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Anitra M. Warrior

University of Nebraska-Lincoln, anitrawarrior@yahoo.com

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THE EMOTIONAL EXPERIENCE OF AMERICAN INDIANS RECEIVING
HEMODIALYSIS AND HOW IT RELATES TO TREATMENT ADHERENCE

by

Anitra M. Warrior

A DISSERTATION

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THE EMOTIONAL EXPERIENCE OF AMERICAN INDIANS RECEIVING HEMODIALYSIS AND HOW IT RELATES TO TREATMENT ADHERENCE

Anitra M. Warrior, Ph.D.

University of Nebraska, 2015

Advisor: Michael J. Scheel

This study used a phenomenological approach as an attempt to capture the essence of the experience of American Indians with diabetes who are receiving dialysis. The purpose of this study and this approach was to develop an understanding of factors that influence treatment adherence, specifically with mental health concerns. As an additional component of this study, this research also followed an advocacy/participatory approach (Creswell, 2007) in which steps to reform services are provided to the Indian Health Service in support of this marginalized group through a written Agenda for Change.

Participants for this study were recruited from multiple states serving American Indians through the Indian Health Service. These sites were specifically located within the states of Oklahoma, Kansas, Iowa, Nebraska and South Dakota. Fliers were posted at dialysis clinics, post offices, general stores and community centers in which there were high American Indian populations. Participants initiated contact and were screened for meeting criteria to participate in the study. Once the participants were identified as meeting criteria for participation, an interview was scheduled at a convenient location chosen by the participant. This particular approach as described by Moustakas (1994) requires a minimum of three participants. In an effort to obtain a

representative sample, the goal was to obtain 10 participants. After three months with fliers posted in multiple locations, the recruitment concluded with six participants (three women and three men). Participants were compensated with a \$20.00 visa gift card upon completion of the interview. Member-checking took place by reviewing the findings with participants therefore, assuring the analyses and interpretations were accurately described. Additionally, the Agenda for Change also needed to accurately reflect the challenges faced by the participants and appropriately provide suggestions for assisting dialysis patients with adherence to the treatment regimen. The experience described by the participants was utilized to recommend a change in processes for dialysis patients in an effort to assist with acceptance for individuals and families as they adjust to the lifetime commitment and changes required by dialysis treatments.

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CHAPTER 1

Introduction

This chapter serves as an introduction to the phenomenological study of how the emotional experience of dialysis is related to treatment adherence for American Indians. To enhance the understanding of this experience and how it is to be studied, this chapter will begin by highlighting the gap in the literature and then follow with a brief discussion of the American Indian population and the disparities faced in health care. The chapter then includes the purpose of this research and the proposed research questions. The chapter closes with a description of the significance of the study and the structure of the proposal.

Background and Proposed Study

Research on diabetes and mental well-being of American Indians is limited; no studies have been conducted that focus on mental health in American Indians receiving dialysis treatment due to complications of diabetes. Additionally, no research has been conducted on treatment adherence of American Indians receiving dialysis treatments due to complications of diabetes. This gap in the literature suggests the need for research to promote deeper understanding of this critical area of need for American Indians. To address the topic of dialysis treatment and diabetes in American Indians, a transcendental phenomenological (Moustakas, 1994) study was implemented to capture the essence of the experience of chronic dialysis treatment and how mental well-being affects treatment adherence within the context of American Indian culture. This study used an advocacy/participatory approach (Creswell, 2007) with the goal of formulating steps for action to promote treatment adherence, acceptance and overall well-being.

Within the United States, approximately 562 federally are recognized Native American Entities (Whitbeck, McMorris, Hoyt, Stubben, LaFromboise, 2002; Bureau of Indian Affairs, 1991) and over 365 state-recognized groups are in existence (Whitbeck, McMorris, Hoyt, Stubben, LaFromboise; Manson & Trimble, 1982). According to the 2000 United States Bureau of the Census, more than 2.4 million Native Americans live in the United States (United States Bureau of the Census, 2000) and as of 2010, 2.5 million reported themselves as Native American or Alaska Native alone (United States Census Bureau, 2012). Additionally, 5.2 million people reported Native American ancestry alone and/or in combination with another race.

A tremendous amount of diversity is present across tribal groups. Individuals within these groups speak at least 200 traditional languages (Whitbeck, McMorris, Hoyt, Stubben, 2002; Fleming, 1992). According to Duran and Duran (1995) the United States has severely neglected Native Americans in regards to education, health, and mental health. Duran (1989) suggests an insignificant amount of ethical research has been conducted in mental health for this population (as cited by Duran & Duran, 1995). A thorough literature review has been conducted and currently, literature specific to Native American populations receiving dialysis treatment for ESRD due to complications of diabetes does not exist, specifically when reviewing the role of depression and treatment adherence for these individuals.

The purpose of this study is to contribute to the literature on American Indian mental health and to the clinical practice addressing the mental health and medical needs of American Indians receiving dialysis treatments due to complications of diabetes. The transcendental phenomenological approach (Moustakas, 1994) and the

advocacy/participatory approach (Creswell, 2007) of this study will provide a foundation for future research by describing the essence of the experience and highlighting areas of need to improve adherence and overall psychological well-being. The findings from this study will be used to formulate an agenda for improvements to dialysis treatments and, in collaboration with the participants, submit this information to the Indian Health Service.

Purpose of Study

The purpose of this study is to understand components of mental health and how it relates to treatment adherence for American Indian patients receiving dialysis treatments due to complications of diabetes. The phenomenon being studied is the psychological experience and the context is American Indians receiving dialysis medical treatment due to complications of diabetes. As stated earlier, no studies have been conducted addressing this specific area of need for American Indians. Additionally, national healthcare disparities for Native Americans are larger than those of other ethnicities (Moy, Smith, Johansson & Andrews, 2006). For American Indians living on reservations, barriers to quality health care include poverty, remote locations, shortage of health care providers and cultural and language barriers (Frankenfield, Roman, Rocco, Bedinger, McClellan, 2004). Retrieval and appropriate study of this type of information is essential for reducing disparities in healthcare and improving quality of care received by American Indians. Without this data, health care problems may go unnoticed and a critical need of Native American people will not be addressed (Moy, Smith, Johansson & Andrew, 2006).

To appropriately serve diverse populations such as American Indians, it is imperative for cross-cultural research to be conducted and reviewed by service providers.

With the increasing diversity within the United States, an understanding of the prevalence rates of diabetes for specific populations will help to increase the understanding of possible trends within a specific culture. Furthermore, this form of research will allow for an understanding of within group differences. Most importantly, phenomenological qualitative research can deepen understanding of experiences of oppression and deprivation that individuals encounter. This depth of knowledge of human experience underscores critical social needs that should be addressed in society.

According to the Indian Health Service (2007), diabetes increases the death rate for American Indians and Alaska Natives by three times. With the already large gaps in healthcare disparities for this population (Moy, Smith, Johansson & Anderson, 2006), further research, active outreach and mental health services are vital for decreasing mortality rates. Accessibility to healthcare facilities and appropriate lifestyle changes should also be monitored. More importantly, the successful changes should be highlighted to aid in successful adjustment to lifestyle changes and therefore, decrease rates of mortality due to preventable complications of diabetes.

As stated earlier, the purpose of this study is to understand the emotional experience of treatment as it relates to psychological well-being and treatment adherence. Because of the void in the research literature in this particular area, a phenomenological study describing the lived experiences of this population may provide impetus to improve services, therefore, increasing adherence to treatment while reducing depressive symptoms. This initial study planned to describe the essence of the experience and has the potential to describe what has been most successful and least successful conditions related to treatment adherence for American Indians. Hopefully, this approach may also

serve as a vehicle for learning and sharing. Through this experience, participants can potentially communicate their success in adapting to the changes in their lifestyle as a result of dialysis to other American Indian patients in the same area. This lived experience may be then shared as an experience to heighten awareness of the challenges for new patients and assist in acceptance of the procedure and the changes that come about as a result of the treatment.

A long term goal of this study is to provide increased knowledge that can be used to modify existing treatment plans and develop new mental health strategies for American Indians by enhancing forms of treatment for depression or the lack of treatment of depression for patients receiving dialysis treatment due to diabetes. It is predicted that the results of this study will suggest the need for mental health services being offered before and after the start of hemodialysis treatments. The act of offering mental health treatment alone will serve as a major modification to treatment as this service is not currently a priority when prescribing dialysis treatments.

Research Questions and Participants

To capture the essence of the phenomenon, semi-structured interviews were conducted. The overall question for this study was: “How is the emotional experience of dialysis related to treatment adherence?” Interview questions were prepared that served as a guide; additional questions were asked in order to gather a rich description of the experience. Three questions, which served as base questions, were formulated for this interview process and a number of sub-questions were created to gather additional information as necessary. The base questions are as follows: “What has been your experience on dialysis?”; “What have you experienced emotionally after starting

dialysis?” and “How are you able to adhere to the treatment regimen”? Sub-questions were created for the three questions listed. These additional questions aided in capturing the personal and emotional barriers encountered by the participants in maintaining their adherence to dialysis treatment. The sub-questions also explored personal and emotional contributors to treatment adherence.

Data for this study were gathered from enrolled members of federally recognized tribes who reside in Oklahoma, Kansas, Nebraska, Iowa and South Dakota. Each participant was receiving dialysis treatments three times per week. Criteria for participants were to be an enrolled member of a federally recognized tribe and reside within Indian Health Service’s Aberdeen or Oklahoma City service areas. Participants must also have a minimum of two years of dialysis treatment, consistent attendance (no more than three absences per month), stable physical health and appropriate dietary changes as prescribed by the medical provider. For purposes of convenience for the participant, interviews were conducted at a site selected by the participant. Once a participant selects a site, issues of confidentiality were to be addressed-but convenience for the participant will remain a priority. This remains a priority because of the number of days and hours spent weekly at dialysis treatments. Oftentimes, dialysis patients are physically tired after treatments. Therefore, respect of their schedules was held in high regard.

Dialysis treatments have been reported as occurring over a three to four hour period (Berman, et al., 2004). This researcher has witnessed many treatments taking as many as eight hours for full treatment. As stated above, oftentimes, the patient is lethargic after being dialyzed and many will return home to rest the majority of the

evening immediately following treatment. Because treatments occur three times per week and the activity level of the patient is greatly reduced immediately after. For this study, 10 individuals receiving dialysis treatments were to be recruited for participation. This sample size was in accordance with the recommendations of Creswell (2007) as the researcher strives to minimize interruptions to the personal schedules of the participants. The interview was conducted at the discretion of the participant and was discontinued if the participant has limited energy or is ill. The interviews ranged between approximately 30 minutes to two hours. If the interview went beyond two hours, the researcher took direction from the participant on either continuing the interview or scheduling for another time.

Significance of Study

Based on the findings of the advocacy/participatory approach (Creswell, 2007) employed in this study, an agenda for improvements to dialysis treatment centers is intended to be submitted to the Indian Health Service's Aberdeen and Oklahoma City Area Offices. This area office oversees federally and tribally managed health service units that are specifically created to serve American Indian populations in Oklahoma, Kansas, Texas, Iowa, Nebraska, North Dakota and South Dakota (Indian Health Service, 2012). Through this collaborative effort, the participant and the community may feel a sense of empowerment by addressing this epidemic at the federal level by calling upon policy makers to formulate improvements in healthcare services for American Indians living on and off reservations.

Additionally, the advocacy/participatory approach (Creswell, 2007) attempts to address what this researcher believes to be internalized oppression for American Indians

as a result of being forced to live on reservations and endure the steps taken by the federal government to assimilate American Indians into Western culture. These actions taken by the federal government distort family and community practices and serve as a severe form of oppression for American Indians. Through this treatment of American Indians by the United States Government, a level of acceptance has occurred in which unhealthy behaviors and their deleterious effects of those behaviors seem to have become an expectation for many American Indians living on reservations. The oppression faced by American Indians over the past several hundred years has led to the internalization of that oppression and is witnessed through the continuously increasing rates of diabetes. This may also be described as historical trauma (Yellow Horse Braveheart, 2000) in which group trauma across generations as a result of genocidal efforts on American Indian people has led to high rates of depression, mortality, substance abuse and other unhealthy lifestyles.

Structure of Proposal

The goal of this research is to inform the doctoral dissertation committee, the larger academic community, and society of the plight faced by American Indians in regards to healthcare. I incorporated my worldview and passion through an advocacy/participatory approach (Creswell, 2007) with the intention of the findings from this study leading to suggested improvements in healthcare for American Indians. Next in Chapter Two, I discuss relevant literature that illustrates the alarming rates of the diabetes epidemic and how complications of the disease could be reduced by focusing on psychological well-being.

Epoche: My Experience with Diabetes and Dialysis Treatments

I begin this epoche initially with intense emotion that may be described as discomfort and sadness as I know I will review personal areas of my life in which my own ignorance makes me feel as though I have unknowingly internalized a form of oppression. I use the term oppression as I have interpreted many aspects of life on the reservation as oppressive. For example, my perspective of oppression for my tribe in particular, is based on the forced relocation of my tribe from Nebraska to Oklahoma. Through this process, survival took place through a paradoxical means in which the efforts to survive have also become inadvertent efforts of destruction.

From my own perspective, this form of internalized oppression, as mentioned above, has had a long term effect on the well-being of many American Indians across the United States. The form of oppression I believe took place, was a forced way of life in which the people saw as a means of survival rather than a form of hopelessness. This paradoxical means of survival consequently became a killer within multiple communities. This disease of diabetes was an unfamiliar experience that has taken lives, limbs and ways of life.

My efforts in completing an unbiased and scientific dissertation that describes a phenomenon from the words of the participants, can only be appropriately completed by capturing the true and uninterrupted voice of the participants. Therefore, this epoche will serve as a medium to removing researcher bias in which my understandings and experiences of the phenomenon are attempted to be removed as to not distort the experience of the participants. This process of the epoche (Moustakas, 1994) is a vital component of this particular approach of study as it aids in removing personal biases in

effort to allow the researcher to visit the phenomenon with clear vision and no predetermined biases.

My exploration of my personal biases begins with my childhood memories of experiences with diabetes. I then describe an intimate relationship with severe diabetes and dialysis treatments of a close family relative. Throughout the writing of this personal perspective, I reflect on my thoughts of internalized oppression and how this destructive form of survival was normalized.

I have wonderful memories growing up in my grandparent's home. A memory I often think of is the card playing or "gambling" as they called it. Memories of this stand out more from my summers during my elementary school years. My grandmother would often wake me up around nine or ten in the morning and I would have to start cleaning so we could turn the air conditioner on so everyone would feel comfortable. She would already have soup on the stove and biscuits in the oven. She always prepared lunch for the gamblers. Around 10 years old I learned to drive and would go around our small reservation and pick up people who wanted to play cards. They were usually well over their 50's and mostly women. I would sometimes have to purchase cigarettes for them as well. I didn't mind, I enjoyed driving and thought it made me seem older. The gambling happened Monday through Friday and usually went from around noon until about four in the afternoon. I remember having so much fun sitting in our patio watching them play or hearing them say different Ponca words and teasing each other. I never understood why they called the "3" card crack. But it was always funny to hear that term. I remember butterscotch candy and juice were always available but I just thought it was a taste preference or part of the treatment/hospitality the gamblers received. Something that was

scary to me was how so many had difficulty seeing and some would show up in there wheelchairs or with medical boots on their feet. I have many memories of just the word “diabetic” but because I heard it so often, it seemed like a natural phase of life. I never put it together that most of these people with amputated limbs and or poor vision were diabetics. I think about the fruit on the table and the fact that my grandmother made phenomenal soups with the government provided commodities and now as an adult I think about the meal as a limitation due to financial resources but also as a mildly appropriate meal for diabetics.

I remember often hearing people grow concerned about others getting sores on their feet or losing toes, a foot or their leg. Again, it seemed as a regular form of adulthood, specifically with the older population. My first memory of a family member with diabetes was with my great grandmother. My great grandmother suffered with diabetes as well as other physical ailments. She enjoyed playing cards as well as bingo and was amazingly talented as a seamstress and with beadwork. But over the years, my great grandmother’s eyesight gradually worsened until she was blind. Her hearing was bad and she had a leg amputated-but she still wanted to come over to my grandmother’s home and play cards as often as she could. With this experience of people close to me having diabetes, I remember wondering when I would get diabetes and start losing limbs. My thought process was, this was normal part of aging. I now see how this became something expected and therefore, a disease I initially had no intention of fighting as I believed this was a normal expectation of aging. I don’t recall ever hearing about forms of prevention for diabetes. I believe this is what led to the expectation of diabetes as a naturally occurring part of life-similar to aging.

The alarm of the disease never seemed to be present because everyone seemed to be diabetic. I cannot say that this was a protective effort because I cannot say that as an adult, I have truly embraced the severity of the disease and I have yet to discuss this with my own children. In writing this, I question what I have truly internalized and how I overcome a thought process of defeat when this is a disease that can be prevented. Have I truly dismissed the prospect of becoming a diabetic? At this point in time, I cannot say I truly have.

Growing up, I remember looking at people's arms and seeing scars and dark spots that I now know were signs of complications with diabetes. But growing up, it all seemed so normal. As an adult, I saw my maternal and paternal grandmothers have diabetes that worsened over time. My paternal grandmother maintained her eyesight but eventually had to have her leg amputated. My daughters loved being around their grandmother but they tell me they were scared of her because of her leg. They never knew why her leg was cut off and to this day, I have not discussed it with them and I think this is because it is still so normal to me. My maternal grandmother had diabetes and her vision increasingly worsened over time. Her skin was dry and she struggled with open wounds. I wished and prayed there was something I could do for her. We tried so many different lotions and powders but nothing seemed to help. The thought remained of when this would happen to me. I later found out my mother, and all six of her siblings had diabetes. I found this out and had no alarming response because this is what we all would get at some point. But I thought it happened to older people and my mother, aunts and uncles seemed to be too young to already have diabetes. I then thought about my cousins who were all younger than me and each of them had diabetes, as did their mother.

I remember hearing about one of my teenage cousins going to the hospital because her sugar was over 500. But I didn't know what this meant. As I reflect upon these memories of diabetes amongst my family and tribe, I am saddened that it was viewed without alarm from me as I was never fully informed of the severity of this situation.

My aunt, my mother's older sister, suffered heavily from diabetes. Her health declined rapidly and she struggled with making appropriate changes to her diet and physical activity. Her diabetes eventually led to renal failure and she had to start dialysis treatments. She was extremely hurt by this and from my perspective, saw it as the end. My uncle had offered his kidney but for whatever reason, a transplant never took place. I remember my aunt being so tired after treatments. She always seemed thirsty and similar to my grandmother (her mother), she had problems with her skin. I would want to visit with my aunt because she was one of my favorite people but because she was receiving dialysis and I knew the treatment made her tired, I rarely went to see her because I didn't want to bother her. My perspective was that she needed her rest. I would discuss my Aunt's eating habits with my mother and she would at times be angry or disappointed and expressed this by saying how she needed to cut out the spaghetti and bread. But when I speculate about my aunt's reality, as a single mother of three (a daughter and two sons) who was unemployed, spaghetti was the perfect dinner. It was an inexpensive meal that could feed all of them comfortably. This is a similar thought process with the use of commodities and the high carbohydrate diets that many engaged in while dependent upon the issuance of government food distribution.

As I think about my Aunt's emotional experience, depression seems to be the most prevalent. She kept her house and her room dark and spent quite a bit of time in her

bedroom. This was atypical of her day to day behaviors. However, her social interactions typically consisted of interactions with family and she enjoyed working in her yard and was very fond of decorating her home. This fondness of her landscaping declined and the regular updates to her home gradually decreased. She loved to see her grandchildren but isolation and withdrawal seemed painfully prevalent. The isolation wasn't always of her choosing. As I mentioned, I would stay away because I thought she needed her rest. The experience was slightly different for my mother. Anytime she would travel to town she would ask my Aunt to go and she often went. But more often than not, even with her adult children at the home, she seemed to spend a great deal of time alone in her room.

I would have discussions with my aunt about her treatment and she would always discuss how people would miss and they seemed to be fine. She would often miss but it seemed to be taking a toll on her physical well-being as she would appear more swollen and it seemed as though after treatment she would often have cramps. As a family, our discussions never went further than what I have shared in this epoche. My aunt's attendance gradually worsened and her medical condition became more and more severe. Consequently, the complications became too severe and she passed away.

My personal experiences with diabetes and dialysis have personally affected my worldview in a sense of internalized oppression. I relate this to oppression because of the dramatic disparities experienced on the reservation. Commodities appeared to be a staple and even now, many people American Indians reference growing up eating government issued commodities. There were not interventions to promote healthy eating habits and

as I talked with others within my community who had diabetes, it never seemed as though they knew what they could eat.

I have been resigned to the presumption of diabetes as a normal aging process. I was not fully aware of the ways to prevent diabetes until I became an adult. However, I now see with my tribe, as well as others, there are educational efforts and programs specific to diabetes prevention. Over the years, education has improved for preventing this disease and active efforts from tribal organizations are attempting to challenge the perspective of diabetes as an aging process.

This process of the epoche has helped me understand my own thought process in regards to diabetes and dialysis treatments. I see how I was misinformed about the severity of the disease and I see how I may have unknowingly contributed to my Aunt's isolation. Although I am only one person within our family, I believe my perspective was shared in regards to believing rest was what was best for her. Therefore, these actions of wanting what was best for her, inadvertently contributed to the experience of depression through isolation. This act of doing what was best is similar to the eating habits as discussed as a form of oppression. Our approaches at doing what was best for ourselves, our families and our tribes have led to a paradoxical reality in which the actions we take to survive, also contribute to our demise. Meaning, we used to accept the government food and survived with these rations. But this survival effort also led to poor eating habits and high carbohydrate intake. Fortunately, over the years, education for diabetes has improved significantly. However, there are still misconceptions about dialysis treatments-specifically in regards to survival rates and quality of life.

As I moved forward with this study, I attempted to gather a rich and textural description of the participants experience on dialysis. This description of the experience is described through an uninterrupted voice of the participants in which my perception is removed and therefore reducing the likelihood of my perspective distorting the subjective reality of the participant. Furthermore, because this phenomenological study addresses a gap in current research, the interview questions were broad but based on literature addressing quality of life for hemodialysis patients.

CHAPTER II

Literature Review

Because there has been no research conducted specifically on treatment adherence as it relates to the mental health of American Indians receiving dialysis treatments, a transcendental phenomenological approach was used to explore how the emotional experience of dialysis is related to treatment adherence for American Indians. Before analyzing the emotional experience of hemodialysis, it is important for the reader to have an understanding of the disease that has led to the dialysis treatments.

As an introduction to the types of diabetes and the factors leading to dialysis, this chapter will begin by defining the disease and describe rates and complications associated with diabetes. The complication of end-stage renal disease for diabetes will be highlighted along with the additional complications experienced with hemodialysis treatments. Depression and hemodialysis are discussed at length to enhance the understanding of the phenomenon to be studied. Throughout these descriptions, concerns for the American Indian population will be provided to further inform the reader of this population's plight. The chapter will close with a summary of the literature which suggests the need for additional research in this area.

Overview of Diabetes

Diabetes is defined by the American Diabetes Association as a disease that prevents the body from properly producing or using insulin. Insulin is the hormone required to convert sugar and starches into energy. Although the actual cause of diabetes is unknown, genetics and environmental factors (e.g. obesity, sedentary lifestyles) tend to play roles in the likelihood of acquiring the disease (American Diabetes Association).

According to the American Diabetes Association four major types of diabetes are: Type 1; Type 2; Gestational Diabetes, and Pre-diabetes. Type 1 diabetes occurs when the body fails to produce insulin. This type was previously known as insulin-dependent diabetes mellitus (IDDM) (Center for Disease Control, [CDC], 2005). Type I diabetes is usually diagnosed in children and young adults (American Diabetes Association) but may be acquired at any age (CDC, 2005). It accounts for approximately 5% to 10% of all diagnosed cases of diabetes (CDC, 2005).

Type 2 diabetes is the most commonly diagnosed form of diabetes (American Diabetes Association); this type accounts for 90% to 95% of all diagnosed cases (CDC, 2005). With Type 2 diabetes, the body fails to properly use the produced insulin. Type 2 diabetes is most commonly found in adults however, the rate of Type 2 diabetes is increasing for children and adolescents, particularly within American Indian, African American and Hispanic/Latino American populations (CDC, 2005).

Gestational diabetes occurs when a pregnant woman who has never had diabetes before has high glucose levels during pregnancy. This form of diabetes affects approximately four percent of all pregnancies. Gestational diabetes is more frequently diagnosed in African Americans, Hispanic/Latina Americans and American Indians (CDC, 2005). Approximately 5% to 10% of individuals with gestational diabetes will have Type 2 diabetes after the pregnancy (CDC, 2005). Within the United States approximately 135,000 cases of gestational diabetes are reported annually. Depending on the population, approximately 2% to 5% of pregnant women have gestational diabetes mellitus (Moum, et al., 2004; King, 1998, Centers for Disease Control and Prevention, 1998, Kieffer, Martin & Herman, 1999).

Over the past three decades, a two- to three-fold increase of diabetes has occurred among Pima Indians (Moum, et al., 2004; Dabelea, Knowler & Pettit, 2000) due to an increase in diabetes in mothers during pregnancy and obesity in childhood and adolescence (Moum, et al., 2004). Over a 12-year period, Moum et al. (2004) also found an increase in the rate of gestational diabetes mellitus in Montana and North Dakota. These findings are similar to rates found across all races within the United States (Moum, et al., 2004; Martin, Hamilton, Ventura, Menacker & Park, 2000, National Center for Health Statistics, 1990). With these increasing rates of gestational diabetes, the risk of childhood diabetes increases.

The final variation of diabetes is pre-diabetes. This occurs when blood glucose levels are excessive but not at the Type 2 level. Recently, research has found that long term body damage may be occurring during pre-diabetes (American Diabetes Association, 2012). Approximately 54 million people within the United States have pre-diabetes. Similar to Type 1 and Type 2 diabetes, pre-diabetes can be managed through good nutrition and physical activity.

Rates and Complications of Diabetes

Over 20 million people within the United States are living with diabetes (Hu, Amoako, Gruber and Rossen 2007; American Diabetes Association [ADA], 2005a; World Health Organization [WHO], 2006). In 1998 the World Health Organization predicted that by the year 2025, the rates of diabetes for the adult population in developing countries would increase from 84 to 228 million; additionally, the worldwide rate of diabetes was expected to reach 300 million. Consequently, in August, 2011, the World Health Organization reported a worldwide rate of diabetes at 346 million. This

epidemic continues to be a threat to mortality rates for children, adults and all races. The sixth leading cause of death in the United States is diabetes mellitus (Kaholokula, Haynes, Grandinetti & Chang, 2006; Centers for Disease Control and Prevention [CDCP] 2004). For those individuals diagnosed with diabetes mellitus, it is estimated that 90% have Type 2 diabetes (Kaholokula, Haynes, Grandinetti & Chang, 2006; CDCP, 2004).

Levels of physical activity and eating habits are important factors for individuals living with diabetes. Diabetic patients are advised to control their eating and participate in physical activity to maintain healthy levels of glucose; these suggestions often present a significant challenge to patients (Rubin & Peyrot, 2001). As part of the treatment regimen, patients must continually maintain awareness of eating, sleeping and physical activity habits (Rubin & Peyrot, 2001). Sedentary lifestyles are continuing to increase through all age ranges and across gender. Current trends across age and gender indicate fairly minimal physical activity (Brownson, Boehmer & Luke, 2005). Men are slightly more likely than women to meet recommended levels of physical activity (Brownson, Boehmer & Luke, 2005). For youth, physical activity levels are similar to adults with an increase in activity occurring from ninth to twelfth grade (Brownson, Boehmer & Luke, 2005).

The National Center for Health Statistics reported the rate of Americans younger than 20 years old who have been diagnosed with diabetes to be 216,000 (as cited by Massengale, 2005). Diabetes is becoming prevalent across all ages, gender and ethnic backgrounds. Therefore, an understanding of factors contributing to complications should be rigorously assessed (e.g. low levels of physical activity).

The consequences of physical complications include expenditure of millions of dollars annually, blindness, amputation and dialysis (Massengale, 2005). These consequences would have a major impact not only on the individual, but on their family members as well. Many patients diagnosed with diabetes exhibit depressive symptomatology. However, Rubin and Peyrot (2001) report certain antidepressants have proven to be effective treatments for individuals living with diabetes. They also report cognitive behavior therapy as helpful in reducing self-defeating thoughts and behaviors.

Additional severe complications that may arise for individuals with diabetes may include heart disease and stroke; high blood pressure; kidney disease; nervous system disease; dental disease and possibly weakened immune system (CDC, 2005). For people with diabetes, heart disease and strokes account for about 65% of deaths. For people with diabetes, the likelihood of heart disease and strokes is two to four times higher than those without diabetes. For adults aged 20 to 74 years, diabetes is the leading cause of blindness. Approximately 12,000 to 24,000 cases of blindness due to diabetes are reported annually. In 2002, 44% of the new cases of kidney failure were directly related to diabetes. Also, 153,730 patients with end-stage renal disease, due to diabetes, were receiving chronic dialysis treatments (CDC, 2005).

As a result of diabetes, changes in lifestyle must occur. These changes include dietary preparation, possible medication plans and use of insulin and home blood glucose monitoring methods (Jacobson, de Groot & Samson, 1997). Such changes and restrictions may prove to accommodate symptoms of depression through loss of autonomy, schedule restrictions and overall declining physical health.

Thus, complications of diabetes may be exacerbated by depression (Massengale, 2005; Musselman, Betan, Larsen & Phillips, 2003). However, the occurrence of depression in individuals with diabetes is not yet fully understood. Possible reasons for the occurrence of depression in patients with diabetes are noted as negative perceptions about diabetes (Massengale, 2005; Egede & Zheng, 2003) and increased alteration of dendrites in the hippocampus (Massengale, 2005; McEwen, Magarinos & Reagan, 2002). Sexual dysfunction is also prevalent in severe cases. Eighty-two percent of male dialysis patients suffer from erectile dysfunction (Rosas, et al., 2003; Rosas, Joffe, Franklin, et al., 2001). Contributing factors to the prevalence of depression have been reported as lower socioeconomic status, lower rates of education and low levels of physical activity (Engum, Mykletun, Midthjell, Holen & Dahl, 2005).

Diabetes has been found to double the risk of depression; unfortunately, proper treatment of the latter is rarely recognized (Rubin, Ciechanowski, Egede, Lin & Lustman, 2007). However, as stated above, the relationship between depression and diabetes is not fully understood and the failure to appropriately recognize depression is a problem within the majority population of clients within primary care settings (Whittemore, Melkus & Grey, 2004). For diabetic patients, a diagnosis of depression is difficult to determine due to the overlapping symptoms of diabetes with depressive characteristics (Whittemore, Melkus & Grey, 2004; Davidson & Meltzer-Brody, 1999; Hirschfield et al., 1997). Without proper care and management diabetes and its side effects, serious complications may arise.

Rates of depression in diabetics range two to five times higher than the general population (e.g. Karlsen, Bru & Hanestad, 2002; Gavard, et al., 1993, Peyrot & Rubin,

1997). However, findings are mixed concerning rates of depression based on the duration of diabetes and how it is psychologically maintained. For example, individuals who have been diagnosed for a longer period of time are more likely to encounter burnout due to the increased stress (Karlsen, Bru & Hanestad, 2002; Davis et al., 1987; Connell et al., 1994) while some are found to develop better coping skills due to the duration of diabetes as the individual adjusts to the necessary changes for maintaining health (Karlsen, Bru & Hanestad, 2002; Lundman et al., 1990). This may include a change in dietary options, increasing physical activity and education about diabetes. These types of changes are essential in maintaining good health and for those who do not already engage in these types of behavior, it may take an additional amount of time to adjust.

According to a Norwegian study conducted by Karlsen, Bru, and Hanestad (2002), depressive symptoms for individuals with diabetes were three times more likely to occur than with the general Norwegian population. Consistent with findings in the United States, they found that younger people were more likely to report a lower level of psychological well-being than older people. Anxiety was also noted more with the younger sample, however; only for those with Type 2 diabetes. The initial onset of diabetes may represent a lifetime of disorders. For a younger individual, reviewing the treatment plans for diabetes management may appear overwhelming. A longitudinal study of younger individuals with recent onset of diabetes may provide a greater understanding of the stages of possible grief.

For patients with severe medical problems due to diabetes, depression can be successfully treated through intervention (Kinder et al., 2006). However, depression is

often untreated in patients with diabetes (Kinder et al., 2006; Katon, Simon, Russo et al, 2004). Kinder, et al. (2006) found that patients with two or more complications who participated in the Pathways collaborative care intervention displayed a decrease in depressive symptoms. Similar results were also found for patients with fewer than two complications. The intervention for this study was an individualized depression treatment program provided by nurse depression care managers and primary care physicians. This treatment included an initial one hour appointment and then two half hour appointments, in person or by phone, each month. Patients were offered two forms of treatment: antidepressant therapy or problem-solving therapy in primary care. Rather than phone calls, monthly group sessions were offered to patients who were socially isolated. Although a specific therapeutic orientation (e.g., cognitive behavior therapy, emotion focused therapy, feminist therapy) was not discussed, these results partially support the use of counseling interventions to treat diabetic patients with severe medical problems through the interaction between the patient and a nurse case manager.

Major depression is a psychiatric disorder common throughout the general population. Therefore, an expansion of treatment modalities needs to be assessed to improve quality of care (Kessler et al., 2003). Exercise has been linked to a reduction in depressed mood by having a positive impact on mood (Vickers, Nies, Patten, Kierkhising & Smith, 2006; Dunn, Trivedi & O'Neal, 2001, Lawlor & Hopker, 2001). However, depressed individuals are less likely to participate in suggested exercise programs (Vickers, Nies, Patten, Kierkhising & Smith, 2006; Wing, Phelan & Tate, 2002). Vickers, Nies, Patten, Kierkhising, and Smith (2006) found that individuals with Type 2

diabetes displayed higher levels of depressive symptoms and were less likely to initiate and maintain exercise regimens.

Tyrrell, Paturel, Cadec, Capezzali and Poussin (2005) found that cognitive impairment and/or depressive mood are more likely to occur in older patients. This impairment may in turn affect behaviors, attitude and compliance to treatment. Additionally, a study of older adults with diabetes (Hu, Amoako, Gruber and Rossen, 2007) found that gender and symptom distress were the strongest predictors of depression specifically in White males. Across ethnicities, African Americans were more likely to reveal diabetes; however, they were less likely to report depressive symptoms when compared to Whites.

Many factors have been found to contribute to poor adherence to treatment and/or depression in younger diabetic patients. Kimmel et al. (1995) found that younger patients were more likely to skip hemodialysis treatments when compared to older adult patients. Nichols and Brown (2003) found that diabetic patients who were younger and female were more likely to be diagnosed with depression regardless of diabetes type. Body weight was also found to be a greater factor in women when the diagnosis of depression occurred. For younger diabetic patients with poor control over their disease, the likelihood of depression was greater than those that had well maintained diabetes (La Greca, Swales, Klemp, Madigan & Skyler; Mazze, Lucido & Shannon, 1984).

Between and within-gender differences in diabetic symptoms have been observed. For example, women may report higher rates of dysphoric symptoms than men (La Greca, Swales, Klemp, Madigan & Skyler; Mazze, Lucido & Shannon, 1984; Sullivan, 1979). Depression is reported at significantly higher levels for women with Type 1 or

Type 2 diabetes (Lustman & Anderson, 2002) which is similar to the findings of Nichols and Brown (2003) for adolescent females. This research was also supported by findings from Lin, et al., (2004) which indicated increased prevalence rates of depression for women when compared to men.

Sacco and Yanover (2006) suggest that depression in diabetics is related to morbidity and mortality. Anderson, Freedland, Clouse and Lustman (2001) conducted a meta-analysis of scientific literature to assess the prevalence of comorbid depression and diabetes in adults in community and clinical settings. Variables for inclusion in this analysis were race, sex, age and diabetes. Results indicate the odds ratio of depression is doubled when a person is living with diabetes. However, when assessing self-report surveys, the rate was found to be two to three times higher. In comparing men and women with diabetes, depression was found to be significantly higher with women regardless of assessment method. This finding is similar to that of the general population without diabetes. Interestingly noted is the significantly higher prevalence rate of lifetime depression in diabetics. Although this rate was found in the Anderson et al. (2001) meta-analytic results to be significant, the onset of diabetes was not included in the assessment nor was the type or severity.

Individuals with diabetes may find it more difficult to deal with major life events and other occurring stressors (Talbot, Nouwen, Gingras, Bélanger & Audet, 1999). This struggle may in turn increase the occurrence of depressive symptomatology (Talbot, Nouwen, Gingras, Bélanger & Audet, 1999; Avison & Turner, 1988). Biologic vulnerability or environmental risk factors may increase the co-occurrence of depression and diabetes mellitus (van den Akker, Schuurman, Metsemakers & Buntinx, 2004).

Depression may also increase the risk of diabetes mellitus by increasing activity in the sympatho-adrenal system or by creating dysfunction in the hypothalamo-pituitary adrenal axis (van den Akker, Schuurman, Metsemakers & Buntinx, 2004; Kawakami, Takatsuka, Shimizu & Ishibashi, 1999). Some antipsychotic medications, which are often used to treat depression, have been found to induce the risk of developing diabetes (van den Akker, Schuurman, Metsemakers & Buntinx, 2004; McIntyre, 2002).

A study by Engum, Mykletun, Midthjell, Holen, and Dahl (2005) found that several factors correlated with depression in individuals with diabetes. These factors include multiple problems with health, problems in the personal lives of the patients as well as social and community interaction difficulties. Other notable findings from this study include lower education levels and increased physical impairments as significant correlates of depression in diabetics. However, these factors were not different than correlates of depression observed in the nondiabetic population.

Although previous research suggests a high incidence of depression, Jacobson, de Groot and Samson (2007) note that individuals with Type 1 and Type 2 diabetes report high levels of well-being, satisfaction and enjoyment (Hanestad, 1993, Myaou, Bryant, & Turner, 1990). However, a difference of increased negative impacts is more likely to be reported by individuals with Type 1 diabetes in comparison to Type 2 diabetics (Jacobson, de Groot & Samson, 1997; Jacobson, de Groot & Samson, 1994, Mayou, Bryant & Turner, 1990). A possible explanation for the findings of increased well being and life satisfaction in the Jacobson et al. study may include the length of time the individual has been diagnosed with the disease. The average age of all participants within this study was 53.2 years. Onset and age may have been contributing factors to

the increased levels of overall life satisfaction. Similar to many other studies within this review, this study fails to include ethnic status as a variable. Previous research has found discrepancies across ethnic groups and therefore will be addressed in the proposed research.

Katon et al. (2004) found that factors associated with major depression in individuals with diabetes included younger age; being female; lower education and marital status. Minor depression, which is defined as “two to four depressive symptoms for at least two weeks, with at least one of these symptoms being either depressed mood or anhedonia” (p. 915, American Psychiatric Association, 2002; Katon et al., 2004) was also assessed and contributing factors included age; education; ethnicity; duration of diabetes and number of complications. Associated with both forms of depression were higher BMI and smoking. Also, decreases in adherence to a diabetic diet occurred as a result of depression. These results mimic previous research findings by supporting age and gender as contributing factors of depression for individuals living with either type of diabetes. However, even with the increased number of variables assessed, the average age of participants in this study was 64.9 years.

Self-management is decreased for diabetic patients with depression when compared to those diabetic patients without depression (Lin et al., 2006). Correlates of depression in diabetic patients include poor physical activity, nonadherence to medications, poor nutrition and smoking (Lin, et al., 2006). During a 12 month period, Lin et al. (2006) found no differences between intervention and normal self-care in self-management. However, duration and onset of diabetes were not included in the study nor was an analysis of ethnicity. The majority of the participants met the criteria for major

depression and many had been prescribed antidepressants previous to participation in the study. Although this study finds no differences between the intervention and self-care groups, an important possible confounding variable is previous treatment for depression. The lifetime prevalence of depression in these individuals may have been a contributing factor for these findings. Furthermore, the study did not include types of therapeutic intervention utilized for the patients who met criteria for depression prior to the study. The long-term struggle with depression may contribute to the difficulty of self-care.

Another study by Lin et al. (2004) found that even when assessing various forms of medications, adherence was low with diabetic patients (Lin, et al., 2004). Although home glucose and foot checks were not affected by depression in diabetic patients, depression was associated with infrequent exercise and healthful diets and smoking (Lin, et al., 2004). Roy and Roy (2001) found that diabetic patients with Beck Depression Inventory (BDI) scores higher than 14 were more likely to be unemployed, less educated and lower socio-economic status. This finding has been supported by additional research linking unemployment and depression (Roy & Roy, 2001; Warr & Jackson, 1985; Warr, 1987; Banks & Jackson, 1982). A strength of this study was the number of participants. The sample size consisted of 581 participants of African American descent with Type 1 diabetic patients.

After controlling for socioeconomic status, the prevalence rates of depression between African American and White women, not identified as diabetic, appear to be similar (de Groot, Auslander, Williams, Sherraden & Haire-Joshu, 2003). However, African Americans are overrepresented among the poor; therefore, depression continues to be a major health concern for this population (de Groot, Auslander, Williams,

Sherraden & Haire-Joshu, 2003; Brown, 1990). The association between depression and poverty has been illustrated in previous research (e.g. de Groot, Auslander, Williams, Sherraden & Haire-Joshu, 2003; Eaton, Armenian, Gallo, Pratt, Ford, 1996) as risk factors for developing Type 2 diabetes in African American women.

The prevalence of psychological disorders for people with diabetes is similar to that of people with other chronic severe medical conditions with depression and anxiety being the most common (Rubin & Peyrot, 2001). According to Lustman, Griffith, and Clouse (1996), three quarters of patients who have recovered from an episode of depression will relapse within five years with an average of four episodes (as cited by Rubin & Peyrot, 2001).

Chou and Chi (2005) found that older Chinese patients in Hong Kong with diabetes displayed symptoms of depression. These results were diminished after adjusting for heart disease, high blood pressure, stroke and vision problems. The overall rates of depression within this population were similar to that of Western countries (Chou & Chi, 2005; Anderson, Freedland, Clouse & Lustman, 2001) However, multiple morbid conditions with diabetes appear to be a stronger predictor of depression within the older Chinese population. The sample included 2003 participants aged 60 years and older. Twenty-six percent of this sample reported elevated levels of depressive symptoms. Even though the study controlled for age, gender, marital status and education, other factors may contribute to the depression of older participants. Such factors may include isolation, loss of autonomy or lack of familial or social support.

Previous studies within the United States have found that younger age is related to increased likelihood of depression in diabetic patients (La Greca, Swales, Klemp,

Madigan & Skyler, 1995; Mazze, Lucido & Shannon, 1984; Sullivan, 1979, Nichols & Brown, 2003). La Greca and colleagues (1995) report higher depressive symptoms for adolescent females but suggest this may also be a developmental process that is unrelated to diabetes. Recognizing the differences across gender and age groups is essential as we continue to see increases in the rates of diabetes at all ages.

For patients with diabetes, glycemic control is an accepted goal of treatment (Gross, Olfson, Gameroff, Carasquillo, Shea, Feder et al, 2005). Glycemic control refers to controlling the blood glucose level or the level of sugar in the blood. If an individual with diabetes has a low glycemic level, which is known as hypoglycemia, the individual may experience trembling of the hands, sweating and increased heart rate (Rubin & Peyrot, 2001). In more severe cases of hypoglycemia, an individual may experience deficits in brain functioning (Rubin & Peyrot, 2001). Conversely, hyperglycemia, which refers to high blood glucose, can lead to difficulties with vision, frequent urination and shortness of breath (ADA, 2012). More severe cases of hyperglycemia may lead to ketoacidosis which is also known as a diabetic coma.

Diabetes is the fifth leading cause of death for Hispanics (Gross, Olfson, Gameroff, Carasquillo, Shea, Feder et al, 2005; Anderson, 1999). A cross-sectional study conducted by Gross, Olfson, Gameroff, Carasquillo, Shea, Feder, et al., (2005) found a significant association between poor glycemic control and depression that was specific to the Hispanic population. Hispanic females residing within the United States have higher rates of diabetes than their non-Hispanic White counterparts and Mexican nationals (Pineda Olvera, Stewart, Galindo & Stephens, 2007; Baezconde-Garbanati, Portillo & Garbanati, 1999). For Latinas with poor control over their diabetes and longer time

living with this disease, depression was found more likely to occur (Pineda Olvera et al, 2007). Social support was also found to be negatively correlated with depression in Latina diabetic patients. Additional studies are needed to gain an understanding of the manifestation of depression within this population. Understanding characteristics of the specific culture is vital in creating an authentic treatment plan for Hispanic/Latino diabetic patients with depression.

Among Native Hawaiians, Filipinos, and mixed-ethnic ancestry individuals, Kaholokula, Haynes, Grandinetti, and Chang (2006) found relatively low depressive symptoms for individuals with Type 2 diabetes. However, those individuals who reported depressive symptoms were more likely to report poorer rates of physical functioning and perceptions of general health along with bodily pains, decreased energy and more emotional problems. The sample for this study consisted of 190 people of Native Hawaiian, Filipino, Japanese and mixed-ethnic descent. Depressive symptoms were measured with the Center for Epidemiological Studies-Depression (CES-D) scale. The average age of the participants was 59 years. Similar to other studies of ethnic minorities, older participants are included in studies. Although this may be a limitation to many studies, access to younger patients with diabetes may be difficult to acquire.

Although there has been support for the efficacy of treatments for depression in the general population, it has been estimated that only one-third of individuals with this diagnosis are receiving necessary treatment (Finkbonner & Kaiser, 2002; National Mental Health Association, 2001). Research has found the prevalence of depression to be higher among women and ethnic minorities, specifically American Indians. The rate of women experiencing depression is twice as high as that of men (Finkbonner & Kaiser,

2002; National Mental Health Association, 2001) and when ethnicity is included, American Indian women report generally worse mental health (Finkbonner & Kaiser, 2002; McGrath, Keita, Strickland & Russo, 1990). Adolescents of American Indian descent generally display higher levels of depression, suicide, substance abuse and leaving school before graduation (Finkbonner & Kaiser, 2002; Mitchell, 1997). These rates are reported for American Indians without including the presence of diabetes. Consequently, across gender and at all ages, rates of depression and diabetes appear to be simultaneously increasing for American Indians.

Based on the literature in this study, the prevalence of depression for individuals with Type 1 and Type 2 diabetes is profound. As exhibited in this review, these rates have been found across all ages, gender and ethnic backgrounds. Therapeutic intervention including medication and mental health counseling has been reported as an effective form of treatment however because the side effects of diabetes are so similar to depression, depression is often unrecognized and therefore, untreated. As evidenced by this review, it is essential that research and practice continue to assess diagnosis and treatment modalities for depression in diabetics as the results of depression may diminish adherence to the appropriate regimens necessary for health maintenance. This inability to adhere to a regimen for sustaining health in diabetes may lead to serious side effects such as acute kidney failure or ESRD.

Depression is not reported as a causal factor of ESRD in diabetes, but the reported findings of complications with diabetes including depression are highly correlated based on the overlap of symptoms. Furthermore, the levels of depression have also been illustrated as strong correlates of decreased treatment adherence and mortality. If the

phenomenon is explored at a fundamental level, further research may be able to diagnose depression sooner and treat in a manner that is most appropriate for the patient. The fundamental level of this phenomenon deserves attention as the literature has continuously illustrated the rates of comorbidity for diabetes and depression. The research in this review also provides contributing factors to depression in diabetics such as required dietary changes and impairments in physical functioning. But even with practitioners and clinicians having the research to support these findings, we continue to see depression go untreated in diabetics.

Another severe complication of diabetes is end-stage renal disease. End-stage renal disease (ESRD) is one of the many complications that may have debilitating effects. Diabetes has been found to be the leading cause of ESRD, which is the final stage of kidney deterioration (National Kidney and Urologic Diseases Information Clearinghouse [NKUDIC], 1995). The rates of diabetic ESRD are much higher for all minority populations in comparison to their white counterparts (Carter, Pugh & Monterrosa, 1996; Agodoa & Eggers, 1995, Brankati, Klag, Whelton, Neaton, Randall, Ford, et al., 1994, Cowie, Port, Wolfe, Savage, Moll & Howthorne, 1989, Kappel & Van Tuinen, 1986, Nelson, Newman, Knowler, Sievers, Kuzelman, Pettitt, et al., 1988, Stephens, Gillaspay, Clyne, Mejia & Pollak, 1990, Teutsch, Newman & Eggers, 1989, USRDS, 1993). Furthermore, ESRD from diabetes has been found at the highest rates for African Americans and Native Americans (NKUDIC, 1995).

Hemodialysis

Hemodialysis treatment is recommended to treat reduced kidney function (Everett, Brantley, Sletten, Jones & Mcknight, 1995) and ESRD. The purpose of this

treatment is to remove toxins and reduce fluid overload (Everett, Brantley, Sletten, Jones & Mcknight, 1995 Everett, Brantley, Sletten, Jones & Mcknight, 1995). This procedure takes place because the kidneys are unable to function properly. Therefore, these toxins remain in the body without treatment. Patients receiving this treatment may attend dialysis centers three to five times per week with a three to five hour stay for each visit (NKUDIC, 2006). Appointments with dialysis centers may occur in the morning, afternoon or evening. Availability of the clinic is the determining factor. Home dialysis is another way to receive treatments. The patient and a personal helper must attend four to six weeks of training to administer treatment in the patient's home (NKUDIC, 2006). Consistency is vital to successful treatments.

For patients with end-stage renal disease, transplantation and dialysis are the only forms of treatment (Martin & Thompson, 1999). Although transplantation is preferred, this option is severely limited by the number of appropriate donors. Therefore, the majority are treated through dialysis (Martin & Thompson, 1999; Renal Association, 1997). According to the National Kidney and Urologic Diseases Information Clearinghouse (NKUDIC) (2006), hemodialysis is the most common form of treatment for end-stage renal disease.

Hemodialysis became a regular form of treatment in the 1960's. Since this time, improvements have been made to minimize occurrence of side effects (NKUDIC, 2006). However, even with the inception of improved machinery, hemodialysis is still a complicated and inconvenient therapy. Patients receiving dialysis treatments must adhere to a strict regimen of care for successful treatment (Tyrrell, Paturel, Cadec, Capezzali & Poussin, 2005). Along with this strict regimen, physical discomfort is also a common

experience (Tyrrell, Paturel, Cadec, Capezzali & Poussin, 2005). As a result of end stage renal disease, individuals experience many disruptions and limitations to their lifestyle due to difficulties in coping and uncertainty about the future (de Jonge, Maarten-Friso, Huyse & ter Wee, 2003; Sensky, 1993, Blodgett, 1981).

For survival during hemodialysis, patients must participate in continuous medical treatment (Everett, Brantley, Sletten, Jones & Mcknight, 1995). Having this procedure has been acknowledged as being restrictive, time-consuming and stressful (Everett, Brantley, Sletten, Jones & Mcknight, 1995; Devins, Binik, Hollonby, Barre & Guttman, 1981). Additionally, psychiatric problems are more prevalent among hemodialysis patients (Everett, Brantley, Sletten, Jones & Mcknight, 1995; Burton, Kline, Lindsay & Heidenheim, 1986). One of the paramount predictors of survival in hemodialysis patients is coping successfully with depression (Elal & Krespi, 1999; Burton et al., 1986). Based on these findings, continued research and treatment of depression for hemodialysis patients may lead to increased treatment adherence and decreased rates of mortality. The studies must be inclusive of all cultures as the rates of diabetes and people receiving dialysis continue to increase across the world.

Effects of Hemodialysis

Symptoms that are commonly associated with dialysis patients include fatigue, dry and itchy skin known as pruritus, muscle cramps and nausea (Merkus, Jager, Dekker, de Haan, Boeschoten & Krediet, 1999). However, the most common symptoms of dialysis include fatigue and itching (Merkus, Jager, Dekker, de Haan, Boeschoten & Krediet, 1999). Fatigue may be a result of anemia (NKUDIC, 2006). Anemia occurs when the kidneys fail to produce the erythropoietin. This hormone produces red blood

cells by stimulating bone marrow (NKUDIC, 2006). Anemia also contributes to heart disease (NKUDIC, 2006). Pruritus occurs when the dialyzer is unable to remove certain wastes from the bloodstream (NKUDIC, 2006). This most commonly occurs during or immediately after treatment.

In addition to the above side effects, sleep disorders and amyloidosis may occur (NKUDIC, 2006). Inconsistencies in sleeping patterns may occur due to restless legs. Over time, these disturbances in sleep may increase the likelihood of depression, headaches and weight loss. Amyloidosis from dialysis is referred to as DRA (dialysis-related amyloidosis). DRA is common for patients who have received dialysis treatments for more than five years. After time, deposits of protein will accumulate on the joints and tendons. These deposits result in pain, stiffness and increased fluid in these areas.

One of the most prevalent psychological problems associated with hemodialysis patients is depression (Kimmel, Weihs & Peterson, 1993). Depression may also be an independent factor that influences survival in hemodialysis treatment (Kimmel, Weihs & Peterson, 1993). For individuals with end stage renal disease, depression has been accepted as the most common psychological effect (Finkelstein & Finkelstein, 2000; Finkelstein & Finkelstein, 1999, Levy, 2nd edition, Kimmel, Peterson, Weihs, et al., 2000, Kimmel, 2000). A clear predictor of mortality in an array of medical conditions is depression (Finkelstein & Finkelstein, 2000; Ruberman, Weinblatt, Goldberg & Chaudhary, 1984, Covinsky, Kahana Chin, Palmer & Fortinsky, 1999). An additional predictor of mortality found by López Revuelta, García López, de Álvaro Moreno, and Alonso (2004) was health-related quality of life during the first month of dialysis. These

results emphasize the significance of health-related quality of life measures on clinical outcomes of patients with end stage renal disease.

In the past decade, rates of cessation in dialysis treatments have tripled and one in four patients withdraw from treatment before death (Cohen, Dobscha, Hails, Pekow & Chochinov, 2002; End Stage Renal Disease Network of New England, 2000, United States Renal Data System, 1998). Cohen, Dobscha, Pekow, and Chochinov (2002) found that most patients that discontinue treatments are not influenced by major depression or suicidal ideation. But the decision to withdrawal does occur. This decision to cease treatment is fatal and is not fully understood (McDade-Montez, Christensen, Cvengros & Lawton, 2006). McDade-Montez and colleagues (2006) report possible contributing factors to withdrawal as an increase in severity of diabetes, gender-females more likely to withdrawal than males (as cited by Leggat et al., 1997), and age-older patients more likely to withdrawal than younger patients (as cited by Mailloux et al., 1993; Nelson et al., 1994; Port et al., 1989).

Increased risk of death in hemodialysis patients was found to be associated with older age and comorbidity, negative perceived illness effects, decreased perceived social support and decreased compliance to treatment (Kimmel, et al., 2000). Although a decline in physical functioning is found with increasing age, psychological adjustment appears to be stable (Singer, Hopman & MacKenzie, 1999). Elderly dialysis patients are more likely to report somatic symptoms of depression rather than symptoms of depressed mood (Kimmel, Weihs & Peterson, 1993). In a study by Knight, Ofsthun, Teng, Lazarus, and Curhan (2003), increased mortality was significantly associated with self-reported mental health and physical function in hemodialysis patients. Strategies for identification

of individuals at greater risk of mortality need to be employed to improve prevention efforts (Knight, Ofsthun, Teng, Lazarus & Curhan, 2003). For individuals aged 75 to 79 years with end stage renal disease, the life expectancy was 2.3 years and 1.9 years for patients aged 80 to 84 years with even lower rates for those 85 years and older (Knight, Ofsthun, Teng, Lazarus & Curhan, 2003; United States Renal Data System, 2001).

Asti, Kara, Ipek, and Erci (2006) researched the relationship of loneliness, depression, social support between patients with continuous ambulatory peritoneal dialysis (CAPD) and their caregivers. CAPD is another form of a safe and effective dialysis treatment that is being utilized more as a treatment to ESRD (Balaji, Digard & Wise, 1996). In comparing hemodialysis to peritoneal dialysis, hemodialysis patients are more likely to experience bruising while peritoneal dialysis patients exhibit decreases in appetite (Merkus, Jager, Dekker, de Haan, Boeschoten & Krediet, 1999). Asti et al. (2006) discuss the possible effects encountered as a result of CAPD and review how these experiences alter psychosocial experiences. Effects from this treatment regimen include manipulation in levels of independence, financial stress, role alterations, changes in family life, and altered views of self-image and self-esteem. They note the results of this regimen as having negative effects on the psychosocial well being of the individual (Asti, Kara, Ipek & Erci, 2006; Weilitz & Sciver, 1996, Smeltzer & Bare, 2000). Also, as a result of CAPD, high levels of loneliness and depression are experienced. Two important factors to consider when interpreting results from this study are that the majority of participants were married and 73.8 % of the participants involved in CAPD were male. Awareness of the interpersonal relationships and manifestations of depression across gender is vital to gaining a concise understanding of the phenomenon

and how treatment options for mental health can be improved for patients participating in dialysis treatments.

As discussed above, an important risk factor for end stage renal dialysis patients is depression (Gençöz & Astan, 2006). Social support has been linked to the relationship between depression and dialysis in that lower levels of social support increased the likelihood of depression (Gençöz & Astan, 2006; Elal & Krespi, 1999). Results from a study conducted by Elal and Krespi (1999) indicate that males are more likely to have larger social support quantitatively and are more likely to report availability of these networks. Meaning males are more likely to have a larger number of accessible people in their social support groups.

Still, hemodialysis patients report less frequent contact and perceive a smaller amount of availability of social support (Elal & Krespi, 1999). A cyclical pattern of negative events is suggested by Sacco, and Yanover (2006) with low social support contributing to the increased levels of depression therefore creating aversive feedback to social systems which in turn reduce social support. Perceived social support seems to play a vital role in the prevalence of depression in diabetic dialysis patients. Social support has been found to have a negative relationship with depression in dialysis patients (Elal & Krespi, 1999; Burton, Lindsay & Kline, 1983).

Family interactions and strong family ties are found to provide a unique sense of support for African-American women (Kimmel, et al., 2000, Akbar, 1979, Holder, 1997). Interestingly, family supportiveness was found to decline after the onset of end stage renal disease for females with no change in perceived support for males with the same diagnosis (Kimmel, et al., 2000; Devins, Hunsley, Mandin, Taub & Paul, 1997). Further

research on family interactions and social support may help in the treatment of depression and in the improvement of adherence to treatment by providing and/or suggesting factors that may harm or help individual treatments.

After receiving hemodialysis treatments, many patients may exhibit tiredness or depression after treatment (Mittal, Ahern, Flaster, Maesaka & Fishbane, 2001). In a study of 134 hemodialysis patients, self-reported physical and mental health was found to be lower than that of the general population with one out four patients meeting criteria for clinical depression (Mittal, Ahern, Flaster, Maesaka & Fishbane, 2001). The age range of this study was 24 to 88 years. While the age range was broad, only eight patients were between 24 and 34. Ethnicity was categorized into four groups: Caucasian; African-American; Hispanic and Others. The “Others” group was not defined. It may be that “Others” includes Native Americans, but this is not revealed in the makeup of the group. The Hispanic and Other group each made up 3.7 % of the total sample (7.4 %). Although this study supports previous findings of depression and dialysis treatment, it also reflects the paucity of research for American Indians.

When compared to the general population, the rate of diabetic ESRD for American Indians and Alaska Natives is 3.5 times higher (IHS, 2007). Approximately 13,716 American Indians and Alaska Natives are receiving dialysis treatments (Hall, et al., 2011). And the death rate for diabetic American Indians and Alaska Natives is 3 times higher than the general population. Due to the high prevalence of diabetes mellitus within the American Indian population, the risk of ESRD is increased (Frankenfield, Roman, Rocco, Bedinger & McClellan, 2004). Even with these alarming rates, no

research has been conducted in regards to the relationship between mental health and treatment adherence for American Indian dialysis patients.

A study by Frankenfield, Roman, Rocco, Bedinger & McClellan (2004) found that Native Americans receiving hemodialysis treatments experience equivalent or better dialytic care in comparison to their white counterparts. This study utilized data from the United States Renal Data System which included 467 Native American participants aged 18 years and older. When compared to black and white counterparts, Native American dialysis patients were more likely to be female. The focus of this study was to review the adequacy of treatment received. The study did acknowledge obstacles to treatment such as isolation, limited health care providers, poverty and language and cultural barriers (Frankenfield, Roman Rocco, Bedinger & McClellan, 2004; Johnson, Anderson & Bastida et al, 1995; Narva, 2002). Although this study highlights adequate care for dialysis treatments, an integrated approach to care has not been addressed and the utilization of other services such as behavioral health may be limited as chronic shortages to funding for the Indian Health Service continue to limit availability of medical resources (James, Schwartz, & Berndt, 2009).

Treatment Adherence

Improving adherence to treatment and satisfaction with life for patients on hemodialysis may be a difficult endeavor due to the numerous personal and ecological contributing factors outside of treatment. Although for patients receiving dialysis treatment, religion has been found to be positively associated with increased levels of patient satisfaction with life and social support (Berman, et al., 2004; Koenig, 2000). Unfortunately, religiosity has been rarely studied as a possible positive influence on

adherence to treatment in kidney dialysis therapy (Berman, et al., 2004). In a study that was conducted with religion as a variable, Berman et al. (2004) found no relationship between religion and adherence to treatment. However; they do find a greater level of adherence when assessing age and number of years on dialysis therapy. Their results also indicate greater satisfaction with life in older patients. The dates of treatment (i.e. Tuesday, Thursday and Saturday) were also found to increase levels of satisfaction with life.

Depression may be related to inadequate compliance to treatment (Kimmel et al., 1995) however; the relationship between depression, compliance and mortality is not well understood (Kimmel et al., 1995; Wirth, Folstein, 1982, Lamping & Campbell, 1990, Agushua et al., 1981). Even without a clear understanding of the relationship, the majority of the research reviewed for this study suggests a high prevalence of comorbid diabetes and depression. Through an awareness of the impacts of chronic medical conditions, it may be possible to improve the quality of life through greater treatment efforts for coexisting psychiatric difficulties (Jacobson, de Groot & Samson, 1997). For individuals with co-existing chronic medical illnesses, psychiatric conditions have been found to be consistently associated with quality of life (Jacobson, de Groot & Samson, 1997).

The prevalence of depression is likely to reduce the adherence to treatment regimens for end stage renal disease (Craven, Rodin, Johnson & Kennedy, 1987). For patients with a previous history of depression, the onset of diabetes and/or dialysis treatment may be an event that is associated with the relapse of depression (Craven et al., 1987). Craven et al. (1987) found that dialysis patients may suffer from loss of energy,

insomnia and decreased sexual interests. These symptoms are similar to the criteria for major depressive episode as described in the DSM-IV-TR (2000).

Summary

The majority of the research reviewed supports the prevalence of increased levels of depression in diabetic patients. The research reviewed also suggests increased levels of depression for patients younger than 20 years and patients 50 years and older. This increase in depressive symptoms has been linked to decreased physical activity which in turn may increase severe complications through poor disease management. Severe complications, such as end-stage renal disease further influence these rates due to the strict regimens, diet restrictions and loss of autonomy. Social support also declines for individuals participating in dialysis treatments (Elal & Krespi, 1999; Burton, Lindsay & Kline, 1983; Kimmel, et al., 2000, Akbar, 1979, Holder, 1997). This lack of social support may also be a contributing factor for higher depression prevalence rates.

For dialysis patients, anxiety and depression are strongly correlated with health related quality of life (Vázquez, et al., 2005). These findings support the need for evaluation of these components in treatment of hemodialysis patients. Because of the increased survival rate of dialysis patients, the number of participants in this treatment group is expanding (Rosas et al., 2003; United States Renal Data System, 2000). Therefore, medical professionals should work to improve treatment modalities for diabetes by increasing the assessment and treatment of depression.

Overall, there were several limitations to the incorporated research. The majority of the studies focused on older populations. Research specific to the American Indian population is severely lacking and was evidenced in this literature review. One article in

the literature review focused specifically on Native Americans receiving dialysis treatments due specifically to diabetes mellitus. However, this study did not include a formal assessment of mental health or depression.

The literature reviewed illustrates the high rates of diabetes, depression and dialysis for American Indians. But historical factors such as boarding schools, reservation living, discrimination and prohibition of traditional practices have been unaccounted for in the assessment of diabetes prevalence. This history of loss and oppression has been described as historical trauma and has been linked to psychological suffering for American Indians and Alaska Natives (Yellow Horse Brave Heart, Chase, Elkins & Altschul, 2011). These factors may increase the likelihood of depression even more than what has currently been reported and further study into the effects of historical trauma on chronic illness in American Indians should be further developed.

Furthermore, factors for successful adherence to treatment have also been overlooked in the limited amount of literature on American Indians receiving dialysis due to ESRD from diabetes. Unique regional or cultural factors may be contributors to improved adherence but these factors must first be incorporated into the current research. A further understanding of how dialysis affects ESRD patients due to diabetes for American Indians and Alaska Natives on and off reservations would provide a greater understanding of proper forms of treatment to potentially reduce mortality rates and improve treatment adherence.

CHAPTER III

Method and Design

In order to analyze and understand how the emotional experience of dialysis is related to treatment adherence for American Indians, I conducted a transcendental phenomenological study (Moustakas, 1994) in which the essence of the experience was studied and investigated through rich and textural descriptions as provided by participants. This chapter is dedicated to the description and processes of this approach. I begin this chapter by describing transcendental phenomenology and the rationale for this particular method. I then describe the projected sites and potential participants. This chapter will close with a description of data collection procedures, data analysis and ethical concerns.

Qualitative Design

To capture and describe the essence of the lived emotional experience of dialysis treatments and treatment adherence for American Indians, a transcendental phenomenological design (Moustakas, 1994) was selected as the most appropriate approach for this phenomenon. The lack of research on this lived experience also supports this decision as transcendental phenomenology has been described as a “*first method of knowledge*” (p. 49, Farber, 1943; Moustakas, 1994). Essentially, the heightened awareness and specification of the phenomenon is the first step of gaining knowledge. We should understand the phenomenon before we describe it through other scientific terms or analysis. Because the disparities in American Indian healthcare continue to exist, this study also takes an advocacy/participatory approach (Creswell, 2007) in which steps to reform services will be provided to the Indian Health Service in

support of this marginalized group. The advocacy/participatory approach will take steps beyond the study by providing an agenda for improvements to hemodialysis treatments provided by the Indian Health Service (See Appendix G).

Transcendental Phenomenology

A phenomenologic study illustrates the meaning of the lived experience for a number of individuals and examines the universal experiences of that phenomenon (Creswell, 2007). A philosophical foundation of phenomenology is studying the lived experience and describing the essence of that experience (Creswell, 2007). Additionally, phenomenology removes any presuppositions and focuses on the wholeness of the phenomenon (Creswell, 2007). Transcendental phenomenology embraces these assumptions and perspectives while focusing “less on the interpretations of the researcher and more on a description of the experiences of participants” (p. 59, Creswell, 2007). The transcendental phenomenological approach is a process by which the researcher strives to view the phenomenon as though it is their first encounter with the lived experience (Creswell, 2007; Moustakas, 1994).

Major components of transcendental phenomenology are intentionality and intuition. Intentionality has been described by Kockelmans (1967) as how the mind perceives an object in an intentional manner or the mind’s orientation to an object (Moustakas, 1994). Moustakas also provides Husserl’s (1931) description of intentionality which is essentially processing the process or “the valuing of a value” (p. 243) or “judging, the judging of a certain matter” (p. 243). Intentionality may also be seen as a meta-analysis of what is perceived. For example, communicating about how one communicates is intentionality of perceived communication for that individual.

Through the process described, intentionality also refers to consciousness (Moustakas, 1994). Through this consciousness, the individual is able to experience the manifestation of emotions or judgments beyond just recognition.

Moustakas (1994) describes intuition as “the beginning place in deriving knowledge of human experience, free of everyday sense impressions and the natural attitude” (p. 32). This intuition includes a reflective process that allows the researcher to become aware of their own biases and therefore, create an avenue to a fresh view. Through the process of intuition, the phenomenon is presented, therefore developing awareness or basically, acknowledging the existence of phenomenon. Combined with intentionality, the conscious concept is free of researcher bias and the essence is captured through the rich and textural descriptions provided by the participant.

Rationale

Transcendental phenomenology has many similarities to other approaches in human science research. Two commonalities described by Moustakas (1994) that highlight the rationale for a qualitative study in this area include the recognition of the importance of exploratory methods as not all human experiences can be approached quantitatively and the recognition of the wholeness of the experience. The importance of the exploratory methods are necessary in this study as no studies have been found that focus on the emotional experience of American Indians receiving dialysis treatments. In chapter two, multiple studies were provided that discussed the complications of diabetes and dialysis treatments. But again, no studies were conducted with a focus on American Indians and psychological well-being. This lack of research and the need for the exploratory method leads to the importance of the second commonality which is the

wholeness of the experience. Recognizing and allowing for the wholeness of the experience creates an open forum in which the cultural idiosyncrasies may be incorporated. An exploratory approach that incorporates the wholeness of the experience will serve as a foundation for future research on the emotional and lived experience of American Indians receiving dialysis treatments.

Additional components of a transcendental phenomenological approach that best fit the study of the emotional experience of dialysis for American Indians as it is related to treatment adherence include data collection and data analyzing. Gathering and analyzing data through a transcendental phenomenological approach is unique from other qualitative approaches. As described by Moustakas (1994),

a transcendental phenomenological approach engages in disciplined and systematic efforts to set aside prejudgments regarding the phenomenon being investigated (known as the *Epoche* process) in order to launch the study as far as possible free of preconceptions, beliefs and knowledge of the phenomenon from prior experience and professional studies—to be completely open, receptive, and naive in listening to and hearing research participants describe their experience of the phenomenon being investigated (p. 22).

Van Kaam (1966) states preconceptions and statistical methodology may distort the experience by restricting the rich description of the phenomenon (Moustakas, 1994).

The transcendental phenomenological (Moustakas, 1994) approach is the most appropriate as this research is engaging in what may be considered uncharted territory for American Indians on dialysis due to complications with diabetes. Therefore, as an initial study into this area, openness to the phenomenon must be allowed.

Transcendental phenomenology provides openness to the lived emotional experience as the researcher strives to remove any preconceptions of the phenomenon through the *epoche*. Furthermore, the exploratory analysis is not limited by a set of answers in which

the participant may choose nor are the responses limited by quantitative scales. Through this investigative process, a foundation for reform and further research may be conducted in a manner that does not limit or deny the lived experience.

As stated earlier, this study will also take an advocacy/participatory approach (Creswell, 2007). The advocacy/participatory approach is a worldview that goes beyond advocacy and attempts to establish an agenda for change for marginalized groups (Creswell, 2007). This approach is an attempt to share the voices of the participants by proposing an agenda for change based on the lived experiences of the participants. This approach creates a vehicle for addressing the injustice of disparities in healthcare for American Indians. These injustices and social issues serve as the guiding framework for the question formulation (Creswell, 2007). The approach is intended to be used to ask participants for their input in the formulation of the interview questions and how to collect and analyze the data (Creswell, 2007). This study will follow up with participants on the agenda for reform which will be submitted to the Indian Health Service Area Offices in Oklahoma and South Dakota. These Area Offices provide direct oversight of Indian Health Service Units and Tribally Managed Service Units in Kansas, Oklahoma, Texas, Nebraska, Iowa, South Dakota and North Dakota (Indian Health Service [IHS], 2012).

Ultimately, the rationale for utilizing the transcendental phenomenological approach (Moustakas, 1994) is based on my personal interests in the health care disparities for the Native American population and the social justice efforts I ascribe to as a counseling psychologist. Moreover, the approach is the first step in gaining knowledge

about the lived experience as this phenomenon of American Indians has not yet been studied.

In the approach of advocacy, as a researcher, this study will strive to promote “action to help individuals” (p. 21, Creswell, 2007). In a system that is dedicated to the healthcare of American Indians, the call to action through the Area Offices for the Indian Health Service is most appropriate in initiating the reduction of healthcare disparities for American Indians receiving dialysis treatments. The advocacy/participatory approach will hopefully serve as a tool of empowerment for the participants as well as the researcher. The experience of internalized oppression may be diminished as we take steps to overcome disparities in healthcare for American Indians.

Projected Sites and Participants

To establish a foundation for understanding the phenomena, this study used a purposeful sampling technique (Creswell, 2007). Because this is a topic that has not been studied for American Indians, the most suitable approach was to include participants who are directly experiencing the phenomenon. Meaning, the participants were active patients of dialysis treatment due to complications of Type 1 or Type 2 diabetes. Creswell (2007) states there has been a range in the sampling size for phenomenological studies; this range is reported by Creswell (2007) as one (Dukes, 1984) to 325 (Polkinghorne, 1989). He also reports a recommendation by Dukes (1984) of three to ten participants. The sample size for this study was proposed as 10 participants. The rationale for this number is that the interview will be extensive and may take a great deal of time away from the participant. The participants of this study are a vulnerable population due to health concerns. Therefore, physical health, time constraints, fatigue, emotional response,

transportation and personal time were all major considerations in participant selection. In my initial visit to one of the proposed sites, there were many patients with high-blood pressure and other health concerns. Therefore, I employed additional strategies in purposeful sampling such as criterion sampling and convenience sampling.

Criterion sampling was employed as “it is essential that all participants have experience of the phenomenon being studied” (p. 128, Creswell, 2007). But because of the major differences in the acceptance and adjustment to dialysis treatment, criteria were established to safeguard the participants (Appendix A). As stated in the literature review, the majority of the studies in this area focused on an older population. And although we are seeing increasing rates in younger people receiving dialysis treatments, this study focused on an adult sample who appeared to have successfully adapted to dialysis treatments. Successful adaption was defined as at least two years of treatment with consistent attendance (less than three missed appointments per month), stable physical health and appropriate dietary changes that enhance overall well-being. The purpose of recruiting participants who were successfully maintaining treatment was to highlight contributing factors for adherence to treatment. All participants were also required to be enrolled members of federally recognized tribes and reside within Oklahoma, Kansas, Nebraska, Iowa or South Dakota. These patients were to be included in this study because their experience will help determine the cultural contributions and actions necessary to assist other dialysis patients with acceptance, treatment adherence and overall well-being.

Convenience sampling was the technique utilized as this researcher made diligent efforts to not impede on personal time or medical treatment as a result of the interview

process. Convenience sampling has been described as more of a benefit for the researcher by saving time and money (Creswell, 2007). Although the researcher had these benefits of convenience sampling, this approach was also the most efficient for the participants as they had flexibility in choosing the most suitable time and location.

Recruitment for participants took place at multiple public sites within the communities of which there was a dense American Indian population. These locations included urban areas and reservations within Iowa, Nebraska, and Oklahoma. Public businesses such as the U.S. Post Office and tribally sponsored community events were targeted for notification of the study. The Indian Centers in Omaha, Lincoln and Oklahoma City also served as locations for recruitment. Multiple fliers were posted and potential participants were informed of the purpose and requirements of the study. Contact information for the researcher was also provided on the flier for the participants. A formal written and verbal introduction of the study was also provided at the dialysis clinics in which recruitment took place.

Due to the lengthy nature of the interview, all participants received a \$20.00 Visa gift card for their participation in the study. Participants had the option to terminate the interview at any time. The expected benefits, risks, compensations and rights of the participant were included in the informed consent (Appendix B) and reviewed with each of the participants prior to beginning the interview. The informed consent was discussed in detail with participants and an explanation of the recording and research process was also provided. Participants agreed to the process by signing the informed consent and all were provided with a copy of the signed document.

The approach for interviewing was culturally based in terms of introduction. As a Ponca woman, I am familiar with the appropriate introduction etiquette that is socially acceptable amongst many tribes within the Midwest. I therefore, began the interview by stating my name, my tribe and provide the same information for my husband. I will state on which reservation I was raised and then inform the participant of my ancestry. I will state the name of the family I come from and who I have relationships with in the area. This introduction will lead to establishing rapport and trust as we connect to one another through this process. Introducing myself in this manner does not guarantee an established rapport however, the introduction is culturally appropriate for tribes in the area where recruitment will take place. This approach is in accordance with the data collection procedure as described by Moustakas (1994) in which a social conversation may take place prior to the interview to establish a safe environment for the participant and the study.

The interviews were initially determined to take place at the participant's dialysis treatment center. The rationale behind selecting this location was for convenience. This was considered to be convenient for clients and transportation would not be an issue as the interview would have been conducted during the dialysis treatment. Permission to conduct the interview at the patient's dialysis center would have been obtained prior to scheduling an interview. If the dialysis center did not allow for the interviews during treatment, the researcher would contact the potential participant and discuss an alternate location for the interview. It was preferred that all interviews be conducted at the site in which treatment was delivered as to not create a burden for the participant. Participant's also had the choice of selecting a confidential location for interviews. Again, the

rationale behind the clients selecting the location is based on convenience for the participant. For clients who choose and alternate location, limits to confidentiality were discussed prior to meeting but the participant ultimately determined the location.

Interview locations are further discussed in Chapter Four.

The timing for the interview was based on convenience for the participant. The participants receive treatments three times per week for three to five hours at each setting. Because of the time away from home for medical treatment, the flexibility in meeting locations and time would be made most convenient for the participants. This approach may also lead to a more in-depth understanding and description of the experience as it is taking place.

Research Questions

The goal of this phenomenological study was to understand the emotional experience of American Indian dialysis patients. This study takes an advocacy/participatory approach (Creswell, 2007) and has formulated steps for action to promote treatment adherence, acceptance and overall well-being. Through this phenomenological approach, this study attempted to attain an understanding of the essence of the emotional experience and this experience has influenced treatment adherence.

Again, because the participants are a vulnerable population, the time was limited for interviewing. The researcher strived to gather the information in one setting but discussed the possibility of multiple visits as allowed by the participants. The overall question for this study is: “How is the emotional experience of dialysis related to

treatment adherence”? This study attempted to interpret the experience of the participants through the following questions:

Research Question 1:

What has been your experience on dialysis?

Subquestions:

- 1.) How has your schedule changed with family and work?
- 2.) What physical changes have you experienced since starting dialysis?
- 3.) Could you please describe what you have gained or lost from this experience?
- 4.) How did you interact with family and friends after starting dialysis?

Research Question 2:

What have you experienced emotionally after starting dialysis?

Subquestions:

- 1.) What emotions did you experience during treatment?
- 2.) What emotions did you experience immediately after treatment?
- 3.) How do you feel about dialysis treatments?

Research Question 3:

How are you able to adhere to the treatment regimen?

Subquestions:

- 1.) Please describe how you feel about your treatment regimen?
- 2.) What helps you maintain your schedule?
- 3.) What obstacles did you face in adhering to treatment?
 - a.) How did you overcome those obstacles?

These research questions served as a guiding format for capturing the essence of the experience. According to Moustakas (1994), a researcher will enter the interview with formulated questions but in gathering the data, some of the questions may not be asked. This process is exploratory and these questions will serve as a guide for the participants but will not serve to limit their responses or what they are willing to share.

Questions regarding cultural influence were not asked during this interview process. It is my belief that engaging in such interrogations leads to a separation of the culture from the individual. The cultural being is holistic and will be discussed through the individual's personhood and not as a separate component of the individual. Furthermore, I believe as a Native Researcher, the intentional highlighting of "Indianness" is a form of exploitation. Although this study is focused on American Indians, the participant's cultural experiences will not be a dissection of their identity. If cultural and spiritual aspects are mentioned during the interview, these will be integrated into the responses through horizontalization (Moustakas, 1994).

Data Collection

As described by Moustakas (1994), the data collection process is made up of a "long interview" (p. 114) in which the first step is essentially developing rapport. This study initiated the development of rapport through the introductory etiquette described above. Upon completion of this introduction, detailed information regarding the study, the benefits and risks of participation and the logistics for timing and follow up were provided. These processes are further defined in the Informed Consent (Appendix B) which was provided to the participant before conducting the actual interview. Following rapport establishment, the interview with open –ended questions began with the format

listed above. This served as the first form of data collection. Additional data collection procedures as described by Creswell (2007) were also utilized to further enhance the interpretation and imagination of the researcher as the essence of the experience was explored.

According to Creswell (2007), aside from the actual interview process, other data collection approaches include observations, documents and audiovisual materials. Observations are made by gathering fieldnotes of the participant as an observer and as a participant (Creswell, 1994). These observations serve to assist in the interpretation of the data collected by allowing the researcher to view behaviors, interactions and physical abilities of the participants. Documents utilized for data collection included a journal from the researcher which was kept daily. This journaling process was separate from the epoche process and served as a continuous self-reflective process that focused on the experience of the researcher during the interview process. Participant and site documentation was to be utilized in understanding and interpreting the experience. This was open to including photos, medical records (as shared by the participant), facility requirements or notices or other public documents related to the dialysis center and/or the treatment provided. Interviews were either conducted in the participant's home, the researcher's home or at a public location. Based on the content of the interviews, there were no follow up questions about tangible items that assisted with comfort or influenced adherence.

Audiovisual materials were also allowed for incorporation into the study. This was open to including songs from the participant, family videos, photographs or any type of electronic or voice correspondence. The purpose for this was to again, further

understand the experience of the phenomenon. This information was not to be explicitly requested unless the participant's responses included a reference to objects or materials outside of the interview. No audiovisual or other collateral information was used for the analysis of the experience.

Data Analysis

The analysis of data took place through a modified version of the Stevick (1971)-Colaizzi (1973)-Keen (1975) method (Moustakas, 1994). The first step in this process was to describe my own experience with the phenomenon. This has also been described by Moustakas (1994) as the *epoche*. In the transcendental phenomenological approach, the *epoche* is a technique utilized by the researcher to remove any prejudgments or preconceptions regarding the phenomenon. Through this process, the researcher “engages in disciplined and systematic efforts to set aside prejudgments regarding the phenomenon being investigated” (p. 22, Moustakas, 1994). The intent of the *epoche* was to allow the researcher to naively view the phenomenon with openness (Moustakas, 1994).

The next step in this process as described by Stevick (1971), Colaizzi (1973) and Keen (1975) included multiple steps (Moustakas, 1994). This process is described by Moustakas (1994) as transcendental phenomenological reduction. Through this reduction, the researcher is taken back to essentially, an existential experience of the phenomena (Schmitt, 1967; Moustakas, 1994) which assists in gathering a textural description. This understanding of the phenomenon may be attained by the following steps:

- a.) Consider each statement with respect to significance for description of the experience.
- b.) Record all relevant statements.
- c.) List each nonrepetitive, nonoverlapping statement. These are the invariant horizons or meaning units of the experience.
- d.) Relate and cluster the invariant meaning units into themes.
- e.) Synthesize the invariant meaning units and themes into *a description of the textures of the experience*. Include verbatim examples.
- f.) Reflect on your own textural description. Through imaginative variation, construct *a description of the structures of your experience*.
- g.) Construct *a textural description* of the meanings and essences of your experience. (p. 122, Moustakas, 1994)

These steps are first followed for the researcher's experience of the phenomena and then each step is then followed for the verbatim transcripts of each of the participants (Moustakas, 1994). Through analysis of all textural descriptions, a "composite textural-structural description of the meanings and essences of the experience" (p. 122) is formulated into a universal description that describes the phenomenon for the group (Moustakas, 1994).

Validation Strategies

In qualitative research, validation has more of a reference to the accuracy of the researcher's description of the participant's experience (Creswell, 2007). This process of validation is vital as this study attempts to influence improvements in hemodialysis treatments for American Indians. In order to insure the accuracy of the findings, I

followed validation strategies as described by Creswell and Miller (2000) which included field to data checking, triangulation, peer review, clarification of biases, member checking, and rich thick descriptions (Creswell, 2007).

In what I call field to data checking, Creswell and Miller (2000) discuss being in the field and making observations, building rapport and learning the culture as the researcher determines what is relevant to the study (Creswell, 2007). Through this process, the researcher was able to determine if there was misinformation based on the lack of knowledge of the setting, person or culture. Triangulation is a strategy I attempted by collecting multiple forms of data (Creswell, 2007) as collateral information to support or highlight the themes found in the data. The peer review process was akin to interrater reliability. Creswell (2007) describes this peer as a “devil’s advocate” (p. 208) in which a peer will question the methods used, the data and meanings the researcher describes to keep “the researcher honest” (p. 208).

An epoche (Moustakas, 1994) was written to clarify any biases I had based on my own personal experiences or through my experiences with family, friends or through my culture. This epoche included my role as a researcher and my personal background as well. I also engaged in member checking (Creswell, 2007). Through this process, I went back to the participants to insure I had accurately gathered and described the information presented. I used rich, thick descriptions to capture the essence of the experience (Creswell, 2007). These descriptions included verbatim examples of the experience as well as constructed themes based on the analysis of the data.

Ethical Concerns

In the formulation of the question and an analysis of participant well-being, I had many concerns about potential risks for the participants. These concerns included fatigue, emotional response, transportation and personal time outside of dialysis treatment. Fatigue was a concern as the treatment often leaves patients with little energy for the remainder of the day. Patients who have successfully adapted to the treatment regimen exhibit symptoms of fatigue after treatments but maintain energy levels in which they may remain active immediately after treatment. This concern led to the criterion (Creswell, 2007) based sampling selection procedure which requires stability in physical health.

Emotional response was also an area of concern as the treatment process is a life and death situation. Health concerns go beyond physical ailments and mental well-being may be an issue based on the changes in lifestyle as a result of the treatment regimen. Potentially conducting the interviews at the site in which dialysis treatments were received was to allow for direct access to physician care if needed. Transportation was also a concern as this interview and their participation should not create a hardship for the participant. Community Health Representatives are available on reservations and often provide travel for patients to and from medical appointments on and off the reservation. Therefore, it was determined to conduct the interviews during the dialysis treatment. This eliminated the concern for travel and did not take away any personal time from the participant. Although this was the expectation for conducting interviews, this was not the most convenient for the participant. Additionally, not all dialysis clinics were willing to allow the researcher to conduct interviews during treatment.

Additional ethical concerns were reciprocity, disruptions to the dialysis centers, consent, confidentiality and storing of data (Creswell, 2007). Reciprocity refers to the benefits received by the participant for their involvement in the study. The participants were asked to spend a substantial amount of time describing their experience on dialysis. A follow up with participants (i.e., member checking) also took place to ensure the experience had been accurately described, therefore, requiring time beyond the interview. Because of the distance between the researcher, and the participants, participants were contacted for member checking by telephone. For participants who were not able to be contacted by telephone, copies of the agenda for change were mailed and time was allotted for follow up. The study was based on an advocacy/participatory approach (Creswell, 2007) and a return to the participant was vital.

Disruptions to service at the dialysis centers was taken into consideration as the interview was proposed to take place at the dialysis centers. The researcher had to ensure the privacy of others was not violated and services were not interrupted by the presence of the interviewer. The researcher was willing to explain the process to all individuals in attendance and ensure their confidentiality through the interview process. Although interviews were originally planned to take place at dialysis centers, all interviews were conducted outside of treatment.

Informed consents (Appendix B) were provided to the participants and thoroughly discussed. The informed consent discussed confidentiality as well as the participant's right to discontinue the interview at any time. The participant was also informed of potential risks such as emotional distress as well physical and mental fatigue. Participants were informed information for mental health services would be provided if

requested. These services would be coordinated with local Indian Health Services or other tribal programs as necessary.

Data was stored in a locked filing cabinet and names were removed. Audio recordings and any other identifying information was also stored in the same location. The researcher was personally accountable for any identifying information as well as accuracy of data. Validation procedures took place to ensure accuracy of interpretation and follow up with participants was to ensure the accuracy of the description.

CHAPTER IV

Presentation of Data

This chapter presents the phenomenological data through structural and textural individual descriptions as well as composite descriptions. Each participant's interview and personal lived experience are described through verbatim examples of the lived experience. Descriptions and themes have been confirmed with participants through individual follow up meetings as referenced in chapter three. In an effort to protect the participant's anonymity, limited information is provided regarding location, tribal identification and locations of dialysis clinics. However, detailed information is provided for the individual about their lived experience with dialysis. When presented with the informed consent, participants were informed about counseling services and coordination. The researcher stated if there were any difficult emotional experiences due to their participation in this study, the researcher would collaborate with them to coordinate behavioral health services through the appropriate Indian Health Service facilities. The counseling services were discussed as directly related to the participation in the study and not promoted as an intervention to assist with adherence because the purpose of the study was to gain an understanding of their current adherence without impeding current well-being. No participants were interested in receiving services for counseling.

As originally stated in chapter three, the projected sample size was supposed to be 10, which is in accordance with recommendations by Creswell (2007). This was to include five women and five men. Recruitment proved to be a challenge for this particular study and the study concluded with six total participants which was comprised

of three men and three women. Posters for recruitment were posted in mid-December, 2014 until mid-March, 2015. Recruitment posters were placed at multiple locations in Oklahoma, Nebraska, Kansas, Iowa and South Dakota. These locations included reservation and non-reservation sites. Sites included dialysis centers, post offices, gas stations, and restaurants. These specific locations were targeted because they were high traffic locations on reservations or they were high traffic locations for American Indians and more importantly, they were directly placed at dialysis centers serving American Indians. As stated in chapter three, participants for the study would initiate contact through the approved fliers (see Appendix A) and within the first two weeks of posting, the majority of the participants had contacted the primary investigator. As interviews took place, it was interestingly noted that all participants who contacted the primary investigator were familiar with the researcher. There was not a personal relationship between the primary investigator and the participants, but each had openly discussed they either knew the researcher's relatives, received services from a program the researcher oversaw or had family members who were former clients of the researcher. But through this, there was some form of connection to the researcher which led to them initiating contact. This will be further discussed as a limitation in chapter and other routes for further research may be pursued when conducting this form of research with the American Indian population.

According to the protocol established for this study, the participants chose the meeting location and time. Although convenience sampling was referenced, the convenience was focused on the participants. The rationale behind this methodology was because each of the participants receives intensive dialysis treatments. These treatments

are provided three days a week with five of the participants receiving services on Mondays, Wednesdays, and Fridays. One participant receives his services on Tuesdays, Thursdays and Saturdays. Each of the participants receives services for a minimum of three hours with a potential of up to four hours and fifteen minutes. When participants selected a location to meet, confidentiality was discussed and the majority of interviews were in participant homes. One chose to meet at the interviewer's home and another specifically requested to meet at McDonalds. When informed about confidentiality and noise, she continued to request meeting at McDonalds.

The interviews with the participants ranged from 30 minutes to two hours. The interviews were recorded on a digital voice recorder which was always placed openly in between the researcher and the participant. The recordings began after the researcher provided a culturally appropriate introduction and presented the informed consent. The recordings were not paused unless the participant asked to take a break. At that time, the recording would be paused and resumed once the participant returned. Transcription was lengthy and averaged approximately two hours of transcription per 30 minutes of interview time. There were a total of 97 pages transcribed and analyzed for this project.

The format for the descriptions is first termed as an individual phenomenon. Through this individual phenomenon, an individual structural description is provided. This structural description provides a context for the experience. The structural description also describes the physical settings within the treatment settings, homes, transportation and experience with families of the individual receiving treatment. The individual structural description is then followed by an individual textural description. Through this textural description, the experience is described through invariant meanings

along with a description of the lived experience as provided through verbatim examples. This process essentially describes what takes place for the individual during their experience of dialysis. An individual essence of the phenomenon is then provided. This individual essence is a description of the phenomenon as best captured by the researcher through imaginative variation which is the researcher's interpretation. The chapter then describes composite textural-structural descriptions which will capture the meanings and the essence of the experience as described by the group. This composite textural-structural description summarizes the group experience through the experiences provided through the interview. The composite descriptions are also based off imaginative variation in which the researcher derives themes of the descriptions provided by participants (Moustakas, 2004).

Through these interviews, many idiosyncratic experiences were recognized. However, even with these distinctive individual experiences, there were also a number of similarities that are written as invariant themes of the experience. Tables are provided as an illustration of these themes. The chapter concludes with these themes as a narrative to capture the essence of the experience of American Indians receiving dialysis due to complications of diabetes and how it relates to treatment adherence.

Suzy

Individual Structural Description

Suzy is 53 year-old divorced American Indian woman from an American Indian/Native American tribe located in the Aberdeen Service Area of the Indian Health Service. She is an enrolled member of a federally recognized tribe and receives her dialysis from a non-Indian Health Service Site. She's been receiving her dialysis

treatments since August, 2010. She receives treatment three times per week (Monday, Wednesday and Friday) for four hours at each treatment. Suzy completed high school and has four adult sons. She lives with one of her children and is currently unemployed. Suzy has Type II diabetes and has had other physical complications. She has had a stroke and is now paralyzed on her left side. She stated she may be going blind in her right eye.

The first question presented to all interviewees is a broad question that asks about their overall experience on Dialysis: “What has been your experience on dialysis”? Suzy states “At first I was really scared, and then seeing all that blood, but I was asking questions: how you know, how does it go, what comes in and what goes out-oh that I’m still learning about because I’m still scared.” This feeling of being scared appears to be based on the knowledge about the procedure and how dialysis was introduced to her. She states her treatments of dialysis started rather abruptly “I just woke up that way so I had no choice, to even think that way you know? But I did like wonder like what your guys doing?”

In general, when a person is referred for dialysis treatment, there is a new patient orientation. This training will cover multiple areas including changes to body, diet, etc. Suzy discussed her introduction to dialysis as a fairly brief orientation. When asked if she received any type of training or education to explain dialysis she stated:

They pretty much did and if I can remember I did it in (clinic location). It was pretty quick, it was pretty fast. Those girls, um, seems like, seems like I was scared because they were younger than me and they pretty much hurried up and put your needles in and you know, sit there and that was it. They didn’t say where that thing was going, you know, where all that stuff was going.

Suzy also describes mixed feelings about what may be viewed as scheduling limitations. It appears to be a developmental process in which adjusting to these life

changes leads to what seems to be appreciation of such a strict regimen for self-care. When asked how her schedule with family, friends, and work has changed, Suzy states that it “changed a lot cause of dialysis. There are days you know I can do things and days I can’t. That’s the bothersome part and if I wanna leave for Christmas, I have to count my days or if I wanna spend the weekend with somebody I gotta count my days and my rides and all that so that’s pretty strict. It turns your life around, it, you get used to it.” She also states “going to bed you know on time is just like being a school person, going to bed on time so you can get up.” Although Suzy describes challenges with scheduling limitations, she also states “I like the way my life is because I’m used of it being quiet and having time to do something for myself and then instead of saying oh no, there, here, I can’t do nothing you know. Cause before they (family) were always here, here, here! But, they know I’m on dialysis, that, you know”? This was described by the interviewer as having structure in her life with people respecting her space and she confirmed this interpretation.

In addition to the changes in scheduling with family, friends, and work, transportation is a constant concern throughout the full experience of dialysis. Suzy is transported to her dialysis treatments by the local hospital. She states:

...it’s a nuisance because the drivers, the transportation, you don’t know when you’re gonna get picked up. Sometimes they’ll pick you up when it’s dark outside and then you’re getting home like about 6:00 at the latest and I’m like geez, I don’t know about that. And we have a new driver, new drivers and it seems like I have to train them. I’ve been on there the longest and what do we do? What are we supposed to do?

A unique experience to Suzy’s life on dialysis is the additional safety precaution her son has her taking by keeping a phone on her at all times. She discussed wanting to call the hospital to make a complaint about how they are treated by transportation but she

did not want to use too many of her minutes from her phone. She stated “I should go down there and talk to her cause my minutes are, I only get 100 minutes. I gotta save this just in case, nobody calls, I usually use it for emergencies. For you know, cause (Son) wants me to have one by me constantly but I got another phone number by me too.”

When asked if that was for safety precautions, she stated “Yeah, that’s why wants me to have a phone because there won’t be anybody here and if I fell or and I can have that phone by me and then call him or call the CHR’s or the hospital or whatever.” Suzy actually carries two prepaid phones with her that are limited by minutes. She carries multiple phones with her because while one is charging, she carries the other. For Suzy and her son, this has proven to be an effective safety precaution in case she is an emergency situation and she is alone.

Individual Textural Description

Suzy has been receiving dialysis treatments for approximately four years. She states it took her about a year to feel like she adjusted to the change in her lifestyle. During this adjustment period, she had many emotional experiences before she became comfortable with her treatments. She states:

At first I was really scared, um, and then seeing all that blood, but I was asking questions, how you know, how does it go, what comes in and what goes out. Oh, that I’m still learning about because I’m still scared. But I like it because I know, I know I can’t go to the bathroom anymore but I know it cleans my blood and I’m glad I don’t have to do it like some people prefer to do it, I’d rather do it myself, I mean go to the dialysis.

In addition, when starting the process of dialysis she states “It was painful, mentally it was painful, ok, and mostly just feeling like it was a hassle.”

Fear and limited knowledge about the dialysis procedure appeared to be the most challenging for Suzy. Without knowing what was fully taking place during the

procedure, her experience of fear continued to increase. She states she was “scared, like looking at everything” and she would ask questions such as “why?” and “where does that go”? She stated she was “scared” and wanted to make sure staff members at the dialysis center knew what they were doing. She states, “Why are you, why do we have to put a glove on and why do you guys gotta wear gloves constantly”? She also states, “I always made sure they wore gowns and stuff when I knew that was what they had to do and I didn’t want them to touch nobody else, you and then come over and use the same glove to touch me.”

Suzy also recalls experiencing withdrawal from interactions with her family members and frustration that eventually led to a release of emotion. She describes this cathartic event as resulting in acceptance of the procedure. She describes her withdrawal as “I used to be like that, I used to be like that, no I don’t wanna talk, nobody talk to me, I don’t wanna say hi to nobody, I don’t want them to say hi to me, I don’t even wanna look at them.” But as she continued adjusting to receiving the dialysis treatments she states:

I got tired of getting ready and going the same time and seeing the same people that I had to be with... And I just got so sick and tired of that and the routine so and that was going to dialysis and having to get ready and make sure they were ready and sometimes they weren’t ready for me and, and so I got mad and just said I’m not going no more! I wanted to quit then and I just started crying loud. I didn’t care how any, what anybody said I was just like (loud crying sound), I just screamed and I screamed that out then after that I started you know, enjoying going to dialysis. I thought it was worth it, I still think it’s worth it.

In addition to this range of emotional experiences, Suzy describes changes in interactions with her family and friends. She describes how her family initially pitied and wanted to wait on her. This was challenging for her as she holds on to what independence she has. When asked specifically about interactions with friends and family after starting dialysis, Suzy states:

Um, well they came around saying oh, oh this you know and I'm like, hey, I'm still me and I'm gonna still do, you know, what I wanna do. Like get up and open that refrigerator door, get up and sweep... I mean I can still move my arm, I can wash it. You know, I'm not gonna baby myself because of that. Cause otherwise that will make me feel really depressed. And before I was started feeling like that, feeling real depressed, feeling pitiful you know, but I'm like my family and my family would make me feel that way too. You know like "Oh, you know help her out" you know and I'm like nope, I can do it.

Through her adjustment to being on dialysis, she talks about the poison. She describes her awareness of this poison as a contributing factor to her adherence to treatment. Suzy states:

Not knowing that you're going to the bathroom and knowing you got that, that poison in you. And I don't want that in me in cause that's what makes you sick and it makes you die you know. And so I don't want that. I tried it once and it took me only one and I got sick. And they took me to (hospital) and they took me out of there, they took me out of the ICU and then I was good. And so, I don't wanna go through that and so that makes me go.

Individual Essence of Phenomenon

The phenomenon includes emotions of fear, depression, frustration and eventually, contentment and acceptance. These experiences as described in the individual textural and structural descriptions suggest the abrupt onset of dialysis treatments without thorough training, increased feelings of fear and being unsafe. As she began the difficult process of dialysis treatments, she questioned the safety of the staff members as well as the function of the machines. She states she is "still learning" but her knowledge base has increased and she will often ask questions about the procedure.

Because of the severity of the treatment process, self-reported depression occurred based on feelings of pity from her family members as well as self-pity. She was able to overcome these feelings of depression by embracing her independence. Her independence was and is valued but this was initially viewed as a challenge by her and

her family members. She discussed family members doing things for her and how she has been able to tell them “I can do it.” But as she continued to receive treatments, the independence was valued and served as a way to combat depressive symptoms. Through this independence, she grew with her acceptance of the procedure and was able to offer support to others who were beginning the process. She talked about the procedure bringing her close to others. She states, “...especially the newcomers-you know, I try to help them out you know or make them get in a good mood you know. Or just talk to them like don’t make yourself feel sad and stuff because you’re on it because, for life, if you wanna live longer.”

Chuck

Individual Structural Description

Chuck was a 68 year-old married American Indian male from an American Indian/Native American tribe located in the Oklahoma City Service Area of the Indian Health Service. He was an enrolled member of a federally recognized tribe and received his dialysis from a non-Indian Health Service Site who passed away shortly after the interview with for this project. He had received dialysis services for about four years. He received treatment three times per week (Tuesday, Thursday and Saturday) for four hours at each treatment. Chuck was a disabled veteran who had completed high school and attended college for about three years. He had Type II diabetes and reported no other physical conditions other than “I’m a pretty old man.”

When asked about his overall experience of dialysis, Chuck states, “I don’t like it.” With starting the procedure and his orientation, he states “They explained it to me and uh, they explained it pretty well. I seen it done and I knew, I pretty well knew what

is, what was gonna happen.” His experience with dialysis suggested a level of comfort with adapting to the intense procedure. He states “Ain’t nothing to it, ain’t nothing to it. You go in there and you get hooked up and kick your feet back, turn the tv on, go to sleep... I go back to sleep when I go in there.”

Chuck mentions positives and negatives of his experience receiving dialysis. He describes the interactions within the dialysis center as friendly and the peer interaction seems to help with adherence as this is a form of positive social interaction. Positive social interaction is fairly limited for Chuck. He had shared that many of his friends had passed on and he is unable to relate to the younger generation. However, he reflects upon how his positive outlook on life has helped him during his time on dialysis. Chuck states, “I’m a friendly person. I go over there and joke with the nurses and and uh, the that are that my buddies that are there, the ones that are still alive, we kind of grin at each other and laugh and uh, like I say, it’s staying alive.” He also describes limitations to his schedule. He states “I can’t travel no more, it ties me down to a certain area. I can’t go to all the pow wows I used to go to. It ties me down.”

Individual Textural Description

Chuck was very limited with describing his emotional experiences while receiving dialysis but he was able to focus on his strengths while adjusting to receiving dialysis treatments. His descriptions of depression were described as experiencing depression but he did not provide examples of what how his depression manifested. He stated “I’m an old Nam vet, I was an old green beret and I know how to stay alive so you know, I got a pretty good attitude of the world. I don’t let things get me down.” With his

emotional experiences he stated, “you know, I’d say you get depressed, you get pissed, but that’s a part of life, that’s it.”

When asked about what assists with adherence, Chuck states “Well, you just go that’s all. You wanna stay alive, you go. If you don’t go, uh something bad happens to you, worse things will happen to you, you’ll lose, you’ll start using limbs, your sight and it takes you in and you don’t wanna do that, you’ve lost enough already by not taking care of yourself so, so you go to take care of yourself.” Interestingly, even as he describes this process as something he does not enjoy, there appears to be thoughts of survival that have kept him regularly participating for this length of time.

Individual Essence of Phenomenon

Chuck’s experience with dialysis seems to have been an experience in which he didn’t fully feel comfortable but he equated his treatment with his time as a Green Beret and recognized this as a form of survival. He appeared to be fully informed about the procedure and had no additional concerns about the efficacy of the treatment. He utilized this time to socialize and have healthy interactions with staff members and peers. His time on dialysis appeared to be viewed as a choice for survival and he was choosing to live.

Chuck was also able to interact with peers outside of his dialysis group. He would visit with his friends and states he would still have a beer every now and then but he didn’t really miss it. He was limited in sharing his emotional experiences and chose not to go into detail about this area of his life. The researcher cautiously hypothesizes this response as an additional form of his survival mentality-a survival mentality that also embraces stoicism. As the researcher, I was unable to do a follow up with Chuck as he

was hospitalized in the intensive care unit before coding was completed. From the Intensive Care Unit he was transferred to a nursing home. He passed away at the nursing home.

Ted

Individual Structural Description

Ted is a 54 year-old married American Indian male from an American Indian/Native American tribe located in the Aberdeen Service Area of the Indian Health Service. He is an enrolled member of a federally recognized tribe and receives dialysis treatment from a non-Indian Health Service location. Transportation to dialysis is provided by an Indian Health Service hospital from the area. He has been receiving dialysis treatments for about 11 years. He has tried peritoneal dialysis and has also considered a kidney transplant but has chosen to stay with dialysis for the time being. Ted receives dialysis three times per week (Monday, Wednesday and Friday) for four hours at each treatment. Ted lives with his wife and is often visited by his granddaughter. He is currently unemployed and completed school up to the 8th grade. He states he has no other physical or mental health conditions.

Ted's wife sat in for the first portion of the interview and left shortly after the questions began. She stated Ted has been diabetic since he was 16 or 17 years old. When asked about his experience with dialysis, Ted states "Um, my experience on dialysis umm... all bad." He laughed after answering and then his wife shared that Ted had tried multiple forms of dialysis. She states "He did peritoneal dialysis, he's done hemo in his arm and then peritoneal and he's gone back to the fistula in his arm." When asked about his orientation to the procedure, he states he did not receive any type of

training or education for the procedure but he was given advanced warning of the possibility of dialysis treatments being necessary for him. Ted states “they were telling me that you’re gonna be on dialysis you know if you don’t take care of yourself.”

Ted states the experience is influenced by his own self-management behaviors but the staff members also contribute to the experience as being positive or negative. Ted states:

It wasn’t bad when I first started, but slowly it started getting worse you know, because uh, when you gain too much weight, you know, they try to take it off, you got a dry weight they want you to go down to and stay at. Sometimes, when they take too much off, it just drains you, you know? You can’t get up, do nothing same day, next day at that you finally get better then turn around and you gotta go right back the next day (laughter). They don’t give you much time to recoup. I mean most of that’s your own, your own fault because you drink too much. You drink too much fluids you know? Lately I’ve been kind of keeping down a little bit and ain’t done too bad you know but uh, lot of it’s uh, those techs up there. Some of them they don’t stick you right and they mess your arm up you know? I had that one for 8 years (points to arm) until they messed it up. Now I got it on this side over here. This one here just now starting, this one here is probably like almost 2 years.

In regards to transportation, Ted has a unique experience as he will, at times, drive himself to treatment. He typically utilizes the transportation service offered by the Indian Health Service hospital in the area and states:

They’re pretty good sometimes. But sometimes they oversleep or get over there late (laughter). I got my own car so if I think they’re gonna be late, I just take off you know. Or, I can tell when somebody is gonna be late or not there you know. Certain guys we ride with, we know what time they’re gonna be there and if somebody switches off to their shift, you know and they a lot of times, they don’t show up or anything or show up real late you know? Then and then it screws you up too when you’re late because when you get up there you know you can’t do the full treatment sometimes. They want you to get out of there because somebody else’s chair there is next you know.

Individual textural Description

As stated earlier, Ted's wife participated in the first few minutes of the interview. She stated "actually, the first 3 or 4 years, I took over his illness, it was my illness, mine to take care of, it was all me. But I finally gave it back to him and said this is you." They both describe a change in his socialization and report they had multiple arguments over his behaviors and they would often be mad at each other. His wife stated he began to isolate himself and he states "I don't know, I quit going around everybody. I pretty much stayed down here." In terms of family interaction, they noticed withdrawal from Ted as family members initially came around to offer assistance but he pulled away from their efforts. He states this isolation doesn't bother him and he is more concerned with spending time with his granddaughter. He states the experience of dialysis affects their interactions and he will at times be "crabby" after his treatments. He states his granddaughter is aware of the changes in his mood because of dialysis and will keep her distance when he is having a rough day. His relationship with his granddaughter also serves as a motivator for adherence and has him reconsidering a transplant. He states "since the grandbaby comes around pretty regularly and she's getting older now you know, I figured it might be better, healthier, might be healthier you know, stay alive a little longer."

Based on the interview, Ted appears to embrace his independence and doesn't want to be treated differently. His independence is evidenced by his willingness to transport himself to and from dialysis. In regards to being treated differently, he states "those guys make me mad up there though because those guys treat you like little kids.

You know, some of those older ones you know, like to be pampered like that, not me man, I don't like that."

Individual Essence of Phenomenon

Ted has been on dialysis for approximately 11 years but has been diabetic since he was a teenager. His adjustment to living on dialysis took about three to four years and this appears to have been related to his wife taking on much of the responsibility. Her taking responsibility resulted in tension within the marriage but once she limited her involvement, Ted began to value his independence and adjusted to the lifelong procedure. His independence is an important component of his adherence and he recognizes he is in control of how he cares for his body. This level of independence lends itself well to the isolation from his family as he does not want to be treated differently or "pampered" in any way. He recognizes he should've taken better care of himself when he was younger and he is making strides to do so. He is not treated differently by his granddaughter and she understands when he needs time alone. This relationship is a significant motivator for his life and his independence strengthens his adherence.

Chantell

Individual Structural Description

Chantell is a 58 year-old American Indian woman from an American Indian/Native American tribe located in the Aberdeen Service Area of the Indian Health Service Area. She is an enrolled member of a federally recognized tribe and she lives on the reservation of the tribe in which she is enrolled. Chantell receives services from a facility within the boundaries of her reservation. She has been receiving dialysis treatments for approximately eight years. She receives her treatments three times per

week (Monday, Wednesday and Friday) for four hours at each treatment. Chantell lives with her husband and her grandson. She has two children and her highest level of education was reported as the 7th grade.

Chantell states she first got diabetes when she was pregnant with her children. Because of her gestational diabetes, her medical providers had given her warnings about the increased probability of getting diabetes later in life. She states:

It's not easy, but I got diabetes when having my children I said. And they told me you'll get it later on when you get older and I didn't listen to them, I said I just kept doing what I wanted to do instead of drinking more water, doing more exercise I said but I figured working, that was exercise and it's not cause I was working at a daycare and I figured running around there with them kids, that seems like it. But it's not. My doctor said that's not even exercise. So I said it is to me! Running up and down the stairs, bending down, kneeling on the floor, playing on the floor. Nope, it's nothing he said. So... yup.

Since starting dialysis, she has gone through many changes for herself. These changes have not been limited to her experience alone. Her family had also experienced changes as Chantell adjusted to her life on dialysis. She initially stopped cooking for her family and limited their diet to rice. She states this was challenging because she grew up on soup and was used to eating much more. She states:

And I can't eat, basically I can't eat anything I said, if I want to then I have to sneak you know and then if I get hungry for it, I told the doctors when I first started I was living on rice. And I had them living on rice. My son and my husband. And my son goes why do we gotta go on a rice diet just you got to and I said, I don't know and then I cried to the doctor one day and he said what's the matter and I said, how come I can't have anything to eat I said and I grew up on tomatoes and soups and everything I said and I can't eat them and I'm tired of rice and he goes you can, you just have to moderize it he said don't overboard it. And I said now you tell me, so I went home and made supper I made ghoulish and everything and my son goes (deep breath/gasp) she's back! (laughter from both), he said Dad, Mom's back he said. She's cooking again, we don't have to eat rice but I made it where they don't care for rice now cause I went I think 3 months with just eating rice.

Along with the changes to diet, Chantell experienced limitations to her physical abilities as well as limitations to scheduling. She states:

There's a lot of things that I can't do and I can't you know do certain things cause I have a fistula and there's a certain way you can't sleep. It's rough and then you gotta take like, for me, this is all my meds right here (shows turquoise bag) I take these every afternoon and in the evening. That's what kind of gets you down cause I can't forget that bag. That's my life. And then it's just, I used to walk around a lot and now I barely walk around. I can't stand too long cause (pause) cause then my husband goes why, how come you don't cook up like used, cause I can't stand at the stove and my back hurts I said, so he's like well show me how to make bread, I'll make it.

Chantell also describes how her life revolves around scheduling of dialysis and she states:

I always think oh I got a day to do nothing. Lay around and get ready for dialysis, like today I'd be sitting here like oh I gotta go to bed at 8:00 cause I gotta get up at 3. And then that's how it is for 3 days out of the week. The weekend when I don't think about dialysis, I don't, thinking about nothing. Just do what I have to do.

The weekend serves as almost a reprieve from the routine of dialysis. She is not concerned with when she needs to go to bed and she tries to be more active and engaged in cultural activities during this time.

Chantell describes the interactions at the dialysis center as a mix of positive and negative interactions. The healthy interactions have been helpful in terms of adherence. She states:

This keeps me alive every other day so I might as well go but then sitting there and watching, the only person that really truly helped me was my friend. And I'd say her name, but she talked me through it. She talked me through it cause I was scared to death of needles. And I was scared of being there. She just talked me through it. She said, it's nothing. It keeps you alive so don't panic and just keep coming. So I did and she made it like a game for me and I understood what I should do.

Her negative interactions are more related to the treatment of the nurses. She describes the interactions as conflictual between the nurses and patients as well as

between the Tribal Council and the nurses. These conflicts have led to high turnover rates for the nurses in the facility as many would either resign or were terminated from the facility. An additional component of this tension was due to issues of race. She states her friend:

...and I were dealing with the dialysis at how we had no nurses and how the people would take them and what would they do, they would cuss them out like they were nobody. And I'd holler don't talk to them like that, they have feelings too. Tribal council wouldn't do them right and then I said there are so many nurses that came through here that we liked and they'd end up quitting or they would take, get rid of them and they just, I don't know, they just put up with a lot. Dealing with Native Americans is hard-especially being White. And then they always, that one lady that passed away always said we want Indians in here working. Well if they're not nurses then they're not qualified, how you gonna get them to work in here? And I, and they'd get mad cause I'd say I want a White nurse. Why? Because I know they went to school and they know what they're doing. And they go well what's wrong with the Native American? Nothing, but I'm, I'm comfortable with who we have here now and with you guys chasing them off, it's hard to let new people in here and stick your arm cause they don't know how to stick your arm and I'm not gonna be a pin cushion for anybody to just stick my arm.

Individual textural Description

Chantell describes being treated differently after she started dialysis. She often felt as though she was treated like she was fragile and she felt as though she and others who received dialysis were forgotten as though they were already dead. She states "when I first started, everybody, when I'd say I'm on dialysis, the look and um like it was my last day, you know. Like Aw man, you're on dialysis? You only live to 7 years, you know"? Conversations she would have with peers would often be about life expectancy. She states "So, but yeah dialysis is really hard and people don't understand and they make it worse when they sit there and go Oh-how much longer do you think you have? You know you only live to 7 years on dialysis and I go no they don't! And I said you could live as long as you want on dialysis." Chantell shared about a conversation she had

with a tribal leader. This conversation reinforced her belief of how they are forgotten. She states “Everybody forgets us, since it’s like we, it’s the end of the world and he goes well it is kind of and I said no it ain’t. I said we come here every other day to stay alive.”

In addition to these interactions, Chantell’s time on dialysis has led to many emotional experiences. She reports psychological effects which were described as feelings of fear, anxiety, depression and isolation. She describes waiting to start because of her fear of death. She states, “I waited a year before going on it because I didn’t want to be like everybody else. Oh man, I’m only gonna live so long and I could go to sleep and never wake up.” She states she eventually started going to dialysis because of her son. She states “he kept saying I want you here forever and I don’t want you to die and you look like you’re miserable. I was so, I was so swollen. I couldn’t move, I couldn’t walk and I just finally, I just went and I said I guess he’s right.”

As she describes her depression, she highlights how the process of grief from losing her son affected her questioning adherence. After her son died she states “I told my husband I feel like just giving up. I don’t want to go anymore.” She states that now she is fine on dialysis but she still has days in which she is emotional. She states, “There’s days where I’ve come home and I’ve cried and I called my sisters and I said I don’t want to do this no more. You guys just don’t know what it’s like, the stress and sitting there and hearing people, it just it gets to you and it gets to you really bad I mean, like you go and you sit there and you hear them say well it’s ok, you know and then a lot of them are sitting there crying and or they’re upset and they’re angry and they cuss everybody out.”

Throughout her time on dialysis, she describes how she has had many physical concerns. There were physical limitations that affected her ability to cook for her family and maintain employment. She also describes the physical pain she experiences through this process. She states:

Yeah, I get dry skin and then we get those, we get those calcium bumps, like I have one right here (points to inner arm) and in my legs. And then they hurt. And then sometimes um, you get boils and then your neenday (English translation: butt) gets tired from sitting in the chair for 4 hours. Mine does, get cramps, cramps are the worst though, cause you get them in your chest and in your legs and that really hurts. And I could see being upset but when I get them I tell them, just take me off, don't try to stand there and say are you ok, are you ok? Cause that makes me mad I said. I'm in pain and you know I'm in pain cause the tears are coming down. And I said I could be like the rest of them and cuss you out and say take me off this got damn machine I said but all I say is take me off please cause I'm cramping and that hurts I said. You guys should know, if anything you guys should know the cramps are the worst here and if you bleed out I said and I know why they have to have so many nurses that are watching everybody cause you move the wrong way, your needle could slip and then you bleed out and they don't know.

Chantell has maintained regular and consistent attendance at dialysis. Factors affecting her adherence include her family, peer interactions and her own personality.

She states:

...a lot of them are sitting there crying and or their upset and they're angry and they cuss everybody out. I said you don't need to do that and me, I like to tease, I like to joke, I like to laugh and I act goofy sometimes cause I'll go in there and I'll start singing, you know hey it's cold in here, there must be some "specific tribe's" in the atmosphere, They're all sitting there going she's retarded. Or I'll dance around or I'll tease the nurses or I, there's another lady that sits next to me and her and I will tease and I'll say if you come in here gloomy then you go out gloomy.

Individual Essence of Phenomenon

Chantell has been receiving dialysis for eight years and she maintains consistent adherence to the procedure. Throughout her time on dialysis, she has experienced many emotions and changes within her life. Her immediate family was the initial reason for

starting dialysis. While family contributed to starting the procedure, adherence was associated with positive peer interactions and her energetic personality. There are days she struggles with dialysis and she feels tired from the schedule and being almost forced to experience the emotions of others who have not yet accepted their involvement with dialysis. Experiencing the emotions of others as well as conflict within the facility can make some days harder than others. But as she states “if you come in here gloomy then you go out gloomy,” her personal characteristics of optimism show as a major contributing factor to her adherence and helps her spread positive energy to others within the facility.

Grayson

Individual Structural Description

Grayson is a 38 year-old American Indian male from an American Indian/Native American tribe located in the Aberdeen Service Area of the Indian Health Service. Grayson has been receiving dialysis for approximately seven years and he originally started treatments in the Oklahoma City Area of the Indian Health Service. He currently receives services from a dialysis center located on a reservation. His treatments are received on Mondays, Wednesdays and Fridays. Treatments typically last about four hours. He is currently unemployed but states he is able to do contractual work teaching cultural practices to adults in the area. Grayson is single and reports he has completed some college.

Grayson describes the experience of dialysis as including a great deal of adjusting to the scheduling of the procedure and limited flexibility which leads to a great deal of planning. He states, “It’s like, like adjusting your life to the whole thing. It’s like um,

it's like um almost like a job. You have to reschedule everything around it cause it's part of your life.” He states:

I think that was the biggest thing for me, just adjusting. I can't get up and go like I want, like if I wanna travel it's hard for me, no, not really hard to do it, it's just I just gotta plan things in advance. I have to be really, oh, what is you have to, I have to be really like uh, definite on my plans...I need to know um two, three weeks in advance that I'm gonna go for sure.

Grayson describes his adjustment to the process but experiencing the procedure and seeing his blood is what actually contributed to his adherence. He states:

the whole weekend I ate nothing but greasy foods like Italian, I love pepperonis. I was eating Italian at the Olive Garden and I was having like Pizza Hut and I was just having like stuff like that and one of the nurses was like what did you eat this weekend and you could see it looked like red cooking oil. It was that greasy, when I seen that I was like, you know what, no.

Individual textural Description

As Grayson continued with his treatment, he experienced many emotions, physical changes, and changes within peer interactions. He discusses losing his sister and how eventually, the emotions became too much to bare. He states he had a “breakdown” and his “emotions run real heavy sometimes.” These emotions include depression and anxiety. His depression was experienced as a result of what he believed he lost, the loss of his lifestyle. He states “I did get depressed cause I thought I can't do what I used to, I can't live like I used to you know, that was it just disbelief and just I, you know, what I used to do you know. I thought that was I would have to live like an old person you know?” The anxiety he experienced occurred directly during treatments and was related to possible complications during dialysis treatments. He states, “your blood pressure will drop or you have a cramp”. He states “I had to train myself not to panic or anything because some people panic and they just really get you, you got to teach yourself you

know, just be calm”. With all of these changes he states “I try to be what I used to be before I went on, I just try and it’s hard to do and sometimes I keep trying to be like how people seen me before that”.

Having people see him the way they always have was an important factor for Grayson because of the changes in peer interactions. He tried to keep people from knowing he was on dialysis but after physical changes took place, it became more difficult to conceal. After his family members and friends became aware, interactions changed. He states “I knew they felt sorry for me or they pitied me so and I know as soon as I seen some of them and it was like it was just like a pity party for a while and I didn’t want that”. He would tell his family and friends “It’s still me, I’m still doing what I’m doing you and so I said, so don’t pity me, don’t feel sorry for me you know, just don’t, I don’t, I don’t want that. You know I said talk to me, don’t talk about dialysis, just talk about what we used to talk about before”. Grayson also experienced physical changes within his body. He states:

You don’t notice it right off but then you start you know your body and as time your chemistry kind of changes, you know not like, not everyone’s the same but your chemistry done changed like I think It’s your body adjusting to it like your skins dryer and then your hair is like finer or it might even thin out. And then it’s just things change, depending on your body. And you’ll notice like, it’s like it’s like maybe you kind of age a little bit and it’s just how you take care of yourself it’s like you don’t have like, like used to, I could just jump off this no problem and now I’m just like I question it if I’m gonna if I’m gonna survive it.

Adherence to treatment came as he saw how his eating habits affected his blood. In addition to this visual experience, other factors that contributed to his adherence include faith and belief in God, family and his friends. Based on his religious beliefs, he states if he were to not adhere to treatment this would be “suicide.” He further states “I just thank God that for my friends and family you know and really truly I don’t think I

would've got through it. Of course, God got me through it but friends and family, I think that's what got me through it".

Individual Essence of Phenomenon

Grayson's experience with dialysis continues to be an evolving process. He states "I continue to be active and I try to dance and I just try to live normal cause in the beginning I thought it's over. I'm not gonna do anything but then I guess I studied, studied and read about it, everything is damned if you do and damned if you don't". And although he makes the statement "everything is damned if you do and damned if you don't," Grayson persevered with positive interactions, appropriate dietary changes, physical activity, and increased knowledge about the procedure.

His experience includes emotional liability and changing peer interactions. Because of the heaviness of his emotions, his self-care includes limiting his emotional availability to his friends and family. His increased knowledge about the procedure and his livelihood helped him realize he was able to continue to engage in the same activities he did prior to receiving dialysis. Family, friends and religion are also significant contributing factors to his adherence.

Olivia

Individual Structural Description

Olivia is a 56 year-old woman from an American Indian/Native American tribe located in the in the Aberdeen Service Area of the Indian Health Service. She is enrolled with a federally recognized tribe and has six children. She lives with her youngest daughter and receives her dialysis treatment from a non-Indian Health Service site. She is transported to dialysis treatments through public transportation that has been

established specifically for individuals receiving dialysis treatments. She has been on dialysis for approximately three years and receives her treatments on Mondays, Wednesdays and Fridays for four hours and fifteen minutes at each treatment. Olivia is widowed, unemployed, and states she has been able to complete one year of college. Olivia has Type II diabetes and she reports additional medical complications of high blood pressure and arthritis in her knees.

Olivia states even with prior warning about the possibility of receiving dialysis treatments, that starting was a “shock”. She states:

That doctor called me and he said Olivia are you sitting down, I said yeah, why what’s the matter...we need you to come in tomorrow, I said ok, what’s wrong, what what’s going on? He said we’re gonna start you on dialysis tomorrow. I said tomorrow? It was like somebody hit me right in the chest and knocked me out of wind. I said, I just sat there for a while, I said um okay, I didn’t know what else to do and then um, like that my daughter came and got her food and I told her but her expression didn’t change but she said she felt the same way.

She describes the orientation as abrupt but helpful in terms of identifying her emotional experiences. She states:

Then when that time they just threw me into it, you know? I got to the hospital, they put me in it, on it and then they told me I would, they gave me the schedule so after that I just started going. And, then they said that I was supposed to go through a training thing that “designated location”, I never did it. I was on dialysis, I started July I didn’t get into it till the end of August so I was on it was almost a month. And then I finally got the training. And that’s the stuff that they explain to you about um being in depression and having people there to help you with it and stuff.

Olivia describes her experience with transportation as challenging because there are two separate companies who provide the transportation and they have multiple people to transport which leads to an extended day. She states:

And then I have a hard time with my cabs because they don’t come on the same time all the time. And sometimes, now they got this program called “name of program” and I have hard time with that because they’ll switch the people. The

program “name of specific insurance company” will have me go with the cab company one day the next time it’ll be with-I forgot what it’s called now-“other transportation program.” That’s a new one and I don’t really know who’s got me so I have to call both of them and find out who I ride with so that way I’ll know.

Olivia states she tried peritoneal dialysis and has looked into a kidney transplant.

She has chosen to stay with dialysis because of how traumatic her experience was with peritoneal. She describes a time at home in which she was receiving her treatment and as she was “reaching for the tape” for her needle, the needle came out of her arm. She states:

It was just blood all over and my little grandkids, my two girls were in there, “name of daughter’s” two girls. You should’ve seen the expression on their face, like they were just staring. I said go watch tv, go turn that cartoons on, I got cartoons in there. They went in there and I said “daughter”, I’m stopping, I’m not gonna do this anymore. I’m gonna go back to the center, she said you sure mom? I said yup, you should’ve seen their faces. And it scares me too to think just that one, by doing it wrong it could put an air bubble in your vein, it could kill you. I told her I said I’m done, I’m gonna go back to the center. And she said are you sure, I said yeah. So I did. I took everything back over there and I went back to the center.

Individual textural Description

Olivia’s experience with dialysis includes changing family interactions, limited interactions with peers, physical limitations, fear and depression. She states:

At first, it was like people were scared of me. Like they didn’t want to be close to me because they still drink, they still go out and stuff. They kind of like, I don’t know what they thought of me. I thought they treated me like I’m real fragile. And I told them why are you doing that, why are you acting funny? They said well, we don’t want to make you do anything you don’t want to do and I said if I don’t wanna do it, I’m not gonna.

She initially experienced withdrawal from her family. With one of her daughters, she states:

She didn’t know how to address it so she ignored it you know and that was for something for a long time. She would kind of stay away, she would call me but

she didn't come. But she said she didn't want to think about, she just she just said she associated it with me dying.

Olivia also describes experiencing physical limitations. These physical limitations have affected her ability to work and hold her grandchildren. She states:

I can't lift nothing cause of this thing on my arm. They tell you not to lift nothing too heavy. Right now, I can't even lift my grandkids because my little baby, he pushed my arm right where it used to buzz right here. They had to change the whole thing.

As a result, she has had a number of complications. She states she regularly experiences physical pain. She states "Even with my sleeves and my coat, I have to move it all the time cause it kinda irritates it, it hurts." In addition to the physical limitations, a unique experience to Olivia's time on dialysis includes her increased allergic reactions. In addition to keeping all of her medications in her purse, which she states sounds like "skittles", she must now carry Benadryl with her. She states:

I have to carry Benadryl with me because they still can't pinpoint what's going on with me. When go to dialysis, some days I can, I will just break out all over my back. Back here, my arms. One time, it got real bad, it was all over my face. I could see welts all over my face.

Olivia's emotional experiences while on dialysis included fear and depression. She describes her fear as being more related to a lack of knowledge about the procedure. She states after receiving her training for dialysis, her daughter had asked her if she was scared. She responded with:

...it just made me realize you know that I said that everything I do, every day it, that's what really makes me think about my day to day life. I said they tell me that some people get mad and don't want to do it no more because they say they're tired of the needles being stuck in their arms. It hurts, it does hurt sometimes, it depends, especially on the side, the side here and that just stings real bad, burns like. But it depends on the people who put it on you-how good they are about it. It's their attitude. But after she started asking me questions about how I felt, it scared me you know, it really did scare me because I said before, I just did whatever, I just ate whatever I didn't even think about it and there telling

me how, how much if you eat too much and stuff it stretches your heart out. And it don't go back. You can't go back to that regular size.

Her depression is more related to her family interactions. She states:

I feel like um, I don't know if it's just me, but I feel like I'm in the way all the time because of the way I am. Um, my kids have to make special things just for me to be with them. Like when we go to "metropolitan area" they make sure I got that cart to go. And when they eat, they have to get certain foods for me to eat.

Her family has responded to her depression by becoming more involved. She states:

But I just feel like um, I don't know, I just feel like because of me they have to make special preparations and stuff. And sometimes it's like I feel like I guess depressed sometimes. It's not all the time I try to get myself out of that when I feel that way. I try to go do something like call my daughters and say hey, I'm starting to feel funny, feel like that in that down mood again. And she'll say hold on, we'll be right over and we'll bring the kids over and when they bring the kids everything's just different, it changes me and they say well Grandma I'm hungry and so that just pops my head away from anything that's bothering me so I try to tend to them.

Individual Essence of Phenomenon

Olivia's experience on dialysis has created many experiences for her family and her. As she began receiving these treatments, she experienced withdrawal from family and peers. She describes being treated as though she was fragile. She talked with her friends and family and encouraged them to treat her the same. After some time had passed, she realized her family would have to treat her differently in terms of the accommodations they had to make for her. These accommodations contributed to feelings of depression because she felt as though she was in the way. Aside from feeling as though she was in the way, she often spent time alone in her room. Her children became more involved and Olivia would communicate to her children when she was feeling down and the family would come together.

Olivia states her adherence is because of her grandchildren and describes how through dialysis, she has gained her family. When describing what she had gained from this experience she states, “I think my family.” She states, “it made me realize a lot. You know what if I didn’t do anything to take care of it? I was thinking my grandkids. They’re all real small and it’s scary to think that, that if I don’t take care of myself, I ain’t gonna be here to see them grow up”. Through her descriptions of her experience, she has also become accustomed to the process of dialysis and she has developed a level of comfort based on her own self-advocacy. She states, “So anything I have a problem with now, I just bring it right out”. And although she reflects upon feeling as though she is in the way, she has positive family interactions that have strengthened the bond between her, her children and her grandchildren. When describing how dialysis has affected her family, she states, “It’s like it really made them realize the seriousness of my illness. Before it was like, oh, you’re diabetic, but nobody really knew about it. And this dialysis thing, it scared them”.

Composite Descriptions

Composite Structural Description

Based on the data analysis, four composite structural themes were revealed. The process for determining themes began with a systematic review of the transcribed interviews. Prior to conducting the interviews, the researcher engaged in the epoche process (Moustakas, 1994). The purpose of the epoche process was to remove any preconceived notions about the experience (Moustaka, 1994). This process serves a vital role as the experiences of the researcher could have had an impact on how the interview was conducted and how information was interpreted. For example, the researcher personally interpreted the experience as a form of historical trauma. The researcher theorized that historical trauma was a contributing factor to chronic illness in American Indians. This particular study was not positioned to study this proposed theory, but had the epoche not have taken place, the researcher's experience may have altered the information obtained from the participants and influenced their description of their experience.

Once the interviews were transcribed, the researcher reviewed each interview and determined themes through a systematic process. The transcriptions were then sent to a reviewer to follow the same steps as described below. Moustakas (1994) lists direct steps for obtaining themes as the following:

- a.) Consider each statement with respect to significance for description of the experience.
- b.) Record all relevant statements.
- c.) List each nonrepetitive, nonoverlapping statement. These are the invariant horizons or meaning units of the experience.

- d.) Relate and cluster the invariant meaning units into themes.
- e.) Synthesize the invariant meaning units and themes into *a description of the textures of the experience*. Include verbatim examples.
- f.) Reflect on your own textural description. Through imaginative variation, construct *a description of the structures of your experience*.
- g.) Construct *a textural-structural description* of the meanings and essences of your experience (p. 122).

The process concludes with composite descriptions of the textural and structural descriptions. These descriptions were then utilized to capture the group essence of the phenomenon.

The themes identified through this process are the introduction to dialysis, transportation, schedule limitations and physical limitations. Each of these themes is first described through a narrative format. See Table 1 for themes, invariant constituents and direct quotes from the participants. Similar descriptors of structural themes and invariant constituents were present for both male and female participants.

Introduction to Dialysis

Through the systematic review described above, the introduction to dialysis was identified as a structural theme. Although prior warnings of the severity of diabetes was given, the actual onset of dialysis appeared to be abrupt. For example, “Suzy” describes waking up on dialysis and it being traumatic because of her initial response after waking, which resulted in her pulling the tubes from her body and intense bleeding. She describes her training as very quick and scary, which she also attributes to the young age of the nurses. As the transition to dialysis took place there was an increase in self-advocacy.

This self-advocacy was evidenced by participants asking more questions about the procedure and learning about the machines. This increased their knowledge and their independence, which in turn, helped them adjust to intensive treatments.

In addition to the abruptness of the onset of dialysis, training that was offered for dialysis treatments was minimal. All of the participants had received a form of orientation with the exception of Ted. He has been receiving dialysis treatments for the longest period of time (11 years) and had received no orientation to dialysis. Olivia had the most to offer in terms of the training she received while others learned more through independent research and peer relationships.

Transportation

Transportation was a continuous concern while receiving dialysis treatments. This concern with transportation revolved around the inconsistency with the drivers which would result in conflicting schedules for services received. This creates an additional stressor for participants because the full treatment may be shortened because of overlapping schedules of patients.

Public transportation is provided to the participants either through and Indian Health Service transportation service or by public transportation services within urban settings. In both instances, the majority of the participants discuss inconsistencies with pickup times and consistent drivers. For example, Ted states he will at times drive himself to the dialysis center. He states he will wait in the parking lot until transportation arrives but if he can see they are going to be late, he will drive himself to treatments.

Overall, the experience with transportation was a regular stressor for participants and has been incorporated into their regular routine prior to treatment. For example,

participants prepare for dialysis the night before by going to bed early and making calls for transportation. Therefore, the experience of receiving treatment also entails regular planning, coordination and flexibility.

Schedule Limitations

Scheduling limitations were also found to be a continuous experience for participants. These limitations were specifically related to limited travel, extensive planning, and limited flexibility. It was found that the limitations in scheduling due to treatments had led to minimal participation in cultural activities and travel. If plans are to be made, they must be planned at least two to three weeks in advance in order to find another location to receive treatments. As a result, participation in out of town cultural events has reduced significantly because of limited connections in terms of places to stay or denial of services from other dialysis centers.

Physical Limitations

Physical limitations is also an experience of dialysis patients. These physical limitations include an inability to work, limited physical abilities and limited physical interactions as a result of the side effects of the procedure. Physical changes to the bodies of dialysis patients are also experienced. Physical limitations were described as limits to pounds lifted. This may include recommendations of not lifting more than 10 pounds. And although there are recommendations provided to the participants, physical limitations go beyond what is prescribed. For example, there are also limitations to doing laundry and taking out the trash because of limited abilities in lifting.

As a result of these physical limitations, all of the participants report they are unemployed. One participant is able to engage in contractual work but with limited

hours. Another states she cannot work because she cannot stand too long or she will get too tired. Another participant is able to engage in volunteer work and is receiving educational training to help her find employment at a later date. This same participant states she believes employment is hard to secure because she is viewed differently by people once they realize she is on dialysis or has diabetes. She states she is looked at differently once potential employers find out. Data analysis revealed limited physical interaction with family members as another form of physical limitations. For example, Olivia states she is unable to hold her grandchildren and Ted states he can do very little outside with his granddaughter. This limited physical interaction is directly related to the physical symptoms of receiving dialysis treatments and how it hinders social interactions and closeness in relationships. There were numerous physical side effects reported by each of the participants. These symptoms included dry and itchy skin, cramps, pain from needles, and calcium bumps that could be painful.

Table 1.
Composite Structural Themes and Invariant Constituents

Theme	Invariant Constituents	Direct Quotes from Participants
Introduction to Dialysis	Minimal training/orientation	They put you in that room and start sticking your arm I studied and read when I went on it
	Abrupt onset of Dialysis	They just threw me into it I just woke up that way so I had no choice He said we're gonna start you on dialysis tomorrow. I said tomorrow?
Transportation	Conflicting Schedules	Show up real late, you can't do the full treatment
	Inconsistency	It's a nuisance because you don't know when you're gonna get picked up I don't really know who's got me so I have to call Sometimes they oversleep or get over there late
Schedule Limitations	Limited Travel	I can't travel no more, it ties me down to a certain area
	Planning Required/ Limited Flexibility	I need to know two, three weeks in advance
Physical Limitations	Inability to Work	I can't lift nothing I can't go and do a job like I used to
	Limited Physical Interaction	I can't even lift my grandkids anymore 10lb weight limit for my arms
	Physical Symptoms	Cramps, pain, needles sticking you, Itchy skin Calcium bumps

Composite Textural Description

Data analysis revealed three textural themes for participants receiving dialysis treatments. These three themes are emotional reaction, isolation/withdrawal, and family and peer interactions. Each of these themes are described through a narrative format and then provided for further review in Table 2. Textural descriptions across gender were slightly different between males and females in this study. Males were less likely than females to describe symptoms of their emotional experiences but were willing to acknowledge they experienced depression.

Emotional Reaction

Emotional reactions are a common experience for dialysis patients. The emotional reactions determined through this study included anger, depression, fear and anxiety. The most prevalent were fear and depression. Two of male participants stated they felt anger or they were “pissed” as they adjusted to life on dialysis. Two of the women in the study reported feeling anger at themselves rather than at the procedure or situation. Their anger was based on their own actions, specifically with their eating behaviors and the food they prepared for their families.

Depression was found to be a lived experience in this study. It was described as either a feeling of being “depressed” or reaching a “depressed mode” since starting dialysis. The female participants, describe bouts of crying and feelings of wanting to give up and stop receiving treatments while the males described experiencing depression but did not give examples of how it manifested. For individuals experiencing grief, adherence proved to be a challenge but familial and peer support assisted with continuing

services. Depression may have also manifested through behaviors of isolation and withdrawal for both genders.

Fear was also an emotion experienced by the group as a whole. This fear appeared to be exacerbated by the lack of knowledge about the procedure. For most, they overcame this fear through self-advocacy (e.g. asking questions, reading, consulting with peers). For some, the fear of death continues. Although all report a level of comfort with the procedure, all three of the female participants discuss mortality. One participant discussed her fear of going to sleep and never waking, another states she does not want to leave her family while a third female participant jokes about her mortality. She states she is not afraid to die and when she is able to see all of her children again, she knows it will be her time to go.

Isolation and Withdrawal

Isolation and withdrawal were found through analysis of the interviews. For example, Ted and his wife confirm he chose to isolate himself. He states he doesn't mind not having company and states he now prefers it that way. For Olivia, her description of isolation and withdrawal were described by her spending time alone in her room. Her family members would inform her of how she was spending more and more time alone in her room and she stated that she was initially unaware of how she was isolating herself. These examples are representative experiences of the group.

The experience of isolation is not limited to withdrawal from family members. Social interactions with peers are also limited. These limitations may be seen through limited engagement in sociocultural activities such as pow-wows or through social gatherings of peers. At some point during the experience of life on dialysis, depression

manifested in a manner that affected emotional responses but may have also been exhibited through the behaviors of isolation and withdrawal.

Family and Peer Interactions

Family and peer interactions changed for all of the participants. Most of the participants (male and female) state they were treated as though they were fragile. Interactions changed with peers and the focus of conversations appeared to be about the procedure and limits to their livelihood. Mixed results were reported with family's initial reaction to the onset of the procedure. For example, Olivia states her daughter withdrew from interactions with her because she equated the procedure with death. While interactions for Ted involved family initially becoming more active but he isolated himself from their efforts. At this point, he rarely has family interaction aside from his granddaughter, wife and brother.

Peer interactions changed for all participants. For most, friendships they had prior to receiving dialysis are no longer in place. Olivia maintains a strong friendship with one of her peers and Grayson works diligently for people to see him as he used to be and he has maintained most of his friendships. The peer interactions while receiving dialysis are of significant importance to these individuals. For example, Chantell describes being at dialysis and hearing the other patients crying and cussing at the nurses. These emotional experiences of her peers are often carried home with her and make the experience more challenging. However, in addition to these experiences, there is a unique bond that forms between the patients receiving treatments. The participants report spending time with other dialysis patients immediately after the procedure. They engage in friendly

discourse and share meals. Others state peer interactions with other dialysis patients help increase their knowledge and have helped them adjust to their changing lifestyle.

Table 2
Composite Textural Themes and Invariant Constituents

Theme	Invariant Constituents	Direct Quotes from Participants
Emotional Reaction	Fear	Scared-I didn't really understand anything I was really scared and then seeing all that blood Biggest fear every day is this (heart) not beating
	Depression	I feel like I'm in the way all the time You get depressed, you get pissed There's days where I've come home and I've cried
Isolation/Withdrawal	Isolation from Family	I don't wanna talk, I don't wanna say hi to nobody, I don't want to them to say hi to me, I don't even wanna look at them
	Spending Time Alone/Limiting Contact	I quit going around everybody
Family and Peer Interactions	Treated differently/Fragile	Oh, you know, help her out They felt sorry for me or they pitied me
	Family Withdrawal	(Son) he knew I got sick cause I don't think he wants to see me this way
	Peer Withdrawal	I lost my friends cause I don't go out no more Some of them don't come around as much

Group Essence of Experience and Adherence

Based on the responses of the participants and a systematic review of individual and composite experiences, seven themes were identified in describing the experience of dialysis (see Tables 1 and 2). These themes are uniquely positioned to develop a further understanding of the experience of dialysis and how it relates to adherence. This effect on adherence was related to either developing personal strengths in self-advocacy or furthering a sense of empowerment through independence and refusing to be pitied. For some participants, this included all three.

The experience of dialysis has an impact on the entire family, specifically for the women who participated in the study. The men in this particular study did not make a reference to their families. Although all participants discussed the impact this procedure has had on their family, the women discussed how this affected diets within the household. The women referenced how, as they explored or settled for what they thought they could eat, their family members would experience those same dietary restrictions. For example, one participant states she had fed her family rice for about three months because she didn't know what else she could eat. This is an interesting experience that differs between men and women and suggests the need for further analysis with female and male roles as they are affected by dialysis.

The experiences with families varied in terms gender. For example, the families experienced changes as the women changed the diets for everyone living in the home. This change was based on what the women thought they could eat. Changes with family interactions changed for both genders as individuals would withdrawal from interaction and at times, it was vice versa meaning the family members would withdrawal from the participants. In addition to withdrawal, treatment towards individuals changed. This

changing interaction was experienced as pity. This pity was reportedly contributing to feelings of depression as well.

Other experiences with family members include family members taking an active role in understanding the procedure and even participating in training for peritoneal dialysis. An interesting individual experience described by a participant is the impact on the marital relationship. One participant's wife took part in the beginning of the interview and states she took on the illness and made it hers. They both confirmed this created a great deal of tension within the couple's relationship and they would often have arguments over his eating habits. Nevertheless, whether a participant's family would withdraw or become actively engaged, family members and the participants had to navigate healthy boundaries for responding to the procedure and side effects.

In addition to changing family interactions, there were changes to peer interactions. When describing what was lost or gained through their experience in dialysis, there was an experience of losing friends yet consequently, gaining friends and family. Initially, the peer responses appear to be that of pity and concern for mortality. These concerns are not negative but when continuously posed to individuals who are choosing to focus on living, the repetitive statements contribute to withdrawal from peers who are not fully familiar with the dialysis procedure. And although the change in interaction appears to be a negative experience in terms of limited interaction, most of the participants have responded with a better understanding of the procedure and the longevity of treatment. The importance of peer interactions is reflected in the statement "I'm kind of used to the people you know everybody in that whole room. You kind of get close to them." Contact with peers prior to dialysis is limited but friends are gained

who have similar experiences. These shared experiences contribute to further understanding of the procedure and the bonds developed within the setting that create a sense of comradery for the patients.

As described above, the initial response to individuals receiving dialysis was that of pity. Through the adjustment to the experience of dialysis, independence grew. Through this growth, independence was embraced and strength was found through volunteer work, cultural events and practices or continued family interaction. Participants were very clear about not wanting to be pitied, and having the ability to maintain certain responsibilities was an empowering behavior most gravitated towards.

Overall, the participants experience a progressive process of acceptance. This begins with increased knowledge and understanding of the procedure. The lack of knowledge contributes to fear about the procedure but is dramatically decreased with understanding the machines and the change in lifestyle. A training or orientation is typically provided. Only one participant stated he did not receive training. Even with the training that was provided, participants took ownership of learning more about the procedure through their own readings, asking questions of providers and learning from peers. Through this developmental process, participants have empowered themselves to engage in physical activity, appropriate peer relationships, healthy eating habits and self-advocacy. All of which are contributing factors to survival and adherence while receiving dialysis treatments.

CHAPTER V

Conclusion and Discussion

This final chapter describes the findings of the research project and interprets how these findings are related to mental health and adherence. The chapter begins by stating the research questions and summarizing a collective response of the participants. These summaries are then aggregated to provide a description of how the emotional, social and familial experiences affect adherence. The chapter will then describe considerations for future research, future clinical practice, and limitations of the study. Further commentary will then be provided through personal comments from the researcher. This commentary will describe the personal experience and gratitude of the researcher as it was experienced throughout this project. Finally, an agenda for change will be referenced and provided in the appendix. This agenda for change has been approved by the participants and upon the successful defense of this dissertation, the letter will be mailed to the Indian Health Service's Aberdeen and Oklahoma City Area offices.

Discussion

This study investigated the influence of mental health on treatment adherence for American Indians receiving chronic dialysis treatments due to complications with Type II diabetes. Because this type of research has not yet been conducted for American Indians, the researcher chose to conduct a phenomenological study, which essentially looks at a concept for the first time. Through a literature review, questions and criteria for participation were created. Criteria for participation in the study were the following:

- Received hemodialysis treatments for at least 2 years (scheduled for 3 times per week)

- Consistent treatment adherence (at least 2 times per week)
- Stable physical health
- Appropriate dietary changes as a result of diabetes and dialysis treatments
- At least 21 years of age
- Enrolled member of a Federally Recognized Tribe

Each of the participants met qualifications for participation and all except one were contacted to verify the interpretation of the study and provide approval for the agenda for change letter. The participant who was not contacted for follow up had passed away shortly after the interview was conducted.

Based on the design and the intent of this study, the following questions and subquestions were developed to capture the essence of the experience and the influence of mental health on treatment adherence:

- 1.) What has been your experience on dialysis?
 - 5.) How has your schedule changed with family and work?
 - 6.) What physical changes have you experienced since starting dialysis?
 - 7.) Could you please describe what you have gained or lost from this experience?
 - 8.) How did you interact with family and friends after starting dialysis?
- 2.) What have you experienced emotionally after starting dialysis?
 - 4.) What emotions did you experience during treatment?
 - 5.) What emotions did you experience immediately after treatment?
 - 6.) How do you feel about dialysis treatments?
- 3.) How are you able to adhere to the treatment regimen?

4.) Please describe how you feel about your treatment regimen?

5.) What helps you maintain your schedule?

4.) What obstacles did you face in adhering to treatment?

a.) How did you overcome those obstacles?

What has been your experience on dialysis?

The experience of dialysis is heterogeneous in nature due to the number of differing variables for individuals (Stanton & Revenson, 2011). These variables include culture, gender, personal history and other individual characteristics. The experience of dialysis for the participants of this study is best described by the textural themes provided through their interviews. These textural themes of emotional reaction, isolation/withdrawal, and family and peer interactions are described below with additional support from research on adjustment to chronic disease. Lubkin and Larsen (2013) are editors of a book titled *Chronic Illness: Impact and Intervention* and in this book, multiple authors describe various impacts of chronic disease. These areas will be highlighted below, with an emphasis on stigma, social isolation, uncertainty and family. An emphasis will be placed on these components as these were apparent in the interviews of the participants.

Stigmatization. Many of the participants describe an experience of stigmatization. This experience includes projections about mortality, ability to maintain employment and helplessness as a result of treatment. This stigmatization appears to have a direct threat on the individual's identity. This threat to identity is exemplified in how participants referred to themselves as being viewed as pitiful or helpless. One participant stated he wanted to talk with his peers about things they used to talk about.

Based on what many of the participants shared, they did not want to be identified only as someone who is on dialysis and viewed as in critical condition.

Stuenkel and Wong (2013) describe strategies used by individuals who are living with stigma due to chronic disease. The strategies they reference are passing, covering, disregard, resistance and rejection, isolation and information management. Each of these strategies has been described by the participants in this study. For example, passing refers to an individual who attempts to pretend there is no disease or illness. There are no physical symptoms and the disease is easily concealed. One participant described keeping his dialysis treatments hidden until there were physical scars he could no longer hide. Covering is a strategy individuals use in which they minimize their disease or illness (Stuenkel & Wong, 2013). Stuenkel and Wong (2013) state “Humor, used in a skillful and lighthearted manner by the stigmatized individual, may decrease the anxiety of others and avoid an awkward encounter” (p. 57). This act of covering was exhibited by one of the participants as she attempted to be humorous about death. The scenario described by the participant seemed to be uncomfortable for the person hearing the joke, but she did this in an attempt to lighten the mood about her condition.

Disregard is a strategy in which an individual will not address the responses of others who stigmatize (Stuenkel & Wong, 2013). This strategy is used most often by individuals who have developed a strong sense of identity. Resistance and rejection is a strategy in which the individual presents as opposed to the judgment and recommendations of the treating professionals (Stuenkel & Wong, 2013). Based on the participants’ responses, these strategies were not exhibited. It is difficult to determine if these strategies were not discussed because the individuals were at a comfortable level of

adherence at the time of the interviews or if their identity as an individual who receives dialysis was strong enough that they do not resist or reject recommendations. This may also mean an example was not provided for these particular strategies during the interview.

Isolation is another strategy used by individuals who experience stigmatization (Stuenkel & Wong, 2013). Stuenkel and Wong (2013) state “Staying with like others may be a source of support, but some individuals with a disability or chronic illness may feel more when they are surrounded by nondisabled individuals” (p. 58). As described in chapter four of this study, isolation and withdrawal were experienced by the majority of the participants. Interestingly, peer support from and for other dialysis patients appeared to be a contributing factor to adherence. One participant also describes his active efforts at staying involved with others and continuing to engage in the same activities he did prior to receiving dialysis.

Information management is a strategy used by the individual and their closest support group (Stuenkel & Wong, 2013). Through this strategy, individuals choose with whom they want to share information. This was clearly evidenced by one of the participants who stated he had only let certain close friends and family know about his condition.

Social Isolation. Separate from the strategy to address stigmatization, social isolation was often referenced by the participants. Biordi and Nicholson (2013) state “...social isolation is the distancing of an individual, psychologically or physically, or both, from his or her network of desired or needed relationships with other persons. Therefore, social isolation is a loss of place within one’s group(s). The isolation may be

voluntary or involuntary” (p.97). The concepts of voluntary versus involuntary are unique components of isolation as the experience of both was described by the majority of the participants in this study. For example, a form of voluntary isolation occurred for one participant as he described his choice to no longer socially be engaged with friends, and at this point in his life, he is comfortable with limited social interactions. The experience of involuntary isolation is based on perceived marginality, a quality also reinforced by participants in the study. For example, one participant described an experience of marginality when talking with a tribal council member who essentially confirmed dialysis meant the end of their lives and that is why these patients are forgotten.

Changes in lifestyle occurred for many in this study and this included limitations to social networks or participation in cultural events. When asked about what was lost or gained, many participants stated they had experienced a loss of friends. One participant stated she no longer partied anymore and because of this, she had lost friends who maintained that same lifestyle. Biordi and Nicholson (2013) state individuals may experience “sadness, anger, despair, or reduced self-esteem” (p. 99) as a result of a limited social network. They state these changes in social networks and emotional responses may affect the identity of the individual.

Overall, the process of isolation is a progression. Biordi and Nicholson (2013) state the withdrawal of family and/or friends may be a slow process or it may happen rapidly. This withdrawal may be based on the lack of information about the disease or the treatment. In addition to the lack of information, other factors contribute such as low levels of education and limited financial resources. These additional factors are present

in the sample of this study with education ranging from 7th grade to some college.

However, not accounted for in the research on social isolation was the integrated social network of the dialysis patients which proves to serve as a contributing factor to adherence, independence and self-esteem.

Uncertainty. The unknown of chronic illness is a challenging concept for individuals with chronic disease. Hummel (2013) states, “Chronic illness is marked by unpredictable changes in physical, cognitive, social, and lifestyle functions” (p. 161). She describes this uncertainty as a “prolonged state of adversity” (p. 161) that affects the livelihood of the individual. The components of uncertainty include a lack of knowledge, unpredictability and an overall lack of control over the disease (Hummel, 2013). These components of uncertainty are individually based and have been exhibited by each of the participants in this study. Examples from participants include the lack of knowledge about the procedure, the uncertainty of death and the uncertainty of consistency in structural variables such as transportation or scheduling.

Uncertainty is centered on the ambiguity of symptoms, livelihood and the effects on social networks. However, a unique aspect of chronic dialysis patients in this study is the uncertainty of mortality for others within the treatment center. For example, although not listed as a structural variable in the analysis, a component described by a few of the participants was the growing concern for patients who were absent from treatment. Based on the comradery and the possible ongoing complications of the disease, the uncertainty of the lives of others may be a contributing factor to adjustment.

What have you experienced emotionally after starting dialysis?

Results from the analysis revealed that fear and depression were common experiences for participants in this study. Additional emotional experiences included anxiety and anger which may be seen as encompassed within the manifestation of fear and depression. Stanton and Revenson (2011) state the assumption of depression as a guaranteed experience of chronic disease is of negative consequence that may affect the individual receiving treatment as well as their support network. For example, the individual receiving treatment may be less willing to receive services based on the negative social construction of the disease. While the support offered by family and/or friends of the individual may be diminished based on stigmatization and the “overprescription of psychological intervention or psychoactive medications by health care professionals” (Stanton & Revenson, 2011, p. 244). Depression was reportedly experienced by all participants within this study but did not appear to be a long term psychological condition. The depression experienced by the participants was described in the past tense and one participant describes reaching depressed moods but pulled out of these moods based on family intervention. For example, if the participant noticed feelings of depression, she would contact her children and they would bring her grandchildren to her home. Another participant states remaining independent and not allowing her family to do daily chores for her, as one way to keep from feeling depressed.

Fear was a common experience for individuals within this study. This fear was related to the lack of knowledge about the procedure which also contributed to anxiety. Another factor that contributed to fear included the fear of mortality or changing lifestyle. This fear continues for one participant as she states she does not know if she will not

wake from sleep. Another participant states he was afraid he would have to live like an old person and wouldn't be able to do the things he used to such as dance at pow-wows. Anxiety was reportedly experienced by the participants as well. Their anxiety was often attributed to the procedure itself and the worry over the level of knowledge of the providers and their abilities to deliver appropriate practice.

How are you able to adhere to the treatment regimen?

Based on the results, a major component to adherence was the participant's cognitive appraisal of the treatment. Additionally, as stated by Stanton and Revenson (2011), control over symptoms is a contributing factor to adjustment. Control was exhibited by the participants by how they managed their diets and physical activity. Based on their experience, control as a contributing factor to adjustment was not only limited to controlling symptoms, but controlling other variables such as physical activity, peer interactions, family interactions and other contextual factors.

The majority of the participants referenced the importance of peer interactions. For many, social support came from other dialysis patients but the unique contributions of a shared experience helped these participants adjust. Stanton and Revenson (2011) describe social support as an indicator of adjustment. They describe components of support as: "(a) expressing positive affect; (b) validating beliefs, emotions and actions; (c) encouraging communication of feelings; (d) providing information or advice; (e) providing material aid; and (f) reminding recipients that they are a part of a meaningful social group" (p. 251). Many of these components were described by the participants who had relationships with others receiving dialysis treatments. For example, Chantell described having a friend who talked her through the procedure and made it like a

“game” for her. Many of the participants transcended beyond receiving support and with their adjustment to dialysis, they eventually began to offer support to others. This support to others appeared to be beneficial in their own acceptance and adjustment to the treatments.

The emotional experience of the individuals was found to be in constant evolution. The participants represented a diverse group in age and education. Thus, the emotional experiences of the participants varied across time and for individual participants. The majority of the participants in this study were over 50 years old with one younger than 40 years. Not all were married and not all participants had children. The educational backgrounds of the participants varied greatly, which as stated earlier, may have an impact on the emotional experience of individuals living with chronic disease.

The relationship between mental health and treatment adherence appears to be both positive and negative. The emotional availability of the participants is limited for families and friends. This limited emotional availability is an active effort of self-care and management by the participants. Experiencing loss of family members exacerbates feelings of grief not only because of the loss of a loved one, but because there appears to be a feeling of hopelessness. This makes struggling with loss more challenging and is directly related to the consideration of limited adherence. However, even with liability of emotional experiences, cognitive appraisal of the treatment appears to be the overarching basis for adherence. Cognitive appraisal is directly related to efforts at survival. But, the emotional experience of the individual has a direct impact on cognitive appraisal. For

example, experiences of anxiety, grief and anger affect thoughts about survival and whether or not the loss outweighs the commitment to the treatment.

What obstacles did you face in adhering to treatment?

Obstacles to treatment were identified as challenges with schedules, transportation, changes in lifestyle, and dietary restrictions. Schedules presented themselves as challenging because many of the participants felt as though they were tied down. Two of the participants stated that they no longer participated or traveled to pow-wows the way they used to because of arrangements to do so necessitated extensive advanced planning. Another participant discussed challenges with going to a family member's home for holidays because she had to account for dialysis treatments when attempting to schedule such trips. Overcoming this challenge appears to be a progressive form of development along with identity formation. This progression evolves over time and is affected by lifetime events such as death of family members, peer and family interactions as well increased knowledge about the procedure. As the individual develops a secure identity related to being a dialysis patient, changes in his or her social interactions take place. Consequently, less resistance occurs as the individual integrates the new identity into the individual's life.

Transportation was mentioned by the majority of the participants as a continuous struggle. For most, transportation was provided either by public transportation services dedicated directly to dialysis patients or through transportation services provided by the Indian Health Service. Conflicts arise with pick-up times as well as with whom the actual transporter will be. Participants of this study described the occurrence of inconsistencies with pick-up times that eventually led to decreased treatment times. This

is a challenge that remains out of the control of the participants and proves to be more difficult to overcome.

Changes in lifestyle are initially viewed as challenges but for the participants in this study, they were overcome as knowledge increased about the procedure. Changes in lifestyle are related to the participation in cultural events, changing social networks and changes in diets. As knowledge increases about the procedure, the effects of diet and physical behaviors, a decrease in the severity of these obstacles is interpreted through the results of this study. For example, one of the participants discussed his unhealthy eating habits citing the physical changes to his blood resulting from poor eating habits. He was able to see his blood and described it as looking like red cooking oil. He reports that seeing it in this fashion led to him making positive changes in his diet. Additionally, multiple participants discussed their fluid intake and the challenges of restricting this part of their diet. However, the cramps and anxiety experienced during dialysis treatments have influenced participants to make the needed adjustments to their fluid intake.

Future Research

There are numerous considerations for future research with American Indians receiving dialysis treatments. Additional research should include qualitative as well as quantitative research for this population. This research may serve as a bridge to reduction in disparities of treatment while increasing the successful adherence to treatment for all individuals. The findings of this study indicate the need for additional research in which anxiety, depression, quality of life, and well-being are assessed with quantitative as well as qualitative studies. Additionally, the transcendence of independence into altruism should further be assessed as a component to adherence. For

example, individuals who developed a strong sense of identity and independence also discuss assisting others in transitioning to life on dialysis. This study did not include specific scales for adjustment and quality of life but research in this area may serve to benefit patients and clinicians as the adjustment process takes place.

Additionally, research that explores effective training methods for family members of American Indians receiving dialysis treatments should be investigated as a means to assist individuals in their adherence. Furthermore, length of time on dialysis, adjustment and age as correlates of depression and/or mortality should also be explored. Other studies should include family and social support as mediators to depression. Moreover, research should examine specific counseling practices that culturally appropriate and effective in counseling patients with chronic illness.

Based on the findings of this project, future research on the introduction to dialysis may inform providers and therefore impact service delivery to individuals receiving treatment. Participants within this study did not begin dialysis treatments being fully informed about the procedure. For the majority of the participants in this study, training as an introduction to treatment was either brief or did not occur. The lack of knowledge about the procedure contributed to an experience of anxiety about the experience. Additionally, the lack of training about the procedure also contributed to the continued misinterpretations about physical abilities and mortality by family and friends. Future research should explore the benefits of training methods to the patient's closest familial and social support and how it may aid in adherence to treatment and/or reducing stigmatizations about individuals who receive dialysis treatments.

Because this work is specific to the American Indian population, future studies should include cultural factors that contribute to well-being. This may include spiritual practices utilized for healing or cultural practices that are highly social and integrative of multiple social networks. This researcher was intentional about not asking specifically about culture because this was the first look at the phenomenon. It is believed cultural factors would have emerged throughout the interviews however, without it being prompted, the participants may have chosen not to share their experiences or beliefs. The participants engaged in the study because of their familiarity with the primary investigator, it is hypothesized the participants maintained a level of protection of their cultural practices because the researcher was viewed as an outsider, which hindered their willingness to share aspects of their culture.

Implications for Clinical Practice

Based on the findings of this project, there are many implications for clinical practice. Stanton and Revenson (2011) highlight the myriad of differences individuals experience as they adjust to chronic disease. There is not one specific description of adjustment to dialysis for individuals. It is difficult to encapsulate the adherence process as there are differences based on culture, gender, socioeconomic status and other sociocultural variables. Additionally, personal characteristics vary from one individual to another: coping skills vary, personalities differ and cognitive functioning is variable. What can be taken from the findings of this study is the importance of increased knowledge for the participants. Therefore, it is important for providers to work collaboratively with patients in increasing their knowledge about the procedure.

Additionally, providers may assist in adherence through reinforcement of training for the patients as well as their closest support network. Based on the results of this study, clinical practice should include a family approach to adjustment. For example, as individuals adjust to chronic dialysis, training for the treatment should be inclusive of patient-designated family members, caregivers or the patient's social network. Caregiver support is often necessary and further research on the adjustment for family members may increase our understanding of how treatment adherence can be enhanced and solidified for individuals receiving dialysis treatments. Additionally, based on the report of self-advocacy and comradery within the dialysis clinics, a mentorship program may be beneficial for incoming patients. Many of the participants in this study discussed how peer support from other dialysis patients was helpful in their level of understanding about the procedure. Patients who have exhibited that form of leadership and willingness to share may be able to serve as ambassadors of treatment. They may be identified as peer mentors and assist with training for the individual as well as the family members. Allowing this practice may enhance the comradery within the treatment setting as well as reduce the onset of anxiety about the procedure itself.

This form of reinforcement suggests a continuous partnership which may also be further enhanced through a provider/patient relationship. This provider/patient relationship would serve as a collaborative effort to maintain adherence and self-management. This collaborative relationship may also serve as a reflective approach of peer support. A partnership in this effort may also decrease the anxiety experienced as the patient increases her or his knowledge of the procedure and symptoms.

Additionally, obtaining lifetime prevalence of depression may also serve as a beneficial component to practice as individuals adjust to the lifetime treatment of the dialysis procedure. This would be a necessary component for future research as individuals who have a history of depression may be more likely to experience depression as they adjust to dialysis treatments. Furthermore, because of the overlap of symptoms between dialysis and depression, patients may benefit from regular assessments of depression with accommodations being made for the overlap of symptoms.

An additional component to enhancing clinical support for the patient and their level of adherence would be to include an assessment of contextual and societal factors that may be inhibiting or advancing the patient's adherence to dialysis treatments. Examples of this may include how patients are transported to treatment as well as support groups or programs available within the patient's community should also be offered as a form additional support for adherence.

As described in the methodology section of this dissertation, an advocacy/participatory approach (Creswell, 2007) also guided this work. This approach is enacted through an agenda for change (Appendix G) in which the above is summarized and mailed to the Indian Health Service's Aberdeen and Oklahoma City Area offices. Participants for this study have approved this agenda for change and one participant has requested the agenda for change be shared with her tribe's governing body as well as their dialysis clinic. Upon approval of this dissertation, the agenda for change will be shared with the Indian Health Service as well as the participants of the study. They will have the opportunity to share the agenda for change with any organization of their

choosing. The researcher's contact information will be provided for additional follow up as requested.

Limitations

This qualitative study was comprised of a small sample of American Indians from the Midwest who are receiving dialysis treatments. Recruitment for the study occurred across multiple states but very few responses were received. In many cases, individuals did not qualify for the study based on the length of time they had been receiving dialysis treatments. As mentioned earlier, participants in this study initiated contact with the researcher for the most part because they had some form of connection with the researcher or the researcher's family. This posed a significant limitation to the study as this reduced the number of participants who actually participated in the study. The study proposed to interview 10 individuals: five men and five women. The participants who initiated contact with the researcher did so because of their familiarity with the primary investigator. Because participation was related to a familiarity with the primary investigator, the number of participants was reduced to six participants: three men and three women. With participants having a distant connection to the participants, this may be seen as a strength because the researcher was allowed to reach a population that may otherwise, continue to be neglected. This same familiarity is a limitation because the location of the participants creates a geographic limitation, therefore, the number of tribes represented through this study was limited.

Another limitation of this study was the age of the participants. Similar to previous research (as referenced in the literature review), the majority of the participants were over the age of 50 years-old. One participant in this study was in his late 30's but as

stated in Chapter Two, most previous research has been conducted on an older population even though for American Indians, the onset of diabetes is occurring at younger ages. This limitation is significant due to the increasing early onset of diabetes. Additionally, differences in lifetime experience may alter adherence and emotional experiences across ages.

Many factors concerned with adjusting to chronic disease and chronic dialysis were not accounted for in this study. One of the limitations of the study was that of criteria for participation; participation was limited to individuals who were diagnosed with Type II diabetes. The purpose of this criterion was based on the increasing rates of dialysis for American Indians. However, individuals receiving dialysis are not limited to this disease. It would be beneficial to be inclusive of all forms of End Stage Renal Disease that led to the requirement of dialysis treatments. Future studies should include all patients receiving dialysis and not be limited by medical condition.

Furthermore, there were limitations as indicated by demographic variables. For example, all of the participants were unemployed. The study did not account for level of education as a factor in adherence to dialysis treatments. This study also did not account for income levels and the effect it may have had on receiving services or service delivery. Depression is highly correlated with poverty and lack of education. These factors were not appropriately accounted for in the assessment for adjustment to chronic dialysis.

Even with limitations provided in this discussion, this study provides a framework for adjustment to chronic dialysis treatments. Specifically for American Indians, the study could be enhanced by cultural variables that might be viewed as protective factors. If addressed with appropriate cultural considerations, studies of this nature may bridge

the gap concerning disparities in treatment involving American Indians as they adjust to chronic dialysis treatments.

Closing Comments

As I started this project, I had continuous thoughts of my own personal theory of historical trauma and its influence on chronic disease for American Indians. Although I was not suggesting a causal relationship in this theory, I hypothesized a strong influence from the trauma based on my personal experience. As I met with participants, my experience of anger which may also be interpreted as grief, transformed to that of empowerment...empowerment for individuals, families and tribal nations. The individuals within this study exhibited a tremendous amount of strength and independence as they adjusted to their way of life with dialysis treatments. I was humbled by this experience of the dissertation and what the participants shared because it felt as though I was drawn in to their challenges and their efforts to survive. I am thankful for the process of the epoche. Had I not completed this process of separation, I was able to see how my personal experience could have skewed my questioning and results.

The participants of the study were willing to share their experiences openly. An interesting component of their willingness to participate was that each of these individuals had some connection to me and this is what led to them contacting me for participation. The connections varied but ranged from knowing my father to remembering from a previous position within a tribe. Nevertheless, I am thankful these individuals trusted me to share their experience in an effort to help others as they transition to living with chronic dialysis treatments.

Because of the participation of these individuals, a deeper understanding of the phenomenon has been established. Through their willingness to share their experience, their subjective accounts have led to an agenda for change that is being shared with the Indian Health Service. The participants were willing to share their weaknesses as well as their strengths and along with their own development and experience of empowerment, they have now contributed to the possibility of change within a system that supports American Indians as they adjust to a life altering treatment.

I hope our work together will serve as a catalyst for change concerning how treatment for dialysis is initiated and maintained within an American Indian cultural context. I am thankful for the individuals and their participation in this study. I respect how they came to participate in the study and I am hopeful our work together will make a difference together as I continue to work with dialysis patients to improve their well-being.

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APPENDICES

APPENDIX A

**THE EMOTIONAL EXPERIENCE OF AMERICAN INDIANS RECEIVING
HEMODIALYSIS AND HOW IT RELATES TO TREATMENT ADHERENCE**

Recruitment Flier

Would you be interested in helping others understand the emotional experiences of dialysis patients? Share your experience through an in-person interview to earn a \$20.00 Visa Gift Card.

Eligibility Requirements:

- ### Participation Requirements:

- One (1) interview lasting no more than 2 hours
- Follow up meeting to review and approve agenda for change

[illegible]

APPENDIX B

THE EMOTIONAL EXPERIENCE OF AMERICAN INDIANS RECEIVING HEMODIALYSIS AND HOW IT RELATES TO TREATMENT ADHERENCE

Phone Screening

PHONE SCREENING PROTOCOL

Hello! My name is Anitra Warrior, I am a doctoral student in the Counseling Psychology graduate program at the University of Nebraska-Lincoln. Thank you for taking the time to call in regards to this research project which is being conducted for my dissertation. This research project looks at the role of mental health in American Indians receiving dialysis treatments and how it helps with treatment adherence. Are you interested in learning more about the project and possibly participating?

Script for Yes or No:

No – Ok. Thank you for giving me the opportunity to introduce myself and my research project. If you have any questions about this project, please feel free to call me at your convenience. My phone number is 402-405-2182. Thank you.

Yes – Wonderful? Would you have time now to discuss eligibility requirements for participation?

Follow the following scripts if participant says no or yes:

No – Ok, when would be a better time to give you a call to review the eligibility requirements

Ok, great! Thank you for visiting with me today. I will plan on calling you on _____(date) at _____(time). Thanks again and have a nice day.

Yes – Wonderful! We will use this time to review the eligibility requirements to see if you qualify to participate and then we can schedule a time for the full interview. First, it will be important to discuss the time commitment required for participation. This includes an initial interview that may last up to 2 hours. Upon completion of the interview, I will provide a \$20.00 Visa gift card for your participation. There will also be a follow up meeting. During this follow up, I will review my findings with you to make sure I have accurately captured your experience. I will also review a document which will be an agenda for change. This agenda for change will be a letter that is submitted to the Indian Health Service in an effort to promote mental health outreach for dialysis patients. The second meeting in which we review my findings and the agenda for change may also take up to 2 hours. Therefore, it is possible that your total participation time may be up to 4 hours. All of the information you share will be kept confidential and no identifying information will be shared in the study or in the agenda for change. Your information will be kept in a locked, fireproof file cabinet in my home until the project is completed. At that time, I will destroy all audio and written information. Along with myself, my academic advisor, my doctoral committee and an additional coder will have access to the transcriptions-again,

this is only until the project has been completed. I will transcribe the interview and again, all information will be destroyed upon completion of the project. Do you have any questions about the confidentiality or the storing of these documents?

As an introduction to the interview process, I will begin the interview with a formal introduction of myself and then I will move into asking general demographic information. Again, you are free to ask questions during any portion of the interview. Aside from the specific demographic questions, the remainder of the questions will be open-ended and specific to your experience on dialysis. Our second meeting will be scheduled once I have completed the transcription, coding and agenda for change. I will contact you by phone and schedule this time. Do you have any questions regarding the purpose of the study or the participation time?

To determine eligibility for participation, I will be asking you questions regarding your experience on dialysis. If at any time, you would prefer to not answer a question, please feel free to pass. May I proceed?

- ☐ Are you at least 21 years old? **NO --- YES**
- ☐ Are you currently receiving hemodialysis treatments? **NO --- YES**
- ☐ Have you been receiving dialysis treatments for at least 2 years? **NO --- YES**
- ☐ Over these past 2 years, have you had consistent attendance meaning you attend at least 2 out of 3 treatments per week ? **NO --- YES**
- ☐ Have you made appropriate dietary changes necessary for dialysis treatments? **NO --- YES**
- ☐ Are you a member of a federally recognized tribe? **NO --- YES**
- ☐ Would you say your health is physically stable? **NO --- YES**

If the participant does not meet the requirements of the study:

Thank you for taking the time to answer these questions. This study requires participants to meet these qualifications as a standardization process for the project. At this time, you do not meet the criteria required to participate in this study. Again, thank you for taking the time to visit with me. If you have any

questions or concerns regarding this project, please do not hesitate to call me.
 You can reach me at 402-405-2182.
 Do you have any questions for me?

Thank you again. Take care.

If the participant meets the requirements to participate in the study:
 Thank you for your time and willingness to answer the screening questions.
 Based on your responses, you are eligible for participation in this study. Would
 you like to be a participant?

Follow the following scripts if participant says no or yes to participate:
No – Thank you again for talking with me today. If you change your mind or have
 any questions regarding this project, please feel free to give me a call at your
 convenience. You can reach me at 402-405-2182. Do you have any questions
 for me right now?

Thank you again. Take care.

Yes – Great! What is the best way for me to contact you?

What date and time would work best for you?

Confidentiality is very important for this interview. I want to make sure you feel
 comfortable and secure as we move forward with the interview. Taking this into
 account, where would be the most comfortable and convenient place for you to
 meet?

Thank you again for talking with me today. If you have any questions prior to our
 interview date, please do not hesitate to call. You can reach me at 402-405-
 2182. Do you have any questions for me right now?

Thank you again. I will plan on meeting you on _____(date) at _____(time) at _____(location). I will call you one week in advance to remind you of our interview time. Again, if you have any questions prior to the interview, please feel free to contact me at your convenience. Thank you again. Have a nice day.

APPENDIX C

THE EMOTIONAL EXPERIENCE OF AMERICAN INDIANS RECEIVING HEMODIALYSIS AND HOW IT RELATES TO TREATMENT ADHERENCE

Informed Consent

INFORMED CONSENT

PROJECT TITLE:

THE EMOTIONAL EXPERIENCE OF AMERICAN INDIANS RECEIVING HEMODIALYSIS AND HOW IT RELATES TO TREATMENT ADHERENCE

PURPOSE OF THE STUDY

The purpose of this study is to understand the mental health needs of American Indians receiving dialysis treatments due to complications of diabetes. With each interview, I will review characteristics of treatment adherence to determine how services can be improved for American Indians receiving dialysis treatments. Completion of this project includes an agenda for change that will be submitted to the Indian Health Service in an effort to improve mental health services for patients. Before submission to the Indian Health Service, each participant will have the opportunity to review and approve the agenda for change.

PARTICIPANT SELECTION CRITERIA

You have been selected for this study because you have met the following qualifications:

- Received hemodialysis treatments for at least 2 years (scheduled for 3 times per week)
- Consistent treatment adherence (at least 2 times per week)
- Stable physical health
- Appropriate dietary changes as a result of diabetes and dialysis treatments
- At least 21 years of age
- Enrolled member of a Federally Recognized Tribe.

PROCEDURES

Participation in this study includes initial recruitment and agreement to participate through the review and approval as acknowledged through this informed consent. Initial recruitment took place through the first call which was initiated by you as a potential participant in this study. Participants are then contacted by the Primary Investigator to schedule an interview that will last no longer than 2 hours. The time and location of the interview will be scheduled based on convenience for the participant. During this scheduling process, the location will be assessed for possible issues of confidentiality and this will be thoroughly discussed with the participant. One week prior to our scheduled interview, the Primary investigator will contact you to confirm the appointment time and location. The interview will be audio recorded with your approval. Upon completion of the interview, the audio recorded interview will be transcribed by the Primary Investigator. Upon completion of the transcription and analysis, a follow up meeting will then be conducted in which the results and the Agenda for Change will be presented for your approval. Fliers informing participants will be posted in the same locations as the recruitment fliers. These fliers will inform participants the analysis has been completed and the Primary Investigator will be contacting participants for the follow up meeting. This follow up meeting will be scheduled at a time that is most convenient for you. This follow up meeting will take no more than 2 hours to complete. The procedure for scheduling the follow up interview will begin with a call from the Primary Investigator which is to inform you the results have been completed and to schedule a time to review

the results. During this call, and at any time during this research process, you may withdraw for any reason without negative consequence. It is expected the results will be completed approximately 2 months after your interview. During this follow up meeting, the Primary Investigator will ask you to review the transcript of the interview to review for accuracy. In addition, you will be asked to review the results of the study and the Agenda for Change. If you are in agreement, a hard copy of the Agenda for Change will be left with you for your records and an original will be submitted to the Indian Health Service for the Aberdeen and Oklahoma City Area Offices. If you disagree with information presented, the Primary Investigator will work collaboratively with you to modify the Agenda for Change during the follow up meeting. If the researcher is unable to make verbal contact via telephone (after 3 attempts), a written letter will be mailed to you along with the results and the Agenda for Change. The Primary Investigator will ask that over the following 3 weeks (from the date of the letter), you take time to review the Agenda for Change. At this time, the Primary Investigator will move forward with your contributions to the study. If you are not in agreement, you may call the Primary Investigator to discuss changes or you may mail your changes to the Primary Investigator. The Primary Investigator's information is listed below and will also be included in the letter.

COMPENSATION

Participation in the study includes compensation of \$20.00. This \$20.00 will be provided at the conclusion of the interview and will be presented through a Visa gift card.

POTENTIAL RISKS AND DISCOMFORTS

Risks and discomforts are expected to be minimal for this interview. However, sharing your experiences on dialysis may trigger difficult emotions. As a licensed mental health professional, I am committed to mental well-being. Therefore, if you experience any emotional struggles during or as a result of your participation, please notify me as soon as possible and I will work with you to coordinate appropriate services in your area. If services are requested, the researcher will contact Behavioral and Mental Health Services provided by the Indian Health Service within your Contract Health Service Delivery Area. This effort will eliminate costs for services. A listing of local providers will be provided to you upon request.

BENEFITS

Benefits for participating in this study may include assisting others in their adjustment to receiving dialysis treatments. Additionally, your participation will result in an action plan which will be submitted to the Indian Health Service in an effort to improve mental health outreach for dialysis patients.

CONFIDENTIALITY

All identifying information will be kept confidential. This includes personal identifying information as well as tribal affiliation. The Primary Investigator will ensure this confidentiality by using pseudonyms, removal of any identifying information from transcripts and by destroying all data at the completion of the project. The pseudonym will be written on this form and will be the only link to identifying information. All

information gathered after obtaining the informed consent will be coded with the pseudonym. The Primary Investigator is solely responsible for transcription and record keeping. The Primary Investigator will remove all identifying information from the transcripts. After all identifying information has been removed from the transcripts, a coder will assist with analyzing the transcripts. This coder will be required to sign a confidentiality statement and will also have current CITI Training which ensures their knowledge of confidentiality and appropriate research protocols. All documents and recordings will be stored in the Primary Investigator's home in a locked, fire proof, file cabinet of which only the Primary Investigator will have access. If at any time you choose to withdraw from the study, all documentation with your information will be immediately destroyed. You can withdraw at any time without harming your relationship with the researchers or the University of Nebraska-Lincoln. Once the project is complete, the Primary Investigator will permanently destroy all handwritten notes, transcriptions and audio recordings. The final results of this project will be presented only to the Primary Investigator's Doctoral Committee and the Agenda for Change will be submitted to the Aberdeen and Oklahoma City Area Offices for the Indian Health Service. Identifying information as well as tribal affiliation will be removed from any data presented.

VOLUNTARY PARTICIPATION AND WITHDRAWAL

Participation in this project is completely voluntary. At any point during this process, you have the right to withdraw from this study. There will be no negative effects of your withdrawal nor will it hinder the coordination of services if mental health services are requested. Your withdrawal, at any time during this study, will not harm your relationship with the researchers of this project or the University of Nebraska-Lincoln.

CONSENT/RIGHT TO RECEIVE A COPY

You are voluntarily making a decision whether or not to participate in this research study. Your signature confirms that you have read and fully understand the information presented in this informed consent. A copy of the signed informed consent will be provided for your records. You are free to decide not to participate in this study. You can also withdraw at any time without harming your relationship with the researchers or the University of Nebraska-Lincoln. Additionally, at any time during this study, you may contact either of the investigators questions at any time. Our contact information is listed below. Sometimes study participants have questions or concerns about their rights. In that case, you should call the University of Nebraska-Lincoln Institutional Review Board at 402-472-6965.

_____ Initial here if you agree to be audio taped during the interview.

Printed Name and Signature of Participant:

Printed Participant Name

Participant Signature

Date

Investigator Contact Information:

Primary Investigator
Anitra Warrior
P.O. Box 461
Winnebago, NE 68071
(402)405-2182

Academic Advisor
Dr. Michael Scheel
(402)472-0573

APPENDIX D

THE EMOTIONAL EXPERIENCE OF AMERICAN INDIANS RECEIVING HEMODIALYSIS AND HOW IT RELATES TO TREATMENT ADHERENCE

Interview Questions

INTERVIEW

Introduction: Hello _____ (participant). Let me start with a formal introduction of myself. My name is Anitra Warrior. I am Ponca and Omaha and I am from Oklahoma. My grandparents are Adolphus and Lucille Warrior. My mother is Sandra Lay and my father is Ivan Cries for Ribs. My Omaha relatives are through the Mitchells and Wolfes. My great grandmother was Jenny Mitchell Littlevoice. She was from Macy, Nebraska and my Ponca relatives are all from White Eagle, Oklahoma.

As discussed during our initial screening for participation, I will be starting our interview with some basic demographic questions. We will then go into open ended questions that describe your experience on dialysis. I want to remind you that at any time during this interview, you can withdraw from participation without consequence. Also, if at any time you would like to take a break, please let me know and we can take break from the questions. If for any reason you would like to skip a question, please let me know and we will move on to the next question. Do you have any questions before we begin or about this interview?

(TURN ON AUDIO RECORDER NOW)**Questions:**

Interviewee Pseudonym: _____ Date: _____

Place of Interview: _____ Age: _____

Children: _____

Tribal enrollment: _____

Address (reservation or town only): _____

Mailing Address: _____

Site receiving dialysis: _____

Current Relationship Status: _____

Highest Education Level: _____

Current Employment Status: _____

Physical, Cognitive and/or Mental Health

Conditions: _____

Research Question 1:

What has been your experience on dialysis? _____

Subquestions:

9.) How has your schedule changed with family and
work? _____

10.) What physical changes have you experienced since starting
dialysis?

- 11.) Could you please describe what you have gained or lost from this experience?

- 12.) How did you interact with family and friends after starting dialysis?

Research Question 2:

What have you experienced emotionally after starting dialysis?

Subquestions:

7.) What emotions did you experience during treatment?

8.) What emotions did you experience immediately after treatment?

9.) How do you feel about dialysis treatments?

Research Question 3:

How are you able to adhere to the treatment regimen?

Subquestions:

6.) Please describe how you feel about your treatment regimen?

7.) What helps you maintain your schedule?

8.) What obstacles did you face in adhering to treatment?

b.) How did you overcome those obstacles?

We are finished with the first interview. Thank you for talking with me today. I appreciate you sharing your experience with me. I will complete the transcription and analysis over the next 2 to 3 months. I will then do a follow up call with you and we can schedule a time to meet for your review and approval of my findings. Do you have any questions for me right now?

If you have any questions prior to our second meeting or would like information regarding the project or counseling services, please let me know at your earliest convenience. Thank you again and take care.

APPENDIX E

**THE EMOTIONAL EXPERIENCE OF AMERICAN INDIANS RECEIVING
HEMODIALYSIS AND HOW IT RELATES TO TREATMENT ADHERENCE**

Follow-Up Flier

APPENDIX F

THE EMOTIONAL EXPERIENCE OF AMERICAN INDIANS RECEIVING HEMODIALYSIS AND HOW IT RELATES TO TREATMENT ADHERENCE

Follow-Up Meeting

Follow Up Meeting

Good afternoon/evening _____ (participant). As discussed during the initial screening and the interview, we would meet a second time for you to review and approve the results of the project as well as the agenda for change. Here are copies for your review. We will go through these together and if at any point in time you feel that my writing has misrepresented your experience, please let me know and I will immediately make adjustments to accurately capture the essence of your experience. Similarly, with the agenda for change, if you feel I have neglected an area based on your experience, please let me know and I will make the necessary changes. Do you have any questions for me before we begin our review?

Changes to Participant Narrative as a result of review:

Changes to Agenda for Change as a result of review:

Thank you _____ (participant). I sincerely appreciate your participation. If you have any questions in the future regarding this project or mental health outreach for dialysis patients or yourself, please do not hesitate to call. My number is 402-405-2182. It was a pleasure to meet you and learn about your experience. Thank you again and take care.

APPENDIX G

**THE EMOTIONAL EXPERIENCE OF AMERICAN INDIANS RECEIVING
HEMODIALYSIS AND HOW IT RELATES TO TREATMENT ADHERENCE**

Agenda for Change

04/25/15

Oklahoma Area Indian Health Service
Attn: RADM Kevin D. Meeks, Area Director
701 Market Drive
Oklahoma City, OK. 73114

Great Plains Area Indian Health Service
Attn: Ron Cornelius, Area Director
115 4th Avenue SE, Room 309
Aberdeen, SD 57401

Dear Mr. Meeks and Mr. Cornelius:

My name is Anitra Warrior and I am recent graduate from the University of Nebraska-Lincoln's Doctorate Program in Counseling Psychology. One of the requirements for the degree is the completion and successful defense of a dissertation. Because of my personal familiarity with the epidemic of diabetes for American Indians, I chose to study the relationship between mental health and treatment adherence for American Indians. I have attached a copy of the approved IRB consent from the University of Nebraska-Lincoln. The study was not specifically focused on patients receiving care from IHS facilities or tribally run programs. The population for this studied was however, identified by Indian Health Service Area Offices for Aberdeen, SD and Oklahoma City, OK. The intent of reaching out to your office, is an effort to help promote awareness of the challenges faced by American Indian dialysis patients and possibly influencing service delivery for those who are able to receive services from the Indian Health Service.

Research over the years has found a strong correlation between diabetes and depression. Additionally, studies have been conducted on the overlapping symptoms of dialysis and depression. However, no studies were found that focused specifically on American Indians receiving dialysis treatments and there mental health. This dissertation was a qualitative study that included three men and three women who have been receiving dialysis treatments for a minimum of 2 years. All participants are members of federally recognized tribes and live within the CHSDA of Aberdeen, SD or Oklahoma City, OK. The age range of participants ranged from 38 years old to 68 years old and three of the participants were married. The questions asked of the participants were the following: (1) What has been your experience on dialysis? (2) What have you experienced emotionally after starting dialysis? (3) How were you able to adhere to the treatment regimen and (4) What obstacles did you face in adhering to treatment? Direct quotations from the dissertation are provided below as a summary to the questions asked:

What have you experienced emotionally after starting dialysis?

Based on the results of the analysis, fear and depression were common experiences for participants in this study. Additional emotional experiences included anxiety and anger which may be encompassed within the manifestation of fear and depression. Depression was reportedly experienced by all participants within this study but did not appear to be a long term psychological condition. Fear was a common experience for individuals within this study. This fear was related to the lack of knowledge about the procedure-which also contributed to anxiety.

How are you able to adhere to the treatment regimen?

Based on the results, a major component to adherence was the participant's cognitive appraisal of the treatment. Based on their experience, control as a contributing factor to adjustment was not only limited to controlling symptoms, but controlling other variables such as physical activity, peer interactions, family interactions and other contextual factors. Many of these components were described by the participants who had relationships with others receiving dialysis treatments. But the emotional experience of the individual has a direct impact on this cognitive appraisal. For example, experiences of anxiety, grief and anger affect thoughts about survival and whether or not the loss outweighs the commitment to the treatment.

What obstacles did you face in adhering to treatment?

Obstacles to treatment were identified as challenges with schedules, transportation, changes in lifestyle, and dietary restrictions. Schedules presented themselves as challenging because many of the participants felt as though they were tied down. Transportation was mentioned by the majority of the participants as it was a continuous struggle. For most, transportation was provided either by public transportation services dedicated directly to dialysis patients or through transportation services provided by the Indian Health Service. Conflicts arise with pick-up times as well as who the actual transporter will be. Participants of this study stated inconsistencies with pick-up times that eventually led to decreased treatment times. This is a challenge that remains out of the control of the participants and proves to be more difficult to overcome. Changes in lifestyle and dietary restrictions are challenges also challenges for participants of this study but appeared to be less challenging with increased knowledge.

Based on the findings of this project, there are many implications for clinical practice. There is not one specific description of adjustment for individuals as there are differences based on culture, gender, socioeconomic status and other sociocultural variables. Additionally, personal characteristics vary from one individual to the other: coping skills vary, personalities differ and cognitive functioning is variable. But a general practice for providers of dialysis treatments may include the following:

- 1.) *Reinforcement of training for the patients as well as their closest support network.*
Based on the results of this study, clinical practice should include a family approach to adjustment. For example, as individuals adjust to chronic dialysis, training for the treatment should be inclusive of patient designated family members, caregivers or social network.

- 2.) *Caregiver Support.* Caregiver support is often necessary and further research on the adjustment for family members may enhance how adherence is solidified for individuals receiving dialysis treatments.
- 3.) *Peer Support.* Additionally, based on the report of self-advocacy and comradery within the dialysis clinics, a mentorship program may be beneficial for incoming patients. Many of the participants in this study discussed how peer support from other dialysis patients was helpful in their level of understanding about the procedure. Patients who have exhibited that form of leadership and willingness to share may be able to serve as ambassadors of treatment. They may be identified as peer mentors and assist with training for the individual as well as the family members. Allowing this practice may enhance the comradery within the treatment setting as well as reduce the onset of anxiety about the procedure itself. This form of reinforcement suggests a continuous partnership which may also be further enhanced through a provider/patient relationship.
- 4.) *Provider/Patient Relationship.* This provider/patient relationship would serve as a collaborative effort to maintain adherence and self-management. This collaborative relationship may also serve as a reflective approach of peer support. A partnership in this effort may also decrease the anxiety experienced as the patient increases their knowledge of the procedure and their symptoms.
- 5.) *Regular Depression Screenings.* Additionally, a history of lifetime prevalence for depression may also serve as a beneficial component to practice as individuals adjust to the lifetime treatment of the dialysis procedure. Furthermore, because of the overlap of symptoms between dialysis and depression, patients may benefit from regular assessments of depression with accommodations being made for the overlap of symptoms.

An additional component to enhancing clinical support for the patient and their level of adherence would be to include an assessment of contextual and societal factors that may inhibit or advance the patient's adherence to dialysis treatments. Examples of this may include how patients are transported to treatment as well as support groups or programs available within the patient's community. This assessment of contextual and societal factors may be best approached through the Provider/Patient Relationship as well as during regular screenings of depression.

Many of the statements above were taken directly from the dissertation titled: *The Emotional Experience of American Indians Receiving Hemodialysis and How it Relates to Treatment Adherence*. Copies of the dissertation may be provided upon your request. As stated above, the intent of reaching out to your office was in an effort to advocate for dialysis patients. Many of the practices mentioned above may already be in place. This may be a limitation to the study as I was unable to determine the services offered across states and at various locations. As a psychologist, if there is any manner in which I may be able to assist patients as they transition to living with dialysis treatments, please do not

hesitate to contact me. My contact information is listed below and I would be honored to assist in reaching out to individuals who receive dialysis treatment.

Respectfully,

Anitra Warrior, PhD

ATTACHMENT: Approved IRB Consent Form