pressure, however the cut became gangrenous and resulted in a lower limb amputation. Similarly, an ear infection was misdiagnosed and Gloria was prescribed the wrong antibiotic. She says, “when I went home that night n’ I took [the pills] n’ I got up the next mornin’, I couldn’t hear nothin’ and that scared me.” The malpractice in dealing with her leg and the misdiagnosis of her ear infection has led to Gloria being permanently in a wheel chair and nearly deaf. Her recent inactivity because of limited mobility has exacerbated her preexisting diabetes and increased her blood pressure both of which make her an unlikely candidate for transplantation. Directly related to issues of transplantation, Alice, a transplant recipient, was first diagnosed with food poisoning on the reservation, a misdiagnosis to which she says, “I could have died!” The misdiagnosis of her Wagner’s disease could have cost Alice her life; luckily her family had the resources to pursue further treatment in Rapid City and then at the Mayo Clinic in Minnesota, eventually leading to a live donor transplant from her father at the age of 13.

6.5.5 Delays of Treatment and Referral

In addition to misdiagnoses, significant delays influence patient perceptions of the healthcare system and erode trust with doctors and medical professionals. These delays are sometimes caused by issues of referral processing and appeals and other times they may be caused by processing time for financial assistance from the tribal government. These delays limit patient capabilities to see doctors and receive treatments in a timely fashion. Shortly after having his catheter placed and starting dialysis, Randall “sat up with the wrong arm... almost pulled out [his] catheter.” He says, “kidney doctor said ‘how soon can you get to the hospital?’ I said ‘whenever, just gas money, I need gas money. I could be up there right now.’” Happening on a Monday, Randall did not receive money from the tribe until Wednesday, having to miss his dialysis appointment on Tuesday because of uncertainties about the functionality of his catheter. This delay puts Randall at risk because of missed treatment and heightened infection risk. In addition, his missed dialysis appointment may be viewed as a lack of adherence, counting against him regarding transplantation candidacy.

Other patients face delays as they wait for referrals to be processed to see a healthcare professional. A couple of patients interviewed claimed that some of their referrals were never processed and they never followed up partly because of issues in maneuvering the healthcare system which will be discussed in the following section. Every patient I spoke with on the reservation is on Medicaid (public tribal insurance) or Medicare, which on Pine Ridge, goes through Indian Health Service (IHS). Therefore, all referrals for services not offered on the reservation must be processed through the IHS offices. Alice, a kidney transplant recipient who sees a nephrologist in Denver, Colorado, must go to the clinic on the reservation to receive a referral. She says her referral is sometimes denied because they say “it’s not a priority...they say since [she’s] not chronically ill or like dying then it wouldn’t be paid for by IHS.” She says, “I always have to appeal it and they usually approve it after I appeal it like once or twice but that’s a big barrier.” The referral system and the challenges she faces with frequent denial of services acts as a barrier to receiving the necessary care to maintain her health.

6.5.6 Maneuvering the Healthcare System

For many patients, a lack of familiarity with the biomedical healthcare system leads patients to have issues maneuvering the system and understanding the necessary steps to receive care. Patients frequently reported feeling uncomfortable with the extensive paperwork and follow-through necessary for listing with a transplant center, seeing a specialist, and filling out tribal assistance requests. Without someone to help patients figure out next-steps, they feel lost in this world they don't fully understand. Linda says "I don't really have help to get to that point [listing with a transplant center]. Just maybe doctor's appointments but really don't have a counselor or I don't have no one to help make that, to make it to that point." While she acknowledges the hard work of the dialysis center social worker, she feels that patients need another person whose sole job is to help in maneuvering this complicated and unfamiliar system. John agrees, saying "most people can't...find resources. They should have something like, class for that." Instead of a second social worker, he feels that a class that breaks down the steps to transplantation would be effective in providing the necessary education and know-how for patients.

With referrals processed through Indian Health Service, most patients only work with one doctor. Beverly says, "It's just like, we work with one doctor, and so it's like we don't have that second opinion." Without knowing how to begin the process of finding another doctor, patients feel limited in their care and believe that their health is being compromised because of it. With the frequency of misdiagnoses on the reservation, many patients feel a second opinion is necessary to fully trust in their treatment plan; yet patients do not know how to go about finding and getting approval to see a second physician. Regarding financial assistance from the tribe, Julie says patients have trouble "following through. It's a long process that they don't understand so they just kinda give up. They just deal with it." If resources were available to assist patients in maneuvering the healthcare system and facilitate the interface between this culturally foreign bureaucratic system, patients would have increased trust in the system and would be better able to take advantage of available resources.

6.5.7 Indian Health Service (IHS)

Indian Health Service is the primary public healthcare system operating on the reservation. With the hospital located a few miles outside of Pine Ridge Village, all health services received by patients living on the reservation go through IHS; this includes initial patient assessments, the emergency clinic, and the processing of referrals. A small hospital, IHS is limited in the services it provides forcing patients to receive more advanced and specific care from nearby hospitals, usually in Rapid City. While a few patients emphasized that IHS has improved in the last decade, there is general agreement that this system is not as efficient or effective as it should be. The dissatisfaction surrounding IHS is suggested to be the result of understaffing, overstretching (number of patients seen per doctor), and general underfunding although these are simply patient speculation. Throughout the course of this research, I had contacted Indian Health Service for interviews but was unable to speak with anyone at the facility and therefore their perspective is not captured in this research.

Complaints about Indian Health Service emphasize many of the institutional barriers as this is the primary healthcare system responsible for patients on the reservation. Randall says “at IHS you get misdiagnosed a lot of times... I know people that are diagnosed as diabetic. They were put on high blood pressure pills, diabetes pills. They went to Rapid where [doctors said] ‘nothing’s wrong with you.’” The frequency (or perceived frequency) of misdiagnoses coming out of IHS contributes to patient’s lack of trust in the healthcare system. For Beverly, it was the extensive delay of treatment that leads to her discontent with IHS. She says “when I first got ill, that made me mad because it took IHS a long time to recognize it. Then I was denied from their treatment for about seven months I count.” Unable to seek treatment elsewhere because “everything we’re going to do, we have to go through IHS”, Beverly had few options for treatment alternatives and suffered for seven months before being able to begin treatment to improve her health. Healthcare educators on the reservation are primarily concerned with the lack of patient education provided by IHS. Nadene says “IHS is crap for patient education. They really are...they

don't assist us in any type of way other than getting us a referral for [patients] to see a nephrologist." This lack of patient education creates additional barriers, further inhibiting access to transplantation.

6.6 Educational Barriers

When examining access to transplantation, previous research has tended to focus on distal barriers while marginally acknowledging some of the structural and institutional barriers discussed above. Throughout the course of this research, streaming through the underlying text of participant interviews were issues surrounding patient education in biomedical constructions of illness. Unacknowledged in the literature, the identification of the following educational barriers is vital to improving access to kidney transplantation. The gaps that constitute these barriers are the ones that can be most tangibly addressed and mediated and therefore may provide the most improvement in terms of access to kidney transplantation. In stating that patients are lacking education, I am not making claims regarding intelligence, educational achievements, or grades completed. Instead, these educational barriers are largely the result of poor communication and cross-cultural exchange between patients and physicians as discussed previously. A lack of understanding regarding one's diagnosis and the root causes for the development of disease make it difficult for patients to accept the necessary lifestyle changes that come with diabetes, end-stage renal disease, and kidney transplantation. In addition, a lack of comprehension regarding health information due to limited health literacy or an inability to consume health information, leads to misunderstandings about their care. Poor adherence is often the result of a lack of education and is further exacerbated by structural barriers on the reservation. Perhaps the most important is basic patient education regarding health maintenance as a diabetic or while on dialysis. Without these necessary tools, patients are limited by a general lack of education and are unable to make informed choices about their care.

6.6.1 Diagnosis

In talking with dialysis patients, formally through semi-structured interviews and informally in casual conversation, it became apparent that patients lacked education about their diagnoses. According to some patients, they never received a formal diagnosis; instead they were told that they would need to start dialysis. This lack of communication regarding diagnosis does not prepare patients to make the necessary lifestyle changes to properly care for their bodies. When Walter first went to the hospital he said, “well there was no diagnosis, they drained me out, they drained it out of me.” Referring to the beginning of his dialysis treatment, he was never informed what conditions led to his kidney failure. When asked if he had diabetes, he nodded, surprised that there was a possible connection between his previously diagnosed diabetes and his end-stage renal disease. For other patients, they receive a diagnosis of end-stage renal disease, but a lack of understanding of what that *means* is the problem. When asked “do you know what dialysis is doing in your body?” Beverly responded “not really, but I’m trying to...its cleaning the poison out of my system? Cleaning the blood out of my system?” Without basic knowledge of one’s diagnosis and the mechanisms of dialysis treatment, patients are unable to make informed choices about things like diet, lifestyle, and healthcare.

6.6.2 Perceived Causes of Illness

One extremely important proximal barrier is the misconception regarding root cause of disease. Understanding what factors contribute to the development of disease is vital because it provides people with the tools to make educated lifestyle choices. With uncontrolled diabetes being one of the largest contributors to end-stage renal disease, this section will primarily focus on the perceived causes of these two diseases. While a few patients mentioned things like diet, sugar intake, pop (soda), alcohol and physical exercise as contributing factors, the vast majority of patients believed these diseases were rooted in genetics. In response to “why do you think you developed diabetes?” most patients responded with claims of heredity. John says “what I heard is that it runs in the family. Yeah. I had a brother though that got like that too...I got an aunt that was like that too. So it runs in the family I guess.” Other patients

echoed this sentiment saying “my mother had it. So did my brother. Then, I think my sister has it too, I’m quite sure. My son has it...my mother had it and now I have it. Could that, could I get it from her?” (Walter); “I think it’s hereditary” (Valerie); “It runs in the family” (JoAnne); and “Hereditary maybe. Could be, my grandfather and grandmother both had it.” (Linda)

With common beliefs that diabetes and end-stage renal disease are hereditary, many have a fatalistic perspective towards the development of disease; if a parent had diabetes, people believe that they too will get diabetes. This biological deterministic perspective provides no incentive for lifestyle change; why fight the inevitable. Despite common beliefs that the development of diabetes is the result of biological determinism, studies abound that demonstrate it is largely due to social factors like diet and exercise. Julie, a health educator emphasizes this belief making a connection to alcoholism:

yep, it’s just like that with alcoholism. Just because you have parents and family members who drink or have alcoholism problem doesn’t mean that you have to or your gonna [develop alcoholism]. That’s the same thing with diabetes. Just because you have a mom or a dad or a aunt or a uncle who have it doesn’t mean you need to get it either. Just gotta work towards it. And I think that’s where the education part comes in...then maybe it’ll stop them from saying ‘I’m gonna get it anyway.’

If patients felt some degree of agency in the future of their health, if they felt they had the power to prevent disease, they may be more inclined to make the dietary and lifestyle changes that have been shown to prevent or reduce the likelihood of developing diabetes in the future.

6.6.3 Poor Comprehension of Healthcare Information

When patients are diagnosed with end-stage renal failure and begin dialysis they should be receiving education about their diagnoses and treatments. While this doesn’t always happen as described above, in some cases patients *do* receive information but do not have the health literacy to fully understand how to maintain their health. In other instances, health information may be conveyed but patients, due to poor health, are not positioned to adequately consume this information. Linda says, “they give us literature but, I don’t know... that’s why I said if you get to have a counsellor, like, someone that actually talks to you...help with all that stuff.” Despite receiving information, she does not feel confident

that she fully understands this information, preferring to work with a person who can explain it in ways she understands. This lack of understanding became apparent for Linda when her catheter got infected. She “poured hot water on [herself] and [she] wasn’t supposed to.” In the hospital, Beverly says “nothing was ever explained to me. Wasn’t explained. That was the problem, that should have been explained to me of what’s going on, what was going to happen...if it was explained to me at the time I was very sick, so then I just don’t remember at all.” Beverly’s poor health in the hospital may have led to an inability to fully register the information being provided. Without further explanation or emphasis at a later date to ensure her comprehension, she feels as though she doesn’t fully understand what is physically wrong.

6.6.4 Adherence

For patients hoping to list with a transplant center, one aspect that is heavily considered when determining active status on the wait list is patient adherence to medications and dialysis treatment. Because of the necessity for strict medication adherence after transplantation to prevent organ rejection, diligence with treatment before transplantation is essential. According to Nadene, “it’s all connected...the more dedication you show to your dialysis, the more dedication the transplant team’s gonna see and they’ll be like ‘okay, well this patient is a very good candidate. He makes it to all his treatments, he is good with his medications. We’ll put him on the list.’” Therefore, any deviation from one’s regular dialysis schedule can negatively impact a patient’s likelihood of being listed for transplantation. While adherence is sometimes the result of personal choice, as was the case of Valerie who intentionally stopped dialysis treatment for a few months, it is often impacted by structural or institutional forces beyond the control of the patient.

Although transportation to and from dialysis is available, many patients rely on family and friends for rides to their dialysis treatments. Finding a ride allows for more flexibility and cuts down the overall time spent at the dialysis center. However, some patients have sporadic and unanticipated challenges associated with transportation. Drivers may have other responsibilities that create time pressures or patients may have car functionality issues. These issues may result in a late or missed dialysis

treatment. For Randall, his challenges lie in the institutional regulations regarding the dialysis treatment. Based on weight, blood pressure, and several other factors, dialysis staff determine how much water to take out when running the hemodialysis machine. When the dialysis staff take too much water off, Randall “starts feeling the cramps in [his body].” He says “my body just gets tense bad and my thinking goes haywire a little bit, and then I start heaving...I don’t just cramp in one place, it travels all over my body.” The extensive and painful cramping he experiences forces Randall to sometimes end his dialysis treatment early, counting against him in terms of his dialysis adherence. Regardless of whether lapses in adherence are the result of individual choice or structural and institutional factors, patients should be educated about the importance of adherence in the transplantation process so they better understand how these actions impact their likelihood of transplantation.

6.6.5 Health Maintenance

One of the most inhibiting barriers that patient’s face in accessing transplantation is education regarding basic health maintenance while on dialysis. If patients do not understand, or do not receive education about proper diet and water intake, they may be making choices that are detrimental to their health. While on dialysis, there are strict limitations regarding the consumption of certain foods. A lack of knowledge about which foods patients can or can’t eat can have catastrophic consequences which can lead to significant declines in health and in some cases, death. According to Nadene, dialysis health maintenance education is supposed to be provided by Indian Health Service, and if patient’s do not receive education there, they receive it at the dialysis center. Based on this assessment, every patient should have received some sort of education regarding dialysis; however, eight out of the nine dialysis patients interviewed claim they never received any dialysis education. Differences in these accounts may be the result of miscommunications about what constitutes education; regardless, patients do not fully understand the dietary limitations that directly impact their health.

When managing diet, many dialysis patients are faced with the challenge of balancing two diets simultaneously: a diabetic diet and a dialysis diet. JoAnne says “When you’re a diabetic on dialysis its

worse...everything is diet. And it's really a balancing act. It's a major, major issue in your life, that balancing of sugars and you have to learn it and you have to keep it in mind every time your gonna fix a meal." Understanding which foods are prohibited for which diet and why is a significant challenge for patients who do not receive adequate education about what foods they can or cannot have. Linda tries to balance diets but she didn't "even know what to eat anymore after a while. You don't have an appetite or you're just going to eat whatever." The deviations from one's normal food routine are sometimes too much for patients to handle without clear recommendations or recipes.

Balancing these two diets becomes extra difficult when patients are presented with conflicting information. Foods that are recommended for diabetic patients may be restricted on a dialysis diet. Understanding which foods they must avoid, which are good, and which can be eaten in moderation (with specific indications of quantities) is extremely important for maintaining health. Randall, wanting to follow the dialysis diet as stringently as possible, said "even the whole diet process with dialysis is really hard because there's some things that I researched that I can't have, then I research something else, it says I can have, and this one says I can't have it so its just really hard...like tomato, there's some that said I can have tomato, some that said I can't have tomato so that's confusing." Conflicting information about diet puts patients in a dangerous position; if a source says they can have a food, even if another source says they should avoid it, patients will generally consume it. Beverly had similar confusion saying:

I put myself on two special, they call it diet. Two special eating habits, I call it, is like my diabetes and my kidney, and I'm trying to watch both of them and know this is like, which way do I go? There's, 'you can't do this and you can do this. No, you can't have that, but you can have that' on different scales. So what do I do? And then I go 'I'm just gonna eat it anyway.'

Juggling two different sets of dietary restrictions creates added pressures on patients to make educated choices regarding diet. Confusion over which foods are allowed leads patients to make detrimental mistakes that can have long-term consequences on their health.

The education that patients do receive, for example a sign in the waiting room warning patients to avoid potassium, is not always presented in ways that patients can understand. Being told to avoid potassium, phosphorous and excess calcium does little to help people identify which foods they should

avoid. Lists of high potassium foods are not comprehensive, meaning patients are often left to determine, without any indication, if certain foods are okay to consume. For Linda, consuming tuna fish sent her to the hospital because of potassium levels. She says “I didn’t really take it [diet] serious ‘til somethin’ like that happened...but your heart could stop.” JoAnne emphasizes the necessity to provide information in a manner that people can understand. She says, “people round here, if you say it gets rid of the starch [talking about double boiling potatoes to leach the potassium], they understand that better than getting the potassium off because the potassium jumps on your heart and you have a heart attack.” After being on dialysis for 12 years, JoAnne makes the following disconcerting observation: “what I’ve discovered, most people I know that have died...that were on dialysis, died from heart attacks because their diet, they didn’t follow their diet well enough.” While I was unable to verify this claim, other patients and health educators on the reservation acknowledged that it was not unusual for patients to have heart attacks while on dialysis. Without basic education regarding healthcare maintenance such as appropriate diet and water intake, health risks associated with diet can cause significant health declines, delays with transplantation centers and even death.

6.7 Biological Barriers

While this research overwhelmingly supports different social factors as the root causes of kidney transplantation disparities among the Oglala Lakota people, there were two biological barriers acknowledged by participants: the presence of comorbid disease and the rarity of the human leukocyte antigen (HLA) haplotype among native populations in the United States. When addressing the issue of disparities in distribution of kidney transplantation, the United Network for Organ Sharing (the overseeing organ procurement organization in the United States) claims theirs is a ‘blind’ system that matches and allocates organs based “only [on] medical and logistical factors” (UNOS 2017). The biological barriers identified over the course of this research support these claims that certain biological characteristics put Oglala Lakota people at a disadvantage in terms of organ allocation. One biological barrier is the high rates of comorbid diseases among Oglala Lakota dialysis patients. Co-occurring

alcoholism, drug abuse, and cardiac issues such as high blood pressure or weak heart vessels are often disqualifying characteristics for patient's seeking transplantation. The presence of these comorbid diseases are often the result of the structural factors that also lead to end-stage renal disease discussed previously.

The second biological barrier is the rarity of one human leukocyte antigen haplotype present on the reservation. A match of the HLA haplotype, a genetic characteristic, provides patients the best chance of recovery after transplantation and significantly lowers risk of organ rejection. Low rates of organ donation among native populations, due to a lack of education or cultural beliefs, results in low rates of this rare HLA haplotype. Nadene says "It's not any of their faults or anything but the genetic makeup is [another barrier]...It may take a while for some [dialysis patients] to get a transplant because there is, there is a different genetic make-up in Native Americans than there is compared to others." Issues of haplotype rarity are predetermined at birth based on individual genetics; however, it does not become a barrier to transplantation until after listing for a kidney transplant when the reduced possibility of organ match significantly increases wait time.

6.8 "Just Keep Swimming"

Despite the multitude of barriers inhibiting access to transplantation on the Pine Ridge Indian Reservation, kidney transplantation is possible. By recognizing the impacts of structural barriers, organizations can work to overcome those that most impact health on the reservation. The identification of institutional barriers examines and exposes gaps in the healthcare system created by poor cross-cultural exchange in resource poor settings. Educational barriers play a significant role in the development of ill health and insufficient health maintenance while on dialysis; and lastly, biological barriers play a supporting (or degrading) role, reducing access to kidney transplantation. If these barriers are addressed, patients will be better suited to pursue transplantation, continuing to 'swim' towards a longer, healthier life.

CHAPTER SEVEN

A Mismatched System: A theoretical interpretation of collected data

As demonstrated in Chapters 4, 5, and 6, the realities of health and healthcare outcomes on the Pine Ridge Indian Reservation are tangled in a complex web of structural inequalities (poverty, geographic remoteness, economic marginalization, food access), inadequate patient education (lack of targeted and effective education, adherence, health maintenance), institutional failures (misdiagnoses, mistrust, miscommunication, delays), cultural norms (perceived heredity, faith and traditional medicine), and to a minor extent individual biology (disease comorbidity and genetic makeup). Each of the primary research areas discussed in the preceding three chapters examines in depth a specific aspect of the healthcare system from the individual's perspective. This individual structural level holds the least amount of power and is often constrained and pressured by other levels within the healthcare system. The discussions in previous chapters have served to highlight the importance in understanding the nuances of this individual level which are too often made invisible by rigid structures, regulations, and bureaucracy of the biomedical healthcare system.

While previous chapters focus on personal experience, traditional systems of knowledge and spirituality, and barriers to accessing transplantation, this chapter situates these localized phenomena within the larger healthcare system under which it operates. Using the critical medical anthropology (CMA) approach to examine this healthcare system as described by Baer and colleagues (2013) we can gain a more holistic picture of the different pressures, power dynamics, and interactions which funnel down through large scale systems to impact the individual. The structural levels identified by the CMA approach include the macrosocial, intermediate, microsocial, and individual levels. Each of these provides an additional layer of explanatory power that helps to clarify and understand the lived realities of patients.

In this chapter, each of the structural critical medical anthropology levels will be examined in relation to the healthcare system in which Oglala Lakota patients participate. These sections will be followed by a discussion regarding the mismatched nature of the hegemonic biomedical system (and its

assumptions of patients) with the real-world capabilities possessed by Oglala Lakota patients living on the Pine Ridge Indian Reservation. Lastly, I will demonstrate how the systemic pressures, assumptions and expectations of the healthcare system, paired with structural social factors creates compounding challenges that make Oglala Lakota patients structurally vulnerable.

7.1 The Macrosocial Level

Within the CMA model, the macrosocial level is the ‘largest umbrella’, encompassing broad scale systems and institutions including political and class structures, as well as the dominant biomedical system of thought and practice regarding health and healthcare. Biomedicine, widely regarded in the United States as the gold standard, treats health as a strictly biological system. Perceived to be superior because of its roots in ‘hard science’ and ‘biological fact’, current biomedical preferences in hospitals and healthcare institutions leave little room for alternative heterodox medical systems or subaltern discourses. The ignorance of biomedicine and biomedical practitioners to differing perceptions of health, illness, and wellbeing, limits its efficacy among minority or culturally different populations. In some cases, the rigidity of biomedicine further marginalizes already marginalized populations. While many Oglala Lakota patients subscribe to aspects of biomedicine, their world view is also shaped by traditional Lakota belief systems which encompass all aspects of life including health.

The macrosocial level also examines the influences of the global capitalist system which has shaped the way healthcare operates in the United States. Neoliberal values and practices adopted by the United States prioritize profit and individuality while limiting the role of the government and inhibiting social welfare. These economic policies have led to the increased privatization of the national healthcare system which limits healthcare options and, in some cases, impacts the quality of care received by patients who use governmental health insurance policies such as Medicaid and Medicare. On the Pine Ridge Indian Reservation, most people have some form of governmental health insurance. In the case of this research, every patient spoken with (including interview participants as well as patients engaged in casual conversation) received insurance through Medicare or the public tribal insurance program

(Medicaid). Because of these large-scale economic policies rooted in neoliberal ideologies, there are limited options for Oglala Lakota patients which impact quality of care and restrict patient abilities to seek out second opinions or access other healthcare institutions believed to be more effective.

Focusing specifically on the system of kidney transplantation in the United States, the United Network for Organ Sharing (UNOS) becomes the focus of the macrosocial level. Operating at the national level, UNOS has the most power in determining accessibility of kidney transplantation. Regulating everything from distribution, to qualification, UNOS sets the standards for how, when, and where organs are distributed as well as who receives them. Breaking up the country into different geographic regions based on characteristics such as population size, patients may be at a geographical disadvantage because of decreased organ availability. UNOS can also grant and revoke transplantation accreditation of healthcare institutions; this has resulted in an unequal geographic distribution of transplantation centers which further inhibits geographically remote patients from accessing transplantation services. In addition, UNOS determines the algorithm for the recipient pool that ranks patients based on factors including current health status, adherence to medications and treatments and biological characteristics (HLA haplotype, height, weight, body proportion, blood type) to name a few. Each of these factors are taken at face value without understanding the nuances that influence the circumstances of patients (including comorbidity, adherence to treatment and diet, health maintenance etc.). As the major regulatory power of organ transplantation, UNOS has created a system that primarily benefits white, urban or semi-urban, middle- and upper-class patients while limiting accessibility to minority, geographically remote, and poorer populations.

7.2 The Intermediate Level

Based on the CMA framework, the intermediate level is traditionally concerned with interactions and relationships built inside healthcare facilities including those between hospitals, clinics, and physician offices (Singer and Baer 1995). In regard to this research, the intermediate level is being adapted to examine the interactions and limitations imposed upon healthcare institutions by the larger macrosocial

level, specifically UNOS. In order to maintain the status and prestige that comes with being a transplant facility, hospitals must abide by the rigid guidelines and processes set by UNOS. These regulations limit institutional ability to modify their medical approaches to cater to minority populations. In South Dakota, many healthcare facilities work to improve access to care among American Indian populations; however, there is little wiggle room to accommodate the necessary changes to improve kidney transplantation access among these same populations.

Clinics, dialysis centers, and Indian Health Service (IHS), all located on the reservation, work with hospitals and organ procurement organizations in the surrounding area to provide appropriate healthcare to patients. Because of the geographic distribution of transplantation facilities, determined by UNOS, the dialysis centers located on Pine Ridge must coordinate with hospitals farther afield to give patients the best possible chance at transplantation. Most commonly listing patients with either Sanford or Avera, transplant centers located in Sioux Falls (approx. 5 hours away), some patients must list with hospitals even further in Omaha, NE, Denver, CO, and in some cases going so far as the Mayo Clinic in Rochester, MN. This physical distance limits patients' ability to effectively utilize the healthcare system to the detriment of their own health.

Operating under the umbrella of the macrosocial level, smaller organizations, individual hospitals, clinics, and healthcare institutions are often limited to this narrow biomedical health perception framework that alienates minority populations and alternative belief systems. These facilities are staffed by physicians who are taught within the biomedical system; their research is funded by biomedical grants; and they are blind to alternative perspectives due to the promise of 'fact' associated with biomedicine. With the ideologies and practices of biomedicine hegemonically imposed upon the entire healthcare system, institutions at the intermediate level must further perpetuate these norms. Constrained by the macrosocial level operating in the United States, individual healthcare facilities are restricted in their ability to adequately deal with cultural differences, subaltern perspectives, and alternative ways of knowing.

7.3 The Microsocial Level

The microsocial level examines interactions between people by highlighting the roles of perspective, belief, culture, and power. Most commonly characterized by the interactions and relationships between patients and physicians, the microsocial level also captures the nuances of clashing belief systems, cross-cultural miscommunication, and the influences of power dynamics on health and healthcare decision-making. Outlined in Chapter 5, culturally specific belief systems may clash with the dominant biomedical healthcare system. These differences may create tensions in the patient-physician interaction as two non-compatible health perspectives intersect. Many interview participants alluded to a general lack of understanding (and in some cases a lack of *desire* to understand) of cultural differences on the part of the physician. These differing perspectives may strain this important relationship that should be based in trust, care, and effective communication. Cultural norms on Pine Ridge shape the way patients interact with the larger healthcare system, oftentimes resulting in a delayed diagnosis. Without acknowledging these norms, physicians may perceive a general disregard for health when there isn't one, further straining this relationship.

Discussed in Chapter 6, one of the institutional barriers faced by Oglala Lakota patients is frequent miscommunication with physicians. As mentioned earlier, these miscommunications are often the result of cultural belief systems including perceptions of health, illness and wellbeing and conceptions of the body. Additionally, miscommunications may stem from a lack of acknowledgement or understanding of the structural challenges Oglala Lakota individuals face daily. From recommendations of unrealistic lifestyle changes such as healthy eating to patient blaming, the ignorance of the structural pressures and limitations imposed on reservation inhabitants highlights the clash between these two very different worlds. These miscommunications discussed above, while not corroborated through interview with physicians, were based on patient's accounts of their experiences working with primarily non-native physicians.

Particularly important to the CMA approach is the examination of power differentials between patients and physicians. Ongoing and historical discrimination against American Indian individuals may cause a general mistrust of the primarily white physicians. The immense education, wealth, and prestige associated with doctors in the United States may further fuel feelings of inferiority among patients. In an ideal situation, patient and physician share power with the patient's voice and concerns heard and considered in the treatment plan. However, in instances of significant power differential, Oglala Lakota patients may feel a lack of agency or trust and/or feel uncomfortable vocalizing questions or concerns about their health.

7.4 The Individual Level

Lastly the individual level gives voice to the lived experiences of people in relation to their health and healthcare. In a system where patients are reduced to numbers and statistics, the personal experiences, thoughts, sufferings, and successes of patients become invisible. This research primarily works to elucidate these individual level experiences and demonstrate their importance in understanding how a multitude of factors impact and influence individual health on Pine Ridge. This individual level is the primary focus of Chapters 4, 5, and 6 and will therefore not be discussed in detail here.

Patient perceptions of health, their experiences on dialysis, the limitations of a dialysis lifestyle, and the emotional responses to such rigorous treatment are discussed at length in Chapter 4. Individual systems of belief, specifically traditional Lakota belief systems and Christianity, are discussed in Chapter 5 to demonstrate how differing perspectives shape individual ideas about the body and influence individual decision-making regarding health and wellbeing. Chapter 6 highlights specific barriers imposed on individuals to limit access to transplantation by examining the relationships between structural, institutional, educational, and biological factors that limit agency, constrain decision making, and shape livelihoods.

7.5 A Mismatched System

Examining the transplant system in the United States, it becomes clear that the experiences and challenges faced by dialysis patients are directly related to and impacted by the larger structural levels previously discussed. Within the transplant system, the macrosocial level is largely represented by UNOS, the organization that imposes the most regulation. This is only reinforced by smaller scale healthcare institutions such as transplant centers, hospitals, and clinics that must adhere to the larger policies and pressures set by UNOS. Cultural differences, power differentials, and miscommunications further complicate patient experience with the transplant system; however, the experiences of patients within this system varies greatly depending on factors such as cultural background, skin color, geographic location, and wealth. The transplant system that operates in the United States, despite claims of ‘colorblindness’ functions to better serve some populations at the expense of other populations. Those communities that most benefit from the current transplant system are middle- to upper-class, middle aged (35-64), live in urban or semi urban areas, and are predominately white (Caucasian) (Cao et al. 2016; US Department of Health and Human Services 2019).

While disparities in access to kidney transplantation between populations is not the specific focus of this research, the assumptions made by the transplant system provides some clarity as to how and why certain populations may be better able to utilize and participate in this healthcare system. At each of the macrosocial, intermediate, and microsocial levels a series of assumptions are made regarding patient capabilities. These assumptions highlight the ideal situations for patients, demonstrating how the system *should* work; but unfortunately, these assumptions are not compatible with the real-world capabilities exhibited by patients on Pine Ridge. The transplantation process, including proximal steps (those that occur at early stages of disease development) as well as distal steps (those that occur towards the later end of surgical transplantation- see Chapter 6) is altogether incompatible with the lives and lifestyles of Oglala Lakota patients. The steps towards transplantation and the corresponding assumptions made along the way have been compiled from interview data, conversations with dialysis patients and healthcare staff,

literature review and notable institutions such as Johns Hopkins Medical Center (Johns Hopkins 2019), the Mayo Clinic (Mayo Clinic 2019), the non-profit National Kidney Foundation (National Kidney Foundation 2019), and DaVita Inc. one of the largest public dialysis providers in the United States (DaVita 2019).

When comparing the transplantation process using the assumptions made by healthcare institutions and medical professionals, there is a stark contrast to how the system *actually* operates in terms of patients on Pine Ridge. Figure 4 outlines these two contrasting models which I have called the Healthcare System Assumptions Model and the Lakota Mismatched Model. Each of the numbered steps within the Healthcare System Assumptions Model (in blue) demonstrates the ideal progression for disease identification, treatment, health maintenance and transplantation. The Lakota Mismatched Model (in red), highlights the incongruities of Oglala Lakota patient capabilities demonstrating that assumptions made by the system are not applicable to this population. The incompatibility of these two systems results in delayed diagnoses, miscommunications, poor health maintenance, extended wait times on the cadaver transplant list, and overall decreased health outcomes.

Included in Figure 4 are 10 primary assumptions made by the transplant healthcare system. These assumptions are made at each of the larger CMA stages, all of which impact individual health. Assumptions about beliefs in biomedicine (macrosocial level) alienate patients that subscribe to alternative world views and differing conceptions of health, the body, illness and wellbeing. Compliance to the rigid monitoring and frequent medical tests and procedures while on the wait list (intermediate level) is difficult for the Oglala Lakota who often have transportation challenges. Mistrust in physicians, miscommunications, and inadequate patient education, strain patient-physician relationships (microsocial level) and create additional challenges in accessing appropriate and effective care. For a full list of primary assumptions and their corresponding realities on Pine Ridge see Figure 4.



Figure 4. Mismatched Systems Model

7.6 Structural Vulnerability

Complementing the critical medical anthropology multi-scaled framework, the theoretical concept of structural vulnerability draws on political economy, social inequality, and historical context to explain individual health outcomes. While the CMA approach focuses on differing levels of interaction and influence on patients in the healthcare system, structural vulnerability uses individual position within a broader structural context to explain conditions of human health and subsequent health outcomes. Conceptualized as a variation of structural violence (Galtung 1975), anthropologists James Quesada, Laurie Hart, and Phillippe Bourgois use the concept of structural vulnerability to encompass the cultural and “idiosyncratic” factors that contribute to individual health (Quesada et al. 2011). Using a structural vulnerability approach for this research has allowed for the identification of “clinically invisible” barriers that limit access to healthcare and result in the development of poor health. The culmination of simultaneous and compounding structural factors enacting pressures upon patients on the reservation lead to limitations to agency, healthcare access and patient wellbeing.

The overlap of structural, institutional, educational, and biological factors (discussed in Chapter 6 and highlighted in Figure 3), lead to a multitude of barriers that limit patient capabilities and inhibit access to kidney transplantation. Each layer, representing a different category of barrier, limits patients in a different way. As the layers accumulate, each additional factor magnifies the barriers of the layers below. Therefore, patients who experience barriers from multiple layers face exponentially greater challenges. The intersection of many health access barriers that occur on Pine Ridge (as discussed in previous chapters) creates a perpetually vulnerable population resulting in poor healthcare access and detrimental health outcomes.

CHAPTER EIGHT

Conclusion

This research began as a means of elucidating the lived realities and challenges of dialysis patients on the Pine Ridge Indian Reservation as they obtain treatment, find support, and attempt access to kidney transplantation. Drawing on ethnographic research methods, three primary areas of research- dialysis patient experience, systems of belief and support, and barriers to accessing kidney transplantation- provide a more comprehensive view of the complexities that surround this population and work to explain the comparatively low rates of kidney transplantation among Oglala Lakota patients. The complicated interplay between cultural norms, belief systems, systemic factors, and historical legacies creates a unique amalgamation of pressures that function together to create a structurally vulnerable population that falls under the umbrella of our dominant biomedical healthcare system.

8.1 Discussion

As discussed in Chapter 4, dialysis patients on the Pine Ridge Indian Reservation often feel as if they are marginalized from healthcare discussions and initiatives because their health is “too far gone” and they suffer from a “chronic and terminal” illness. Therefore, this research provided an outlet for dialysis patients to tell their stories and share their experiences. All patients interviewed as a part of this research fell into one of two categories when expressing sentiment about dialysis treatment: grateful or resentful. Those who are grateful for dialysis acknowledge the difficulties associated with this treatment plan but are appreciative of the health benefit the treatment confers, specifically that it is keeping them alive. Those who have a negative perspective of dialysis acknowledge the benefits of treatment but are annoyed by the challenges and limitations it imposes. Patients’ emotional responses to dialysis often correspond to the number of years on dialysis treatment; recently diagnosed patients often experience denial and disbelief which then turns into anger and fear as they begin to process their new realities. After some time on dialysis many patients experience some form of resignation or depression as they come to

terms with their diagnosis and acknowledge that this new life is forever. Looking back on their diagnoses, experiences with doctors, and the beginning of their treatment, many patients feel as if they had been neglected by the healthcare system which contributed to their current poor health circumstances.

The physical, spiritual, and emotional challenges that come with dialysis treatment create a strong need for systems of support. Discussed in Chapter 5 are two primary belief systems, traditional Lakota belief systems and Christianity, that provide support to patients while also influencing healthcare decision making. Understanding the roles of belief systems regarding health helps to illuminate where patients gain strength and explain why certain healthcare decisions are being made. The role of one's *tiospaye*, the Lakota word for extended family, bridges the gap between these two dominant belief systems and highlights the importance of family, friends, and community regardless of the belief system to which one belongs.

The focus of Chapter 6 is the identification of specific barriers that inhibit patient ability to access kidney transplantation as a treatment for end-stage renal disease. While other studies highlight factors such as financial stability, geographic remoteness, and access to transportation as primary challenges, the focus on these distal barriers ignores the multitude of proximal barriers that more effectively bar patients from receiving transplantation. Structural, institutional, educational, and biological factors pressure patients throughout their lives, playing a large role in the development and persistence of poor health on the Pine Ridge Indian Reservation. Further limiting patients is the limited access to live donor transplantation due to poor family member health, traditional conceptions of the body, and hesitations in “asking” for such a magnanimous favor. Identifying and working to mediate these proximal barriers provides the greatest possibility for improvements to health and healthcare access.

Chapter 7 situates the individual experiences of Oglala Lakota patients within the larger healthcare system. Using a critical medical anthropology approach, the different levels of this healthcare system are analyzed to demonstrate the disadvantages the Oglala Lakota population faces within this structure. The largest macrosocial level describes the overarching influences of biomedicine and the power of UNOS in determining system-wide regulation. The intermediate level examines the constraints

enacted on healthcare facilities, institutions, and clinics by the macrosocial level to the detriment of minority populations. At the microsocial level the focus is on the patient-physician relationship which is characterized by cross-cultural miscommunications and unequal power dynamics, both of which degrade the effectiveness of this relationship. Lastly the individual level provides intimate detail about patient experience, perceptions of health, and the role of belief systems in determining healthcare seeking behaviors.

The ways in which barriers and challenges overlap and influence patients on Pine Ridge create a structurally vulnerable population. These compounding barriers inhibit individual agency and limit patient capabilities. With different categories of barriers influencing patients at different times and in different areas of life, all combine to contribute to the lived realities of poor health on the Pine Ridge Indian Reservation.

8.2 Research Limitations

While rich in scope, collected data, and results, this research has some limitations which must be addressed. First is the sample size. With 12 participants this sample is not fully representative of the dialysis patient population. A larger sample size would have provided more stories and information that may add further detail and nuance to this research. Additionally, the sample collected may not be representative of the full spectrum of patient ideologies; those interested in participation may be more open to the idea of transplantation and therefore not representative of the dialysis community. The original conception of this research project included interviews with healthcare professionals at transplant facilities, organ procurement organizations and at UNOS. These additional interviews would provide a more comprehensive picture of the healthcare system and provide differing perspectives on the functionality and efficacy of the system. Additionally, these types of interviews may further highlight additional barriers at the institutional levels that are not readily apparent to individual participants on the reservation. Despite these limitations, this research has illuminated several areas in which gaps can be filled to improve patient health outcomes and access to kidney transplantation.

8.3 Recommendations

Many of the barriers to transplantation discussed in Chapter 6 are structural in nature and therefore will need comprehensive systematic changes to be addressed. However, there are several barriers that are smaller in scale which can be mediated through minor changes and small-scale initiatives on the Pine Ridge Indian Reservation. Now that these barriers have been identified, steps can be taken to bridge these gaps improving health outcomes and healthcare access on the reservation. The following four recommendations have been devised based on collected data and participant observation with additional input from study participants.

1. Increased breadth and depth of patient education at dialysis facilities

In conversations with patients, there were inconsistencies about where diagnostic, health maintenance, and basic health information comes from. Some patients and healthcare staff claimed that Indian Health Service was responsible for patient education regarding dialysis, while others claimed that education should be received in the dialysis centers. These differing accounts lead to confusion about what information has or has not been communicated. While all patients receive education at the dialysis centers, there may be an assumption that necessary information (regarding diagnosis, root causes, and health maintenance) has been communicated elsewhere and would therefore be redundant. In some cases, this information may have been communicated previously but at a point where the patient, due to health issues, was unable to adequately consume healthcare information. Adding a recurring education program for dialysis patients at the dialysis centers would make it possible to address those educational gaps discussed in Chapter 6. Instead of assuming previous education, the dialysis centers could increase the breadth of their educational programs to encompass the types of healthcare information that should be communicated by physicians and Indian Health Service. Whether patients have previously received this type of education or not, patients expressed an interest in having this type of information reiterated or reexplained by someone at the dialysis centers; by someone they trust, who understands local challenges, and has worked to get to

know them on a personal basis. Expanding the education program to improve understandings of patient health conditions as well as providing education about mental, and spiritual wellbeing may greatly improve health management and lead to improved health outcomes on the reservation.

2. Inclusion of dialysis education in diabetes education programs

In conducting interviews, two participants emphasized misconceptions about dialysis commonly held by diabetic patients and the general population on Pine Ridge. JoAnne says, “there’s two types of people, people will say ‘oh my god you’re dying you’re on dialysis’ and other people say, ‘oh I could just get on dialysis’”. Both of these patient “types” perpetuate fallacies about dialysis. Those who think patients are dying because they are on dialysis further isolate dialysis patients. This view works under the assumption that dialysis patients are all suffering from terrible health and close to dying when patients can lead relatively healthy lives for an extended period of time. The second perspective takes a blasé approach to dialysis, simply viewing it as the next step in treatment if lifestyle changes aren’t made by diabetic patients. This too is not an accurate view of dialysis; most patients are not fully aware of the necessary lifestyle changes, limitations, and daily challenges associated with dialysis treatment. While dialysis exists as a later step in the treatment process if necessary, it should not be something one willingly falls back on. Instead emphasis on appropriate health management of diabetes, regulation of high blood pressure, and cardiovascular disease can prevent the development of end-stage renal disease and the start of dialysis treatment. Accurate education about the realities of dialysis treatment to diabetic patients or others as part of health education programs can help to inform about the realities of dialysis and may instigate lifestyle changes among diabetic (and other) patients.

3. Increased focus on diet education as part of dialysis health maintenance

As part of standard dialysis patient education and continuous education as suggested above, there should be an increased focus on diet education. Discussed in Chapter 6, there is significant confusion

among dialysis patients about what foods patients can or cannot eat. Both dialysis centers included in this research provide information to patients about which foods to avoid. This type of patient outreach and education should be expanded and clarified to prevent confusion and dietary ‘mistakes’ that are costly in terms of health maintenance. At the very least, patients should be provided with a reference list of foods with columns as follows: Never eat, Can eat, Sometimes in moderation (with specific quantities and frequency). The ‘never eat’ column would include foods that patients should strictly avoid such as those high in potassium and phosphorous. The ‘can eat’ column highlights common and popular foods that are healthy for patients to consume. The final column, ‘sometimes in moderation’ specifies which foods can occasionally be eaten with specific quantities and frequencies listed to provide guidance for patients about how to safely consume foods in this category. In addition to a basic list provided to dialysis patients, there should be additional lists for dialysis patients who are also diabetic as that further limits which foods patients are able to consume. Paired with this reference list, patients would also benefit from suggested meal plans and recipes which can be adapted on an individual basis as part of continuous patient education. This would help patients with the transition to a limited diet while also help to clarify healthy food options in order to maintain health while on dialysis. Examples of content and format of patient food reference list can be found in Appendix III (D’Alessandro et al. 2015)

4. Cyclical education and prevention initiative

Current education and prevention initiatives operating on Pine Ridge have a linear trajectory. The goals of these programs are to provide education to youth on the reservation so they can make healthy lifestyle choices and influence those around them to make similar choices. Separate initiatives focus on diabetes education and prevention among pre-diabetic and diabetic patients. Figure 5 shows the linear progression of poor health from childhood to the development of end-stage renal disease highlighting the education and prevention initiatives enacted at earlier stages. As discussed in Chapter 4 and visually represented in Figure 5, dialysis patients feel isolated from ongoing education

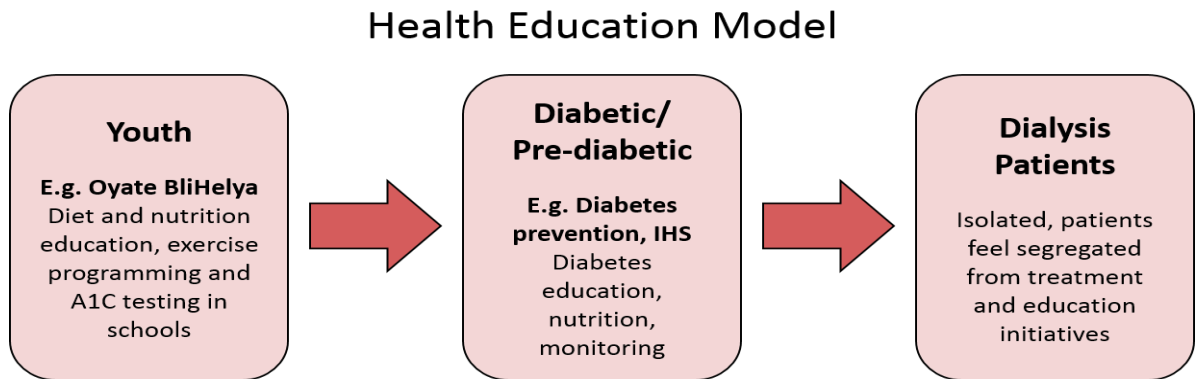


Figure 5. Current Health Education Model

initiatives because of their diagnoses of *end-stage* renal disease. In contrast to this linear model, I recommend the implementation of what I am calling a cyclical education and prevention initiative that draws on the knowledge, experiences, and recommendations of current dialysis patients to educate youth, diabetic, and pre-diabetic patients (Figure 6). The cyclical nature of this education and

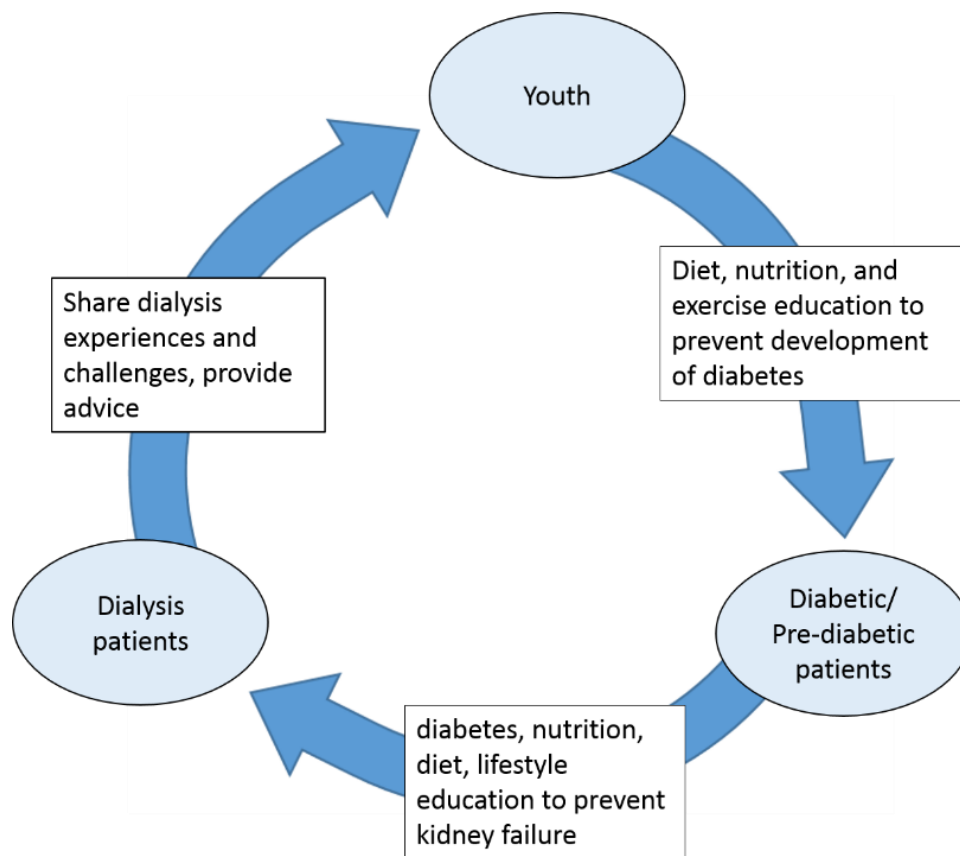


Figure 6. Cyclical Education and Prevention Model.

prevention initiative embodies the cultural significance of the circle, symbolic imagery found in the medicine wheel, the shape of the *inti*, and the conceptually cyclical nature of time. This cycle, instead of marginalizing and isolating as occurs with a linear model, is instead uniting. This model has the potential to be immensely impactful in terms of education and prevention, but also reinforces community and systems of support on the reservation. The reintegration of dialysis patients into social circles also has the potential to bolster individual agency. Encouragement and support from one's *tiospaye* may empower patients to ask questions and demand the right to improved care, access, and treatment.

5. Changes to institutional definitions of “adherence” definitions

On an organizational level, there are a number of changes that should be made to improve access to kidney transplantation. The first is a change to UNOS definitions of adherence. Assumptions that are made by large scale healthcare institutions often do not account for the extreme variability in patient capabilities both on the Pine Ridge Indian Reservation and across the country. Perceived lack of adherence is often caused by external structural pressures that have little to do with patient desires to adhere to treatment. Therefore, maintaining a singular definition of what constitutes adherence puts patients lacking in capabilities in a further disadvantaged position regarding access to transplantation. I suggest that adherence be determined by a social worker or physician who can better speak to a patient's *actual* adherence instead of making adherence assumptions based on proxy characteristics.

8.4 Areas for Future Research

This research is a novel attempt to provide voice to dialysis patients on the Pine Ridge Indian Reservation while simultaneously attempting to expose the myriad barriers that inhibit this population from accessing adequate and effective healthcare. Additional studies should be conducted to expand on these results both on Pine Ridge and among other native communities in the United States and elsewhere. While this research has uncovered key issues of access and patient experience, it is important to note that

these results are location specific and unique to Pine Ridge. Other native communities in the United States and elsewhere may face similar challenges (and therefore this research can be used as a starting point); however the cultural backgrounds, geographic locations, histories, and circumstances of other groups mean each should be looked at as a unique and separate entity that has unique experiences and faces unique challenges. Of specific importance are issues of access to healthcare faced by native communities across the United States. Low rates of kidney transplantation and correspondingly high rates of diabetes and kidney disease among American Indian populations means that the phenomena examined here can and should be replicated elsewhere. These future studies may provide the necessary information to take steps towards health and equity in healthcare access among native populations.

Additional research should also be conducted on Pine Ridge to expand these results and further explore different aspects of the healthcare system. One area of importance is the patient-physician relationship. Future studies may specifically examine this relationship, beyond the limitations of dialysis and diabetic patients, to understand the role of power dynamics and how that impacts patient health. As part of this future research, the perspective of physicians should be included to understand how healthcare professionals (including doctors and nurses) perceive their relationships with patients.

The results of this research have utility beyond this particular population. The assumptions model discussed in Chapter 7 (Figure 4) and the lack of capabilities exhibited by Oglala Lakota realities provides a clear demonstration of the mismatch that exists between this specific population and the larger healthcare system. Future research should examine the assumptions that are made regarding other diagnoses or healthcare needs and compare those with the realities of any given population. This approach identifies gaps in care and access and demonstrates the incongruities between the patient and healthcare systems which lead to poor health outcomes.

8.5 Concluding Statement

The morning of July 2 I left the house with a pair of scissors and a small canvas bag and walked down the drive toward Mouse Creek, a short mile away from the Wounded Knee Massacre site. I

followed the dirt road, jumping to avoid the shallow puddles which dotted the driveway. About a quarter-mile from the house I climbed up the hillside into a lush patch of sage, shimmering silvery green in the early morning light. I slowly and methodically began collecting the sage; cut the stem, gently shake it out, and place it in my bag. Thinking back on my time spent on Pine Ridge thus far, I was surprised to find my thoughts wandering, not to the topic of my research which had consumed all space in my mind for the last month, but instead to the small everyday moments that make this place special...

Stopping by a house where a group of men and women, strangers to me, were sitting outside. They welcomed me into their conversation and in no time the oldest of the men, wearing a veteran's hat, brought out a guitar and began to play. He began by simply strumming, providing a soft ambiance to our conversations. Then he broke into song, switching back and forth between Lakota and English without realizing, asking us to sing along if we knew the words. At one point, the musician began playing taps singing "Day is done, gone the sun. From the lakes, from the hills, from the sky. All is well, safely rest, God is nigh". One of the other men in our small circle stood up, and with tears in his eyes did a soldier's salute before sitting back down to join our collective silence.

Visiting with an 88 year-old woman living near Dry Wood whose strength, resilience, and zest for life is inspiring. Living a life of contradiction, she is surrounded by trash collected by her late husband in the most beautiful location, in view of both the Badlands bluffs and the White River; a small, frail woman, she chops her own wood, regularly fixes her generator, and cares for her ill nephew.

Sharing a meal after an *inipi* ceremony, the full moon glowing above surrounded by brilliantly bright stars that blanket the midnight sky. Steam rising from our bodies as we cooled ourselves in the crisp night air. Bowls of stew in hand, we sat around the fire laughing, talking, and listening. Slowly the group shrunk as people said their goodbyes giving hugs and handshakes to everyone in attendance.

Saying hello to new friends and acquaintances at the grocery store and in line at Common Cents; hiking through the Badlands learning about different plants and their many uses; sitting in the shade on a blisteringly hot day sharing conversations with research participants; learning new things about Pine Ridge; learning new things about myself.

... With my small bag full, I headed back to the house stopping once to flick a rogue spider off my leg. At the house, I sat in the shade of the back porch; despite the early hour, the day was already sweltering. Picking stalks out of my bag and shaping them into a neat bundle, I carefully wrap them in cream colored yarn and set them aside. Each bundle a gift for those who shared their experiences, provided support, opened their homes, and helped me throughout my research. Each bundle expressing my love and gratitude of this place, this culture, and most importantly these people. Each bundle a thank-you for letting me tell their stories.

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APPENDIX I

Patient Interview Protocol

Gender?

Age?

Are you married?

Do you have children?

What is your highest level of education completed?

Are you employed?

What is your income status?

What religious beliefs do you hold, and/or what religious organizations are you affiliated with?

How long have you lived on Pine Ridge?

What do you believe led to the development of your health condition and need to be on dialysis?

What could have been done, if anything, to prevent the development of your health condition?

How long have you been on dialysis? How many times a week do you have dialysis and for how long?

Tell me a bit about your experience on dialysis.

How do you feel physically on dialysis?

How does your current condition impact your lifestyle?

Do you have health insurance?

If yes, what health insurance do you have?

If no, do you pay for your health care yourself?

Have you found acquiring dialysis to be an easy or difficult process? Please explain.

Have you ever spoken with your doctor or another health care professional about the possibility of a kidney transplant as a treatment option?

Why or why not?

When?

Are you currently (or have ever been) on the UNOS (United Network for Organ Sharing) waiting list for a kidney transplant?

What influenced your decision?

If yes, which transplant center(s) did you list with?

If the opportunity became available, would you receive a kidney transplant as a means of treating your kidney failure?

Tell me a bit about your views on kidney donation or transplantation.

According to Oglala Lakota cultural knowledge, do you think it is acceptable for Oglala Lakota people to receive a kidney from another person?

Would it matter to you whether the person who may donate their kidney to you is living or deceased?

Has anyone discussed with your family members the possibility of donating one of their kidneys to you while they are alive?

If yes:

How do you feel about this?

How have your family members responded to this suggestion?

Do you believe your views on organ donation are common here on Pine Ridge? Do others share your opinions regarding organ donation?

Do you have family members who are also on dialysis?

If yes:

How many?

Does having family members who are also on dialysis influence your decision to undergo kidney transplantation?

What do you think are the barriers preventing Oglala Lakota members on the Pine Ridge Indian Reservation from getting a kidney transplant?

What do you believe is the first step in overcoming the barrier(s) you previously mentioned?

Do you know of anyone living on Pine Ridge who has received a kidney transplant?

Do you know of anyone who has had a kidney transplant or is currently on dialysis that may be willing to participate in an interview with me?

If yes, will you pass on my information and have them contact me if they are interested?

Health Educator Interview Protocol

Gender?

Age?

What is your profession?

How long have you been working in this profession?

What kind of institution do you work in, and is it located on the reservation?

How long have you been working with/educating patients with diabetes or on dialysis?

How long have you been working with/educating Oglala Lakota patients with diabetes or on dialysis?

When diagnosed with ESRD, what are patients' treatment options?

Which of these treatment options has better long-term outcomes?

At what point does a physician begin to discuss kidney transplantation as a treatment option with their patient?

What are the advantages and disadvantages of remaining on dialysis long term?

What are the advantages and disadvantages of kidney transplantation?

If an educator on the reservation, have you ever worked with an individual who has received a kidney transplant?

What is the norm here on the reservation regarding treatment for ESRD?

What specific challenges (if any) do you believe American Indian, specifically Oglala Lakota of the Pine Ridge Indian Reservation, individuals face regarding organ transplantation that other ethnic groups do not encounter?

What do you believe are the barriers which prevent American Indian, Oglala Lakota of Pine Ridge specifically, individuals from receiving a kidney transplant?

What do you believe is the first step in overcoming the barrier(s) you previously mentioned?

Have any of your Oglala Lakota patients/students received a kidney transplant?

If yes:

Do you know the current health status of these individuals?

Do you know if these individuals faced any health or economic difficulties following their kidney transplants?

Do you face any difficulties in providing health care to patients who need dialysis or a kidney transplant?

If yes, please explain.

Are there any patients/students who have received a kidney transplant or are currently on dialysis who may be willing to participate in an interview with me?

If yes, will you pass on my information and have them contact me if they are interested in participating?

Study Summary

This research will explore the political, economic, and historical context in which the Oglala Lakota of Pine Ridge are currently situated in relation to their health and access to health care options on and off the reservation. Despite having the highest prevalence of End-Stage Renal Disease (ESRD), in the US American Indian populations have the lowest rates of kidney transplantation.

I plan to identify through semi-structured interviews cultural beliefs, opinions, and norms about kidney transplantation on the Pine Ridge Reservation. I intend to examine, within the broader political, economic, and cultural context whether or not Oglala Lakota patients currently on dialysis are choosing to enlist with the United Network for Organ Sharing (UNOS) to receive a kidney transplant and why. Lastly, this research will attempt to uncover barriers faced by patients in accessing kidney transplantation and work to minimize or reduce barriers in accessing this potentially life-saving treatment if desired.

Contact Information

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If you have any questions about your rights as a volunteer in this research contact the Colorado State University Institutional Review Board Coordinator

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Exploring Political Economic Barriers and Cultural Norms

Surrounding

Kidney Transplantation on the Pine Ridge Indian Reservation

Julia Reedy
Co-Principal Investigator
Masters Student, Anthropology
Colorado State University

Eligibility

You are eligible to participate in this study if you fit one of the following criteria: you are currently a patient on dialysis or have previously received a kidney transplant as a means of treating end-stage kidney disease. Participation for this study is completely voluntary.



What will you be asked to do?

For this study, you will be asked a series of open-ended questions which will ask you to describe your experiences with and attitudes towards diabetes, dialysis, end-stage kidney disease, and kidney transplantation. In addition, you will be asked about cultural beliefs, opinions, and norms commonly held regarding kidney transplantation among the Oglala Lakota. Lastly, you will be asked about challenges which may exist which make it difficult for Oglala Lakota individuals living on the Pine Ridge Indian Reservation to get a kidney transplant.



Where and when will interviews take place?

Interviews will occur in a location chosen by you, the participant. Interviews are estimated to last between 1-2 hours. However, depending on the length of responses- indicated by the participant- the interviews may last longer.



Confidentiality

This study is confidential. We will assign a code (e.g. Participant 01) to each participant so the only place your name will appear in our records is on the consent form and in our data spreadsheet. The research team will be the only individuals with access to this information.

The only exceptions to this are if we are asked to share the research files for audit purposes with the CSU Institutional Review Board ethics committee, if necessary. When writing about the results of this study, pseudonyms will be used in place of your name and no identifying information will be included in the products of this research.



What are the goals of this study?

This study has the potential to benefit the Lakota community. By identifying difficulties in access to kidney transplantation and health care services more broadly, we can work break down these barriers. Based on the results of this research, I will provide targeted suggestions for non-profit organizations, IHS and the Tribal Government regarding possible means of reducing challenges in obtaining health care and kidney transplantation.



What else should you know?

- Audio recordings will be requested when conducting interviews upon consent from participants. Only researchers will have access to the audiotapes and they will be erased once they have been transcribed.
- Your participation in this research is completely voluntary. You have the option of withdrawing your consent and stopping participation at any time!
- Participants may be asked to pass on research information to other individuals who may fit research criteria. This of course is optional!

APPENDIX III

D'Alessandro, Claudia, Giorgina Piccoli, Adamasco Cupisti. 2015. "The 'phosphorous pyriamid': a visual tool for dietary phosphate management in dialysis and CKD patients." *BMC Nephrology* 16(9)

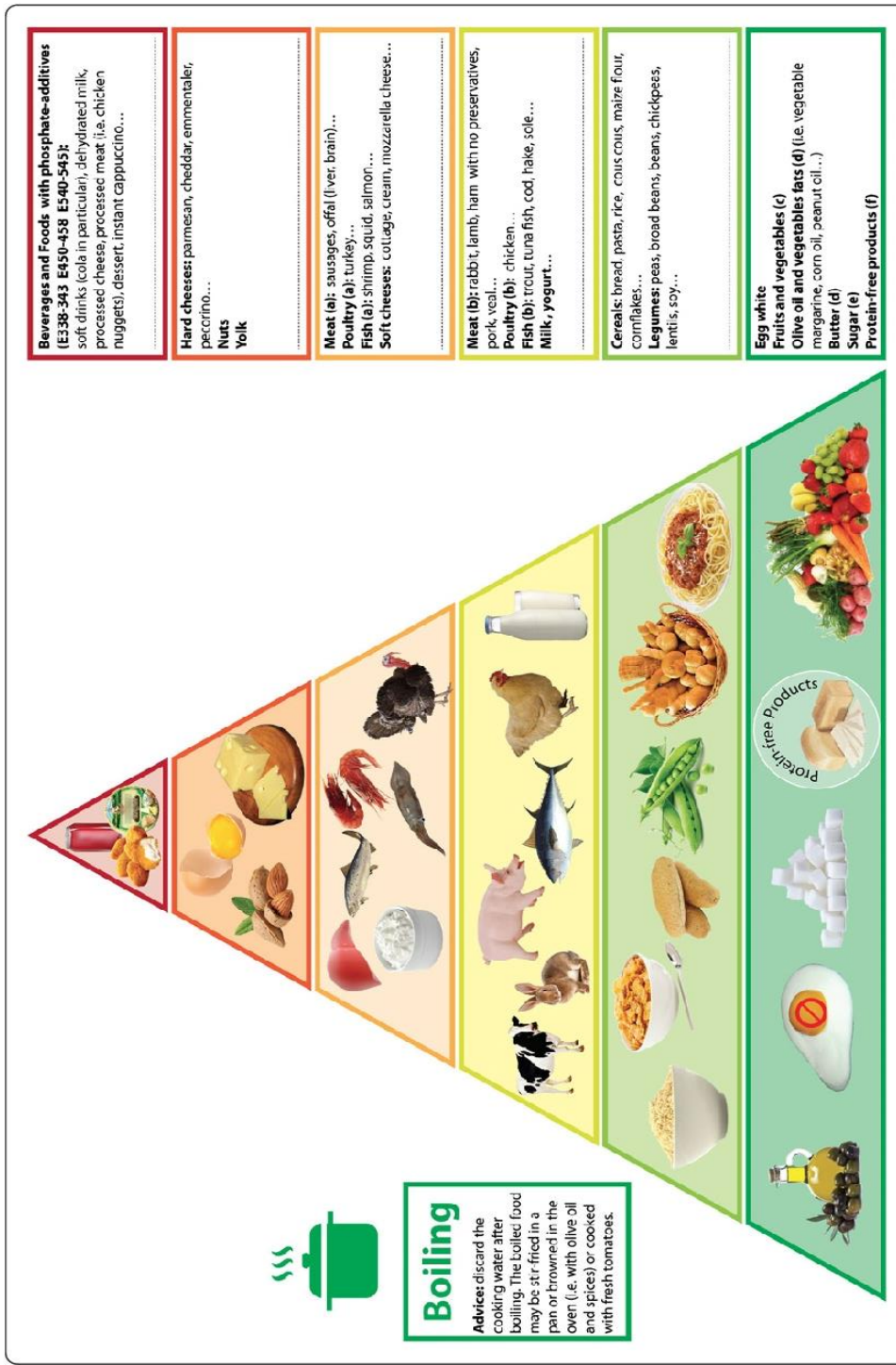


Figure 7. The phosphorus pyramid. Foods are distributed on six levels on the basis of their phosphorus content, phosphorus to protein ratio and phosphorus bioavailability. Each level has a colored edge (from green to red, through yellow and orange) that corresponds to recommended consumption frequency, which is the highest at the base (unrestricted intake) and the lowest at the top (avoid as much as possible). a) foods with unfavorable phosphorus to protein ratio (>12 mg/g); b) foods with favorable phosphorus to protein ratio (<12 mg/g); c) fruits and vegetables must be used with caution in dialysis patients to avoid excessive potassium load; d) Fats must be limited in overweight/obese patients, to avoid excessive energy intake; e) sugar must be avoided in diabetic or obese patients; f) protein-free products are dedicated to patients not on dialysis therapy and who need protein restriction but a high energy intake.