

ABSTRACT

THE LIVED EXPERIENCE OF NATIVE AMERICANS DIAGNOSED WITH TYPE 2 DIABETES MELLITUS

By Travis R. Novy

Background: Type 2 diabetes (T2DM) is a deadly condition and is endemic among Native Americans. When T2DM is mismanaged or undermanaged there can be severe long-term disability including blindness, heart disease, and kidney failure. Managing T2DM involves significant lifestyle changes, including weight loss and exercise. There is a dearth of information regarding the understanding of T2DM among Native American cultures.

Purpose: The purpose of the study was to extract essences of meaning of what it is like to live with T2DM. Implications for advanced practice nurses were to better understand and to provide effective, culturally congruent care to Native Americans living with T2DM.

Research Question: The research question was, "What is the lived experience of Native Americans diagnosed with Type 2 diabetes mellitus?"

Theoretical Framework: Both critical theory and Leininger's theory of cultural care diversity and universality were used as the theoretical frameworks.

Design: The study was a qualitative phenomenological design that used face-to-face interviews as a means of data collection.

Setting: The study was performed on the Oneida Nation Reservation in northeast Wisconsin.

Sample: Participants were Native Americans who have been diagnosed and are living with T2DM.

Data Collection: Data were collected through face-to-face interviews by asking participants the following question: "Please explain your experiences of living with Type 2 diabetes?" Prompting and clarification questions regarding perceptions of the disease, education, quality of care, effects on daily life, and stress were asked to aid in discussion.

Data Analysis: Colaizzi's procedural steps were used to guide the data analysis.

Results: Analysis of results revealed T2DM as an unfortunate rite of passage for Native Americans living in northeast Wisconsin, further acknowledgment included a long, hard fought battle accompanied by many ups and downs requiring an emotional support system to overcome the constant battle of T2DM. Additionally, participants expressed the increased need for education for future generations.

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TYPE 2 DIABETES MELLITUS

by

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First and foremost, I would like to give praise to the Lord God for all he has given me in life and for this I am eternally grateful.

But Jesus beheld [them], and said unto them, with men this is impossible; but with God all things are possible (Matthew 19:26 King James Bible).

I would like to dedicate this paper to my family, who has supported me through this entire educational process with kind thoughts and prayers, even when I didn't believe in myself, you were all there. Special thanks to my wife, Becca, without you none of this would have been possible nor would it have ever begun. All of you have given me help on this journey in your own individual way. Thank you to everyone for believing in me.

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Chapter I

Introduction

Type 2 diabetes mellitus (T2DM) is a chronic endocrine disease ultimately causing elevated glucose levels that lead to arterial plaque and microvascular blockages (McPhee & Papadakis, 2010). Approximately 90% of people living with diabetes have T2DM (McPhee & Papadakis, 2010). It is a disease that affects all ages and heritages, especially Native Americans (NA). According to the National Diabetes Information Clearinghouse (NDIC) (2008), T2DM is a chronic disease that ultimately causes cardiovascular disease and stroke, renal failure, neuropathies, hypertension, amputations, and retinal damage leading to blindness. It often affects individuals who are obese, have a family history of T2DM or gestational diabetes, and are sedentary. The most overlooked populations with T2DM are Native Americans, Hispanic Americans, African Americans, Pacific Islanders, Asian Americans, and Native Hawaiians (NDIC, 2008).

There are numerous research studies (Holm, Vogeltanz-Holm, Poltavski, & McDonald, 2010; Jernigan, Duran, Ahn, & Winkleby, 2010; Jiang, Beals, Whitsell, Rooubideux, & Manson, 2009; O'Connell, Yi, Wilson, Manson, & Acton, 2010; Pouter, Geelhoed-Duijvestijn, Tack, Beekman, & Rienhart, 2010) investigating different aspects of diabetes involving diabetes and depression, myocardial infarction, smoking, obesity, alcohol use, coping, treatment options, quality of life, and relationship effects. Several of these studies acknowledge the epidemic status of T2DM among the Native American populations of the United States (Parker, 1994). The NDIC (2008) noted that the estimated number of Native Americans living with T2DM was upwards of 16.5% in 2005

and as high as 29.3% in specified Native American communities. Perhaps the most devastating evidence, according to the NDIC is that, "Once seen only in adults, type 2 diabetes is increasingly being diagnosed in youth, especially in American Indian and other minority populations." Another concerning fact is that the worldwide population of people living with diabetes is expected to double, from 180 million to 360 million, by the year 2030 (George & Thomas, 2010). These are troubling numbers. The United States (U.S.) is among the top three nations with the most T2DM, over 23 million incidents, making it the sixth leading killer of Americans every year (George & Thomas, 2010).

Although there is a vast array of knowledge about T2DM, there is limited information regarding lifestyles and experiences of those affected in the Native American Culture (Parker, 1994). Most of the current research focuses on statistical analysis of perceptions, coping, depression, resiliency, and quality of life in a general melting pot of information related to diabetes. Little has emerged in the qualitative realm of research regarding Native Americans living with T2DM (Duangdao & Roesch, 2008; Huang, Courtney, Edwards, & McDowell, 2010; Yi-Frazier et. al., 2010). Hence, the purpose of this study is to evaluate first-hand the lived experience of Native Americans diagnosed with T2DM.

Problem and Purpose

Native Americans are currently being plagued by an epidemic that is damaging the very fabric of their people. Type 2 diabetes mellitus has gained a foothold in Native American communities and is leading to multiple health problems. Native American culture has a prominence of genetic factors that lead to T2DM, in addition to high risk lifestyle behaviors (McPhee & Papadakis, 2010). There is also a misalignment of

patients' perceptions of compliance, self-management, and provider cultural sensitivity (Clark, 2007). Consequently, T2DM often goes unmanaged or undermanaged in Native American communities. The proposed research analysis will focus on the lived experience in order to understand the worldviews of those affected by T2DM in the Native American culture. The results of this research analysis may increase provider awareness toward cultural implications of care.

Research Question

What is the lived experience of Native Americans diagnosed with T2DM?

The research question was answered using face-to face-interviews, followed by exhaustive review and analysis by the researcher. Once data saturation had occurred, the process of intuiting, phenomenological analyzing, and phenomenological describing began. Common themes or phenomenological essences were extricated. Critical theory and Leininger's culture care theory were used to understand essences that were pertinent to the lived experience. These essences, when applied to the theories mentioned, may provide understanding of Native American lifestyle as it related to T2DM.

Definition of Terms

Conceptual definitions.

Type 2 diabetes mellitus: Type 2 diabetes mellitus is defined by the NDIC (2008) as a disease marked by elevated blood glucose levels resulting from faulty insulin production by the pancreas, ineffective insulin utilization, or both.

Lived experience: Rooted in the French phase of phenomenology is the lived experience, defined as a phenomenon that is derived from the basic embodiment of being in the world (Speziale & Carpenter, 2007). This allows the development of a set of principles based on experiences and adaptations to life according to perspectives.

Native Americans: For the purpose of this study are those individuals recognized by the tribal leadership as members of their associating tribal nation.

Operational definitions.

Type 2 diabetes mellitus: Type 2 diabetes mellitus is an endocrine disorder that affects Native Americans at much higher rates than the adjacent population, in addition to the formal definition of the NDIC (2008).

Native Americans: For the purpose of this study are those individuals recognized by the tribal leadership as members of their associating tribal nation.

Lived experience: The self-described day-to-day experience of Native Americans living with T2DM, as told by the Native American participants of this study in northeast Wisconsin. This involves personal and cultural perceptions of the disease process.

Assumptions

As healthcare providers, assumptions generally are generated by word of mouth or personal experience (Polit & Beck, 2008). Assumptions are those basic principles surrounding a particular topic or situation that is believed by the researcher to be true, but are unable or have not yet been substantiated by absolute facts (Polit & Beck, 2008). In order to control bias in the study, it was important for the researcher to identify any

assumptions in addition to presuppositions in order to maintain an objective approach to the study. The following are those assumptions:

1. Native Americans feel a sense of burden by T2DM, and it affects them not only physically but mentally, as well.
2. Participants will answer the question(s) honestly.
3. Participants are engaging in the study to benefit their community.

Embarking on this research study brought with it a set of presuppositions that included the following:

- Native Americans generally do not control their diabetes effectively using diet and exercise.
- Native Americans are often noncompliant regarding medication use and monitoring of blood glucose levels.
- Native Americans want to manage their diabetes well, but there are cultural barriers that prevent this from happening.
- Native Americans, given the proper environment for change, would be motivated to improve their lifestyles.
- T2DM alters the worldview for those affected in the Native American culture.
- Native Americans would like the chance to help their culture overcome the burden of T2DM.

In order to control bias in the setting of the mentioned assumptions and the bulleted presuppositions, the researcher asked only questions directly related to living with T2DM. None of the questioning attempted to lead the participants into discussing their heritage. If they chose to discuss topics that involved specific cultural

involvements, it was their choice. By this approach the researcher remained neutral in the process in order to gain unbiased information.

Significance Related to Primary Care

The significance to primary care regarding the lived experience of Native Americans diagnosed with T2DM is straightforward. Type 2 diabetes mellitus can be managed by primary care practitioners effectively and efficiently in the primary care setting given the proper tools and resources. There is often a cultural barrier between effective primary care and the Native American culture (Berry, Samos, Storti, & Grey, 2009). Native Americans have been long misunderstood and mistreated in the United States, dating back to the time of the earliest settlers in this nation (Kinsey, 2010). An unbiased approach allows for a complete and honest understanding of the most effective way to care for Native Americans affected by this disease.

It was an expectation of the researcher to gain knowledge and insight toward the experiences of the Native American people regarding their expectations of the healthcare providers and themselves. Ultimately, the goal was to spur future conversations on the effectiveness of the approach to T2DM management by advanced practice nurses (APNs) encompassing holistic nursing practices in conjunction with medical therapies.

Method of Analysis

Data were collected from participants through an interview format in order to understand the ontological realm of Native Americans living with T2DM. Data saturation occurred when recurrent themes began to emerge. At that point, two more interviews

were conducted to ensure saturation. In order to operationalize the concepts of this study, it was necessary to use a guide to collect and evaluate data. In this case, Colaizzi's procedural steps were used to aid in the research process (Speziale & Carpenter, 2007).

Theoretical Framework

This was a qualitative phenomenological research design rooted in the naturalistic paradigm. Theoretical framework was embedded in critical theory to ensure rigorous review and analysis of data in addition to supportive aspects of Leininger's cultural care diversity and universality theory. This naturalistic paradigm aided in understanding the lifeways of Native Americans with T2DM (Leininger & McFarland, 2006).

Chapter Summary

Chapter I focuses on establishing the ground work for the research study regarding the lived experience of Native Americans diagnosed with T2DM. The goal of this study was to understand how living with T2DM affects or alters Native American's worldview and lifeways in relationship to their overall health. Common themes provided by the participants conveyed holistic primary nursing care approaches of providers to those individuals affected by T2DM. Though this was not an ethnographic research study, there were components of such a study involved, especially mild cultural immersion (Speziale & Carpenter, 2007). The knowledge and insight gained in relation to the Native American culture can improve not only the quality of care provided, but also establish a healthcare provider based relationship for future Native American healthcare

improvement. This relationship may be grown by provider engagement in care of Native Americans with T2DM.

Chapter II

Theoretical Framework and Literature Review

Introduction

As mentioned in Chapter I, this research study asked the question: What is the lived experience of Native American's diagnosed with T2DM? Chapter II will illustrate the theoretical framework that provided strength of data for the research study. Additionally, a systematic literature review will contextualize the problem and provide evidence for essential exploration of those Native Americans affected by T2DM.

Theoretical Framework

The theoretical framework for this study utilized the principles of critical theory along with Leininger's cultural care diversity and universality theory.

Critical theory.

Recently, the concepts formulated from traditional critical theory have been explored and applied to the context of a nursing approach to care for disadvantaged groups of people (McEwen & Wills, 2007; Polit & Beck, 2008). The principles utilized for the purposes of this study were those of critical theory that focus strictly on the ideology that social change can occur for the betterment of a specific social group. McKenna (1997) describes critical theory as an ideology that assists disadvantaged groups to become aware of the circumstances by which they are being oppressed allowing them to be free and empowered. More importantly, the use of critical theory was the guide of the study in addition to Leininger's theory to provide the supportive cultural aspect.

Polit & Beck's (2008) descriptions of critical theory implies that within the context of social groups, the application can bring about change that can improve the quality of life of certain individuals affected by disparities within that culture. Dickinson (1999) describes critical theory as whole societies transforming from a state of crisis to a state of harmony by identifying oppressive concepts in situation. Possible opportunities for change are those found at the primary care level of nursing to improve upon individualized care delivery at the level of the nurse practitioner/patient relationship. We recognize that there is ultimately a dialog between patient and provider that is of the most vulnerable sense. Patients often reveal their darkest moments with their trusted provider. Hence, using critical theory involves the researcher analyzing taken-for-granted aspects of a cultural group by actively utilizing participants' expertise (Polit & Beck, 2008). This process allows the researcher to triangulate the information using participants' understanding, as well as, in this case, Leininger's culture care theory, their expertise to support research findings and strengthen the findings of the study.

Critical theory is described by Habermas, as cited by Speziale & Carpenter (2007), "...as a way to develop knowledge that is free, and undistorted, and unconstrained." Speziale & Carpenter (2007) suggest that such a study can be liberating to a group in order to understand their lifeways and worldview, as it encompasses their healthcare. Critical theory applies to the understanding that Native American's diagnosed with T2DM must be heard and fundamentally understood from their point of view. By doing this, primary care can be functionally altered to effectively apply health care principles to Native American culture.

The approach of Sigsworth (1995) is recognized as a reasonable approach to critical theory for the purposes of this study that involve feminist principles. Speziale &

Carpenter (2007) summarize seven essential points that illustrate the usage of critical theory in this context:

1. Research should be focused on the experiences of the population studied, their perceptions, and their truths.
2. Artificial dichotomies and sharp boundaries are suspect in research involving human beings.
3. History and concurrent events are always considered when planning, conducting and analyzing, and interpreting findings.
4. The questions asked are as important as the answers discovered.
5. Research should not be hierarchical.
6. Researchers' assumptions, biases, and presuppositions are part of the research enterprise.
7. Researchers and research participants are partners whose discoveries lead to understanding (p.14).

These seven principles helped to frame this study in order to provide evidence that is deeply rooted in Native American culture. Furthermore, using the above principles as a guide, opened doors of new understanding toward Native American cultural perceptions and preferences of primary care, as it related to the treatment of T2DM. In 1991, Habermas (in McEwen & Wills, 2007) recognized the use of critical theory as a means of a broken culture to address a problem in a manner that promotes an open dialog free of bias and coercive elements. An example of this would be the bracketing of researchers' presuppositions in order to remain objective in their evaluation.

Additionally, critical theory provided a basis for approaching a research topic from a philosophical, sense while using conjunctive theorists to support statements and triangulate data. Critical theory suggests that bringing attention to disparities and recognizing the negative impact on a culture is a driving force to focus on improving a situation (Polit & Beck, 2008). These thoughts align with Leininger's culture care theory, in that lack of knowledge regarding a particular culture simply creates a missing link in a provider's ability to provide quality care (Nelson, 2006).

Leininger's culture care: Diversity and universality theory.

Based on the fact that this study was exclusively immersed in the Native American culture, it seems only appropriate that Leininger's culture care: diversity and universality theory be applied. Leininger's works are briefly summarized by Tomey & Alligood (1998) by stating, "(T)he belief that people of different cultures can inform and are capable of guiding professionals to receive the kind of care they desire or need from others." These ties connect the critical theory principles that a troubled culture can achieve quality care when the problem is approached from both sides in an altruistic manner. Leininger's approach takes into account the social structure of a culture and the holistic aspects necessary to provide culturally congruent care (Tomey & Alligood, 1998). Common themes within the study may illustrate the following terms laid forth by Leininger:

1. Cultural congruent care is a cognitively base care that is rooted in assistive, supportive, facilitative or enabling acts by providers to ensure support of cultural lifeways. Consequently, care that is molded to fit a particular culture in order to maximize the effectiveness of care provided to benefit values, beliefs, and well-being (Tomey & Alligood, 1998).

2. Lifeways is a term often used by Leininger when referring to the cultural practices, beliefs, perception, languages, and health care practices regarding a particular group of people (McEwen & Wills, 2007).
3. Health is the total unity and harmony of mind, body, and spirit that involves an individual perception that varies from person to person regarding how they feel in relation to their needs and desires for personal quality of life (McEwen & Wills, 2007).
4. "Worldview is the philosophical frame of reference used by a social or cultural group to describe that group's outlook on their beliefs about reality" (McEwen & Wills, 2007, p. 29).

As it was applied to this research proposal, the interview process attempted to extract the emic beliefs of the Native American culture, as it related to primary care in relation to the treatment of T2DM. The emic view of care for the Native Americans is vital to understanding the lived experience through their perceptions and belief systems. The ultimate goal aligns with Leininger's (2008) statements that transcultural nursing continues to expand in order to have cultural beliefs, lifeways, health, and well-being upheld in the manner that most closely aligns with their traditional practices. The lived experience topic guided the study in a fashion that attempted to magnify aspects of the Native American culture for future research. This approach has the opportunity to mold a highly effective model of care that meets Native Americans at the point of their most vital needs.

Although this study focused on the lived experience aspect, it was felt by the researcher that without a long term goal in mind the findings would have been noncontributory to nursing. This is why the emersion of culturally congruent care, as

defined by Leininger (2008), was essential to bear in mind while researching the lived experience. Without cultural congruent care in mind, it is impossible to relate Native American worldviews to the process by which they approach healthcare. The worldview of the Native Americans is essentially the sculpture of ideas in day-to-day life that will emerge through the understanding of their lived experience. The following illustration depicts the process of relating the theoretical framework and the perceived results and application for future cultural nursing.

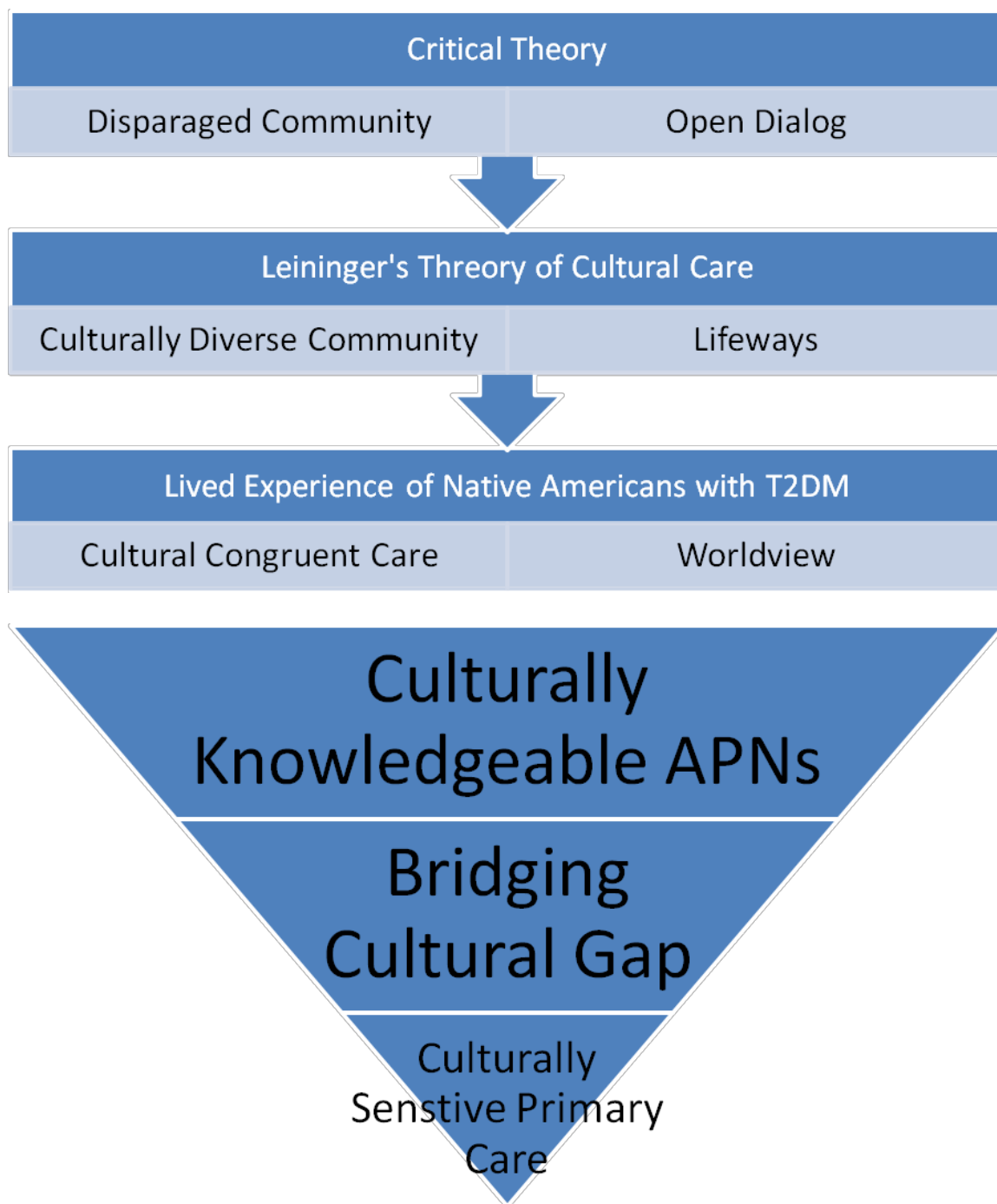


Figure 1. Theoretical Model

Case Study

Understanding how Native Americans perceive and approach healthcare in regard to T2DM can only be understood through the personal experiences of the Native American population. JD is a 48-year-old Native American who was diagnosed with T2DM 12 years ago. He has three children and is married. He attends a local tribal clinic and attempts to follow his provider's orders on maintaining a healthy lifestyle. His glucose checks are often out of range and his hemoglobin A1C is out of range for what is considered normal. He currently is on insulin but does not like having to stick himself with a needle multiple times a day. He tells his provider that he feels as though no one understands his situation in the clinic. He goes on to discuss how all of the doctors are from other cultures, and he often does not know if they think about how Native Americans feel about T2DM in the community. He is not sure if he wants to continue to take his insulin. He also expresses approaching a traditional Native American healing process rather than western medicine. JD's provider explains the significance of insulin to him, but the provider feels as though JD has mixed emotions as a result of many years of uncontrolled blood sugars. JD's provider wishes there could be some way to help his patients to have a clearer understanding of T2DM that would help to motivate the community to work harder to overcome T2DM. JD and his provider then have a short conversation about what it is like living with diabetes and the barriers that cause problems and the way it affects his day-to-day life. Together they come up with a plan to use the resources available at the clinic and in the community to motivate JD in new ways to stay healthy and control his T2DM. JD's provider also vows to learn more about the culture in order to change his approach to treating his patients. JD agrees to continue taking his insulin and together they set goals for the next visit.

Case study summary.

Leininger's theory of culturally congruent care allows healthcare providers to explore new options to approaching unique populations. Leininger's theory helps us to understand a cultural group's lifeways and, ultimately, their worldview, which dictates how they perceive the environment that surrounds them. Additionally, critical theory in conjunction with Leininger's theory supports an approach that identifies a disparaged cultural population that is on the brink of recognizing and empowering themselves to alter the course of their oppression. In this case, the oppression is the disease process of T2DM and the lack of understanding by their providers of care. With this understanding, culturally sensitive APNs can bridge the gap between patient and provider in order to provide culturally sensitive primary care. This model not only applies to Native Americans, but to any disparaged group of people.

Literature Review

In order to protect the researcher from developing preconceived notions of the lived experience of Native Americans diagnosed with T2DM, a conservative approach to locating similar studies was attempted. A CINNAHL search revealed minimal relevant research studies and forced one study of starkly similar substance to emerge. Four other studies of similarity were located and able to be retrieved. They focused on the lived experience of married elderly couples and the other on couples with diabetes living within a rural setting. Another study involved adolescent females diagnosed with type 1 diabetes and their experiences. One last study that was quantitative in design focused on the physical burden of T2DM and its association to other illnesses. Quantitative

diabetes research is extensive but also limited in the realm of psychological understanding and cultural phenomenon.

Although few studies were isolated, several concepts emerged from those that were located. The concepts that were noted to be of relevance were caring, cultural care, worldview, environmental context, health perception, and quality of life (Clark, 2007; Dickinson, 2000; George & Thomas, 2010; Parker, 1994). These concepts closely resemble and, at times, mirror the concepts outlined for the purpose of the proposed study. In addition, many, if not all, are similar and comparative to Leininger's established concepts under her theory of cultural care (Tomey & Alligood, 1998).

Several of the studies mentioned below are examples of lived experience studies in order to draw similarities and gaps in order to illustrate the need for continued research in this area. Only one study mirrored the proposed study and was conducted in a separate geographical region from the proposed study. Additionally, a quantitative study was included to enforce the importance of the research given the disease burden of T2DM within the NA culture.

Racial disparities in health status. A comparison of the morbidity among American Indian and U. S. adults.

O'Connell et. al. (2010) conducted this study to compare morbidity among Native Americans and U.S. adults with diabetes. The authors used a quantitative approach by using demographic and health data from the Indian Health Service (IHS). The study proved a higher rate of T2DM in Native Americans that seemed to coincide with hypertension, cerebrovascular disease, renal failure, lower-extremity amputations, and liver disease. The disease burden of this group exceeded that of the rest of the U. S. population studied. O'Connell et. al. firmly state that limited studies exist that compare

Native American comorbidities and how to treat in order to prevent the effects of end organ damage. Ultimately, the authors suggested that information concerning prevalence of comorbidities may inform health officials to increase the efforts on the tribal level to reduce premature mortality. They did not specify what form of advancement was necessary, just that further attention was needed.

Prior lived experience of noninsulin dependent diabetes mellitus (NIDDM)

Native Americans.

This study by Parker (1994) illustrated the epidemic of NIDDM on reservations in Oklahoma. The researcher's efforts were to advance transcultural nursing knowledge of Native Americans living with NIDDM. A phenomenological qualitative study design was used to open a door to an area of study that had not yet been approached. The results of the study focused on participant reactions, responses to loss of health, culturally associative properties, fear, peace, and grieving processes. Ultimately, Parker noted that NIDDM has become a way of life for Native Americans living in Oklahoma, and that living with the disease in their culture is much different than Anglo American's experience. Parker speaks of a *non-visible enemy* that attempts to ravage their culture. Leininger's cultural care theory is used to illustrate the transcultural nature of the study.

Parker (1994) did not, however, focus on Native Americans with T2DM who were insulin dependent or taking insulin. She focused solely in one geographic area and encompassed several Native American tribes, but failed to include mention of several tribes located in northern Wisconsin.

Lived experiences of diabetes in older people.

This study focused exclusively on the elderly population living with diabetes and noted the gap in the educational process that is guided by the medical community.

George and Thomas (2010) discussed the need for a nursing focus in the educational department surrounding the ever-growing elderly living and managing T2DM. The aim of the study was to understand the experience and perceptions of elderly living with diabetes in a rural setting. This was a phenomenological study that was rooted in the French philosophy of Maurice Merleau-Ponty given direct description of experience (George & Thomas, 2010). George and Thomas' findings suggest the need for specific structured and individualized education is necessary to provide quality care of elderly people diagnosed with diabetes. Additionally, they noted that compliance may not be an issue of patient understanding but a lack of innovative education. Limitations of the study were noted to be an absence of Native Americans and minority groups in the study who have a high incidence of T2DM (George & Thomas, 2010).

Lived experience of elderly couples.

Clark (2007) focused on the experience of married elderly couples and alterations and interpretations of life with a diabetic spouse. The design of the study was a qualitative phenomenological approach. Only six couples were interviewed for the study. Clark identified that three themes regarding support of spouse, compliance, and complications. Lack of education of participants proved to be the overwhelmingly significant finding by Clark. Clark suggests that not only is this a problem on the part of the patients, but the providers, as well, when it comes to providing adequate information to the patient. Gaps in the patient understanding of the disease and how this deficit affected management of disease was noted. Recommendations for further research included behavior modification and adherence to treatment plans (Clark, 2007).

Lived experience of adolescent females with diabetes.

Dickinson (2000) focused on type 1 diabetes in female adolescents and how that experience shapes their worldview. The design of the study was qualitative phenomenology. The study focused on enhancing treatment protocols in the described population. Perspectives of life views were established and evaluated for future understanding. The study found that adolescents do not always make diabetes a priority, as a result of social perception of peers. In addition to this, it was noted that adolescents with diabetes view it as a hassle and often do not follow specified regimens recommend for their medical care, resulting in long term complications (Dickinson, 2000). Participants did note regardless of hassle, diabetes was part of daily routine (Dickinson, 2000). Limitations to this study were sample size and generalized application, in addition to suspected lack of openness on the part of the participants. Future research suggested finding alternative treatment approaches for this population.

Literature Summary

To summarize the five focus studies pertinent to the proposed study would be to state that an overall understanding of people living with diabetes is not well-established. There are vast treatment plans and numbers of medications and different types of insulin. There are statistics regarding Native Americans with diabetes and their comorbidities and the effects of the disease on the person and the rate it affects the community. Multiple studies discuss endless phenomenon revolving around this topic, but each has their own set of limitations in regards to Native Americans. Postulation of thoughtful and effective care is not found in the highlighted studies. Focusing on lifeways and worldviews pertinent to the health of the patients affected by diabetes

cannot be found in statistics or studies about adolescents or elderly couples living with diabetes. Educational approaches to Native Americans are absent in the literature. Thus, the advancement of up-to-date understanding of communities affected could give insight to culturally sensitive approaches that bear in mind unique qualities and needs of Native Americans.

Chapter Summary

The need to connect with the worldview of patients can ultimately improve quality care. Chapter II focused on theoretical foundations and review of pertinent literature for understanding the direction of the proposed study. Critical theory was discussed to frame the approach to the study in a fashion rooted in an attempt to apply high quality care to a disparaged group of patients. Leininger's theory of cultural care was applied to generate a culturally sensitive approach to understanding the lived experience of Native Americans with T2DM. Together, these two theories strengthened and validated the findings of the study. The literature review supported the continued need to approach specific groups, especially Native Americans, regarding the treatment and education of patients with T2DM. Much is known about diabetes, in general, but there seems to be a disassociation between providers and patients that causes a lack of understanding on both sides.

Chapter III

Methodology

What is the lived experience of Native Americans diagnosed with T2DM?

Chapter III will discuss the design, population sample, data collection, analysis, and ethical approach to this study. Limitations will also be discussed.

Design

The study related to T2DM and the Native American culture was a qualitative phenomenological approach. The naturalistic paradigm recognizes a world that provides multiple approaches to answering a research question. Phenomenology has long been focused on understanding the lived experience (Speziale & Carpenter, 2007).

Phenomenological analysis is a rigorous, critical, systematic, method of investigation of a specific phenomenon that has not been adequately established (Speziale & Carpenter, 2007). Phenomenology involves three phases: the Preparatory phase, the German phase, and the French phase. These three phases help to frame and establish intentionality and consciousness of the world as ever changing. The phases link together the following principles: essences and ideals, intuiting, phenomenological reduction, bracketing of presuppositions, and embodiment of being-in-the-world (Speziale & Carpenter, 2007). All together, they focus on the lived experience of a population and their perception of a specific phenomenon.

Several steps are used in the phenomenological process to enable the researcher to extract meaningful evidence. Descriptive phenomenology aids in exploration and analysis of the phenomenon of the lived experience (Speziale &

Carpenter, 2007). Phenomenology of essences probes the data for common themes, while reductive phenomenology offers a pure interpretation of the phenomenon as to eliminate bias and presuppositions (Speziale & Carpenter, 2007). This naturalistic process, given the opportunity, can reveal unique understanding of a particular phenomenon related to a population, in this case Native Americans living with T2DM.

Population

The target population in question was Native Americans living in northeast Wisconsin. They are human beings recognized by the United States and Bureau of Indian Affairs as being American Indian and by Certified Degree of Indian Blood Card (CDIB). They are a people of strong heritage who derive their belief systems from longstanding cultural traditions. Within this population is a vast group plagued by a spreading epidemic of T2DM. The accessible population for this study was a group of patients that utilize a Native American tribal clinic in northeast Wisconsin.

Sample

Purposive sampling and snowball sampling was used in this phenomenological study. Members of a Native American nation in northeast Wisconsin were the primary focus group established through a tribal clinic. This clinic has an exceptional diabetes program focused on specifically managing Native Americans with T2DM. Members of the tribe were selected by the diabetes team at the clinic based on willingness to participate and fulfillment of inclusion and exclusion criteria. Sample size was determined during the study based on data saturation, as redundancy began to be noted. A qualification questionnaire was passed out to patients at follow-up T2DM visits

at the clinic if they wished to participate (Appendix A). Note that there was no attempt to discriminate in the sampling of this study based on age, education, culture, religion, or socioeconomic status. The following criteria were chosen to locate participants who would provide the most candid representation of their lived experience.

Inclusion criteria: Inclusion criteria were those who have T2DM, are over the age of 21 years, and have a willingness to participate.

Exclusion criteria: Exclusion criteria were those that were under the age of 21 years and those who had type 1 diabetes.

Setting

The setting of this study was located in a rural Native American community in Wisconsin. Services available to the community range from internal medicine and primary care to dental and optical, as well as behavioral health, at a community tribal clinic. The clinic was chosen to aid in the sampling process, as a result of the researcher's prior experience with the clinic as a student during a family nurse practitioner clinical rotation. It was noted to have an exceptional T2DM program, which spurred the idea for a study involving the Native American population. The clinic personnel were highly receptive of the study. Location of interview took place in a neutral comfortable setting chosen by the participant.

Institutional Review Board

Institutional Review Board (IRB) approval was obtained through the University of Oshkosh (Appendix D). Approval for the study was given by the Oneida Nation Tribal Clinic medical director.

Ethical Considerations

There was an informed consent letter that outlined the process of the study to the participants (Appendix C). The letter discussed the interview process and the fact that none of the interviews will be used in a manner that negatively impacts their lives. In addition, the interviews would not be able to be traced to them other than by the interviewer. If, at any time, the topics discussed cause any emotional distress, there are nurse practitioners, physicians, and counselors available at the community clinic who can aid in this area. Institutional Review Board approval was achieved prior to the data collection. The results of this study were intended to benefit Native Americans and healthcare providers.

Data Collection

Data collection took place in the previously identified setting and involved face-to-face interviews that were tape recorded using a new cassette for each interview. The cassette was tested for sound quality prior to the start of the interview. It was anticipated that the interviews would take approximately one hour. Prior to beginning the interview, written consent was obtained and a demographic questionnaire was completed. (Appendix B). The following open-ended prompting question was asked, "Please explain your experiences of living with T2DM?" Additional prompting questions regarding perceptions of the disease, education, quality of care, effects on daily life, and stress were asked to aid in discussion if necessary. When warranted, clarification questions were asked by the researcher to achieve clear understanding of the statements. It was conveyed to the participants that there were no "right" or "wrong" answers, and that they were to simply tell the researcher how they perceive life with

T2DM. Upon completion of the interview, the participants were given a \$20 gift certificate for gas in appreciation for their time. These gift certificates were similar to what their clinic provides for maintaining regular medical checkups.

Data Analysis

After all of the interviews were completed, they were transcribed verbatim and prepared for analysis. Data analysis followed Colaizzi's (in Speziale & Carpenter, 2007) procedural steps in regards to this study to guide the collection, analysis, and validation, of the data. Colaizzi's process is as follows:

1. Describe the phenomenon of interest.
2. Collect participants' description of the phenomenon.
3. Read all participants' description of the phenomenon.
4. Return to the original transcripts and extract significant statements.
5. Try to spell out the meaning of each significant statement.
6. Organize the aggregate formalized meaning into clusters or themes.
7. Write an exhaustive description.
8. Return to participants for validation of the description.
9. If new data are revealed during the validation, incorporate them into an exhaustive description.

Colaizzi's method aided in extracting the phenomenological essences of the interviews. Descriptive phenomenology was used in attempt to respectively represent the worldview and experiences of the participants. The process of intuiting, analyzing, and describing were key components of this process (Speziale & Carpenter, 2007). Other components of phenomenological study are phenomenology of essences,

phenomenology of appearances, constitutive phenomenology, and reductive phenomenology. They were all integral parts of the analytical process. Ultimately, these components brought forth the core conceptual meanings set forth in the interviews.

Anticipated Limitations

Three limitations were immediately obvious to the researcher. The first was the ability to achieve data saturation based on the willingness of the population to participate in the lived experience study. Second, was the level of trust that the participants' felt towards the interviewer, as it is recognized that the interviewer was not culturally connected to the Native American population. Lastly, was that trust preceded by the participants' candor. Without candor, reliability would have been jeopardized. It was recognized that the results of the study were affected by the quality of the data collected.

Chapter Summary

Chapter III discussed the qualitative phenomenological design of this proposed study. It is recognized that the naturalistic paradigm aided the researcher in finding truths related to the lived experience of Native Americans with T2DM. The study followed Colaizzi's procedural steps to gather and analyze data, as well as the principles of phenomenological analysis. A purposive sample of Native Americans from a northeast Wisconsin tribal clinic was the key informant for data collection. It was the researchers desire to ethically gather quality information that would serve to gain further understanding of the experiences of Native Americans living with T2DM and improve their quality of care through future research.

Chapter IV

Findings and Discussion

Introduction

The purpose of this study was to establish the phenomenological essences of meaning that represent Native American opinions and beliefs surrounding the topic of T2DM. The research question was: What is the lived experience of Native Americans diagnosed with T2DM? In this chapter, the study sample, the themes that represent the Native American interpretation of T2DM, and the significance to the future of family practice nursing will be discussed.

Demographics

Data collection for the study consisted of face-to-face interviews and began immediately after IRB and the tribal clinic approval. A purposive sample was selected through the tribal clinic by way of the diabetic team's request. Each participant had agreed to the study prior to contact with the researcher. Overall, 10 participants agreed to be interviewed, and several more declined after being approached in the community tribal clinic. Initially, six participants were obtained, followed by four participants that were a product of snowball sampling. The interview process was generally 30 minutes in length and took place in the homes of the participants. Demographics can be found in Table 1. The sample consisted of seven females and three males, ranging in age from 43 years to 75 years. The sample consisted of nine participants from the Oneida Nation who lived on the reservation. The remaining participant represented the Stockbridge Nation and lived off of the reservation. The participants' duration of illness since

diagnosis of T2DM ranged from 5 years to greater than 20 years. All of the participants were on either insulin or an oral antihyperglycemic medication or both to control their blood sugars. Three participants were using medications alone, two were using insulin alone, four were using both to control their blood sugars, and one participant was diet-controlled. Seven of the participants felt that their T2DM was under control; the remaining three participants felt they needed more control. They reported seeing their nurse practitioner for follow-up and management of their T2DM multiple times per year, ranging from twice to greater than or equal to four visits per year. Incomes ranged from less than \$10,000 to greater than \$40,000 per year. Six participants reported having a college education and the remaining four had a high school education.

Table 1. *Demographics (n=10)*

	Frequency
Age range 43 – 75 years	
Sex	
Male	3
Female	7
Marital Status	
Married	6
Single	4
Tribal affiliation	
Oneida	9
Stockbridge	1
Years with T2DM	
5 – 10	3
10 – 15	5
>20	2
Medication	
Oral	3
Insulin	2
Both oral and insulin	4
Feel their T2DM is under control	7
Nurse practitioner visits per year	
2	2
3	1
≥4	7
Education level	
College	6
High school	4
Living on reservation	9
Income	
>\$40,000	6
\$30,000 - \$40,000	2
<\$10,000	2

Themes

An extensive analysis of the data gathered in the study followed Colaizzi's procedural steps, as cited by Speziale & Carpenter (2007). The process included reading all of the transcripts and extracting the essences of meaning set forth within the interviews. While analyzing the transcripts, continual attention was given to details that connected the common themes in order to extract the most accurate representation from the Native American cultural standpoint. The following themes were extracted from the transcripts in representation of the sample.

- Unfortunate rite of passage
- The personal battle
- The long and winding road
- Someone to lean on
- Let our story live on

Theme 1: Unfortunate rite of passage.

The theme of *unfortunate rite of passage* emerges in the interviews, as a result of many references to family members who have T2DM. Many family members had serious complications, or unfortunately died, as a result of the comorbidities that accompany T2DM. The rite of passage was described as though it was something they were destined to acquire at some point in their lives. One of the participants made reference to the very words of this theme stating...

Living with T2DM, having heard of it throughout my childhood, early adult and adult life, and expecting to get it eventually, having many family members with it. It's kind of like a *rite of passage* that it came. Now that it is here it is just like a

part of life, you know, taking your pills and getting up and checking your blood and seeing how you feel.

Participants simply expected it to happen. The term *rite of passage* often has positive relational meaning attached to it, but in this case, the overarching suggestion is that of an unfortunate, almost inevitable, process. Culturally speaking, it has become just one of the many lifeways incorporated into the day to day of being Native American (Leininger & McFarland, 2006). Acceptance of being diagnosed with T2DM was varied; some just accepted its challenges. The following illustrates those emotions in one participant's own words, "So I just assumed I would be diabetic because of my mother being diabetic, and then my husband being diabetic. So, it was really no surprise and I didn't feel any different. I just expected it." Yet others admitted to feelings of denial and anger, referring to the diagnosis as something that would not affect them because it was just too much to bear...

... when I was first diagnosed...to me, it was, it was traumatic. Not even a year after I watched my mother pass away from the complications, I think maybe, I was in denial for a long time about it....I was deathly afraid of needles...I felt as though life had come to an end.

Ultimately, the analysis revealed many raw emotions that were woven into the interviews. In summary, those emotions were anger, denial, acceptance, frustration, pain, trauma, and sorrow. This makes the rite of passage truly an unwelcomed, but accepted, part of life.

Theme 2: The personal battle.

The theme of *the personal battle* emerged, as the participants discussed the day-to-day challenges accompanying T2DM. The lifestyle changes that were required seem

to pose the most difficulty. Participants reported that they had difficulty keeping up with exercise, following a healthy diet, checking blood sugars, and remembering to take medications. They felt a constant awareness of personal deprivation, such as not allowing themselves to fall for temptations that would alter their health. This personal battle seemed to affect them in many ways. The following quotes represent many of those feelings:

“Well everything I do is a challenge.”

“Probably the challenge for me is trying to focus on it regularly, you know, to think, check, or don’t eat so much or watch your diet.”

“I take my shots... I quit smoking...I have to exercise.”

“In the beginning it was really hard because it was something added to do...now I’m pretty used to it... I try walk on the treadmill four to five times per week.”

“The trials and tribulations of everyday life, new medications, and sometimes medications make you sick.”

The participants frequently discussed the struggles with T2DM, as if they had just become part of everyday life for them. As mentioned earlier, they had gone through the rite of passage and now are working through or have worked through many of the daily burdens of T2DM.

Theme 3: The long and winding road.

The theme of *the long and winding road* represents not only a day-to-day battle, but that it is a lifelong struggle, as well. Staying the course seemed to be an underlying topic that emerged. Participants discussed how “each day had its challenges” and sometimes those days were portrayed as difficult and some days were rewarding. This theme is represented by the following excerpt from the interviews:

I suppose the experience of seeing the cycles, you know, like a personal growth...you grow some and you drop down some and you grow some. I think the challenges in lifestyle really helped, you know. Diabetes didn't change, you know. You can grow and change and things happen and you can crack down on things, but it's kind of always there, always a reminder.

Participants focused on the importance of staying the course by keeping the small things in perspective and keeping their eye on the long term goal of health maintenance through therapeutic lifestyle changes.

With diabetes its that just the numerous times you really have to stop and think, oh yeah, I have to take my blood sugar, I have to do this, I have to check that. And then it's like, you know, every three months I follow up with my diabetic doctor, and he, you know, check the glucometer...the change in the whole thing with being diabetic is that you have to be more aware and more alert and more on top of everything than ever before.

Theme 4: Someone to lean on.

Throughout the interview process many of the participants alluded to some sort of support system that helped them on a regular basis. For some of the participants, it was active involvement in their spirituality or church, for others it was family or friends, and still for others it was the comfort of having a supportive and knowledgeable healthcare provider.

Spirituality is one of the coping mechanisms of the day-to-day stressors of T2DM. One participant noted:

My lifestyle has changed. I became more active in church. I took a course in life skills, and actually during that course, my sugars dropped and my daily stresses

dropped. And the more that I've been involved in church and have been dealing with, I don't know, issues of, life, and learning to deal with people and think differently...I think of eternity and you're less stressed over small things that happen.

Support of family and friends who truly understand the trials and tribulations of T2DM became very evident and was a common thread through all of the interviews. The following excerpt illustrates family and friend support system:

It's definitely not the easiest thing in the world to live with, and you definitely have to have people around you that understand and support you, and support you 100%...It really helps to have someone who's in the same situation that can be there, because you know, my husband is there, and you know, he supports me, and my kids do, you know. They always ask me if I take my pills or I do this or that...it's easier if you have someone who has the same problems

Many of the participants discussed how much they appreciate what their healthcare provider does for them, especially when they take time to help them through difficult times. One participant described her experience regarding the need to begin taking insulin to control her blood sugars, "He said he was going to sit there with me and practice (giving insulin) until I got it so that I could do it." All participants expressed appreciation for the efforts of the local clinic, "I think having somebody to talk to about different problems or concerns in your life is very important, because I think you need to talk to somebody who understands and is concerned your wellbeing."

Theme 5: Let our story live on.

All of the participants felt that it was very important to educate the next generation about their heritage and the history of T2DM in their community. The

participants expressed the importance of understanding the relationship between the current food choices and T2DM. They indicated that the foods they eat now and the activities they partake in are much “different from their ancestors.” It was evident that they wanted their story heard and passed on for generations to come.

I’d like to add that I hope that the time that I’ve taken to speak about what I have learned can be passed on to somebody that will listen...Part of it is cultural, I believe, and the impact of being in this area that was so depressed earlier. I wasn’t born and raised here, but I know the history – the high unemployment, and you know, no indoor plumbing in the 70s, and water, it was pretty bad, you know. Getting people disciplined to really follow it and do it. If you take care of it, eventually, it’s going to get it and eventually you’re going to have troubles, but many of us, if we were more disciplined in the beginning and try to prevent it from coming, and then when it hits to stop it, we’d probably be better off, maybe in the next generation or two...I think if they (Native Americans) learn more about their food and what to choose in their foods, we could get rid of diabetes on the reservations.

Discussion

Results of this study revealed that Native Americans living with T2DM share common concerns and aspirations. The results revealed a high level of knowledge and understanding of the disease process, as well as a respect for the seriousness of it. Each participant recognized that T2DM has become a way of life for the people in their community. The prevalence of T2DM is an indicator of the drastic change in their way of life in recent generations. Much of what was discussed revolved around the trials and

tribulations of the disease process. The interviews also drew awareness to the fact that there are many outlets for support throughout the community involving family, friends, spiritual involvement, tribal community services, and healthcare providers. Type 2 diabetes mellitus is a lifelong battle of ups and downs that can be discouraging at times and uplifting at others. However, the fact remains that T2DM is a struggle for those affected, and in this case, it is a community health problem. With that problem comes opportunity to change the way these participants approach the disease.

The research study was limited by its sample size. Qualitative research is an excellent way to understand a problem from those well-voiced in the experience. The study sought to learn about the lived experience of living with T2DM from a Native American perspective.

Expanding the size of the study would have allowed for a broader representation of the Native American population in question. A pilot study would have been beneficial to determine a more precise interview process if time would have permitted. Perhaps this would have allowed for more detailed information and improved interview formatting that would focus directly on specific topics. A follow up study would be beneficial to advance these topics.

Differences from previous studies.

Prior studies did not reflect the lived experience of Native Americans diagnosed with T2DM in the form of overt detailed personal accounts nor did they reflect specifics to populations of Native Americans in Wisconsin (Dickinson 2000; George & Thomas, 2010; O'Connell et. al., 2010). Participants readily shared their feelings and emotions with the researcher throughout the interview process. This appeared to be a motivation for the participants to tell their honest and truthful story. They wanted to explain and

share their personal stories. They focused on the inner struggle they face on a day-to-day basis, as well as the support systems that play a major role in their continued perseverance. Another difference between this study and prior studies was the small community location of the study. Other studies suggested this to be a limitation; however, this proved to be an advantage for the present study. The Native American participants shared personal accounts that highlighted the importance of connections to the community. It was evident that this Native American tribal community shared a closeness and desire to improve the health of their tribal nation. The benefit of such a study on a smaller scale is that the essences of meaning ring true, they are almost palpable. Previous studies were often straight-question format with mail-based questionnaires of interviews. This study was an open forum style of interviews designed to allow the participants to tell their individual story as it pertained to T2DM and the Native American culture. Traditionally, storytelling in Native American culture was intended to convey important issues (Lipson & Dibble, 2005). Careful listening to stories and metaphors often reveals many important topics in Native American culture. The format of the interviews seemed to capitalize on this Native American cultural detail.

Similarities with previous studies.

Similarities to other studies were found in the desire of researchers to understand how T2DM affects the people of the Native American communities (Dickinson 2000; George & Thomas, 2010; O'Connell et. al., 2010; Parker, 1994). It seemed as though comparing previous studies after completing the data collection revealed a desire of the many researchers to understand what the exact details about Native Americans that allow for T2DM to gain such a strong foothold, and why is it so difficult to treat. Based on the beliefs of the participants interviewed, this study revealed a belief that their

current lifestyle is disassociated from their traditional lifeways (Leininger & McFarland, 2006). One of the participants spoke of his grandparents' diet,

The foods that our society has to eat today is tainted with a lot of preservatives and dyes..., and as a Native American, our foods were always fresh games, like deer and goose and duck. I remember my grandfather telling me they ate raccoon, rabbit, and squirrels, and they ate the white Indian corn that the Oneida Native Americans have grown and prospered for many generations. And they ate fish, fresh fruits, and vegetables.

Examples, such as this, point to the fact the Native American worldview and lifeways have moved almost polar opposite of their earlier days in relation to lifestyle and diet.

All of the related studies had a common link to the theoretical foundation of Leininger (Leininger & McFarland, 2006) that focused on the cultural implications of care, knowing that the humanistic approach helps to understand the underlying importance culture as it affects a certain issue. For this reason, the importance of each study was to bring to the surface some small piece of vital information to combat the effects T2DM on certain populations and cultures. The author is in agreement with Berry et. al. (2009) that educational programs must be integrated and modified to the specific needs of the community and presented in a cultural sensitive manner that reaches out to all members of the community.

Implications for Practice

The results are suggestive of the need for a truthful and sincere approach when interacting with Native American patients. Family nurse practitioners (FNP) must demonstrate attributes of caring and cultural sensitivity in the presence of Native

American patients. The initial diagnosis of T2DM is a sensitive matter that would be representative of a time when the FNP can portray these attributes. It is important to apply cultural integration to T2DM care in order to advance awareness of T2DM to Native Americans affected. Social support systems must be emphasized to aid in assistance for those diagnosed with T2DM. Recognition for the need of culturally competent FNPs is necessary. This specific sample emphasized the importance of the FNP being knowledgeable and available to the needs of Native American populations. Providers need to possess cultural awareness to provide adequate care to Native Americans with T2DM. Provider/patient interactions must capitalize on the time provided to give valuable information for individual therapy. Providers must give continual support and empathy to each individual within the culture. Additionally, the provider must give verbal representation of the population's struggles with T2DM in order to validate cultural sensitivity. In their role as providers, they must encourage others in the environment to understand the severity of the disease. Cultural sensitivity allows for the essential understanding that T2DM is not a disease that defines Native Americans.

Significance

The significance of the lived experience of Native Americans diagnosed with T2DM is that it provides a lens for family practice providers to see what a day in the life of a Native American living with T2DM in northeast Wisconsin is like. Awareness of difficulties, successes, and daily struggles that dictate decision making are the reasons for frustration. Each patient is an individual and is defined by their experiences, both individually and culturally, not by their disease.

Chapter Summary

Within this chapter, the sample, results of the study, and findings compared to previous studies are discussed. The purpose of this study was to understand the experience of Native Americans living with T2DM. The sample consisted of Native Americans in northeast Wisconsin ranging in age from 43 years to 75 years who had the diagnosis of T2DM. Interview transcripts were analyzed, and five common themes were established in regards to statements made during face to face interviews. Those themes were as follows, *unfortunate rite of passage*, *the personal battle*, *the long and winding road*, *someone to lean on*, and *let our story live on*. These themes represented similarities and differences related to prior studies. Ultimately, the results portrayed a need for special individual attention related to the culture, as well as an observant provider who is culturally competent toward the worldview and lifeways of Native Americans. Sensitivity to the needs of the individual is essential to providing a sense of compassion.

Chapter V

Summary, Conclusions, and Recommendations

Introduction

Within this chapter is a summary of the results of the lived experience of Native Americans diagnosed with T2DM. Additionally, the final conclusion of the study will be discussed as it relates to the theoretical framework, implications for practice, and future research recommendations.

Summary of Findings

Current literature related to Native Americans living with T2DM suggested the need for further qualitative research in regards to the understanding of personal perceptions of what it is to live with T2DM as a Native American (Duangdao & Roesch, 2008; Huang et al., 2010; Yi-Frazier, et. al., 2010). Several studies have focused on perceptions, coping, comorbidities, and resiliency related to T2DM. There was limited information regarding the affects of lifestyle and experiences on T2DM while living in Native American communities (Parker, 1994).

In order to explore the lived experience of Native Americans with T2DM, a qualitative study was arranged. Face-to-face interviews were conducted, and participants gave their account of what it is like to live with T2DM as a Native American. The participants possessed a great deal of knowledge related to their experiences with T2DM. The results revealed an unwelcomed rite of passage that brings with it multiple long-term personal challenges. Participants emphasized the importance of a support system that helps to deal with the day to day challenges. Additionally, a need for

increased awareness within the community related to treatment options and lifestyle changes was found to be necessary. The study revealed that T2DM is an unfortunate part of life for many Native Americans, but the personal accounts support a desire for the opportunity to aid in increasing preventative measures by making their stories known.

Participants of the study focused on spreading awareness within the Native American culture to help benefit future generations. Interviews reflected a lack of community awareness regarding cause and effect of T2DM. This study did not focus entirely on that issue, because the primary goal of the study was not in that arena. However, it was noted that this was a desire of the population in Native American population studied. Qualitative phenomenological studies, such as this one, often bring about topics that may have otherwise been left untouched in a more restricted interview formats (Speziale & Carpenter, 2007). This is an area where future research would be warranted.

Conclusion Based on Results of the Study

Based on the data supplied in the interviews and the previous literature, there is still much to be learned in order to fully understand what it is like to live with T2DM as a Native Americans. Healthcare providers, such as FNPs, may take the knowledge from this study to enhance their perspective of Native Americans and T2DM. The study revealed many areas of Native American life that pertain to holistic care surrounding treatment of T2DM. Within the context of the study, several needs were identified, they are listed below:

1. The importance of capitalizing on programs offered on the reservation for Native Americans living with T2DM provides added benefits to quality of life.

2. Having a strong support system of family and friends that recognize the severity of the T2DM disease process is imperative.
3. Having a culturally sensitive healthcare provider who is able to recognize personal needs under the conditions of T2DM is essential.
4. Recognition of T2DM being as a lifelong struggle with many twists and turns that can in time cause great emotional distress is imperative.
5. Recognition of knowledge advancement of T2DM within the community is necessary, as well as a vital understanding that more provider and patient education for prevention is need.

The above-mentioned needs seem simplistic, but simple things are most often overlooked. The purpose of this study was to understand the Native American experience of T2DM and in doing so many details emerged. The participants had an overwhelming appreciation for those individuals who put forth extra effort to help them overcome their obstacles related to T2DM. They feel that supplying themselves with information will help to provide solutions when approaching complicated situations related to T2DM.

Relevance to Theoretical Framework

Dickinson (1999) suggested that the use of critical theory allows us to look at self, society, and history. Dickinson went on to state that “one’s life experience shapes an individual’s understanding and personal meaning” (p. 147). In the context of the study of the lived experience of Native Americans with T2DM, Native Americans, as a specific group, illustrate oppressive components of disease and environment. The approach of Sigsworth’s (1995) seven steps, mentioned in Chapter II, helped to shape

the study to include the fundamentals of critical theory. The analysis of the data revealed a personal and social understanding of the oppressive nature of T2DM in relation to the Native American people. Applying the principals of critical theory to the results of the study allowed the researcher to see the following oppressive issues:

1. Native Americans with T2DM understand the grip the disease has on the community.
2. Native Americans have a desire to learn about the nature of T2DM in order to overcome it.
3. Native Americans do not want to be held hostage by T2DM
4. Native Americans would like to spread awareness to the community to overcome the oppressive nature of T2DM in their culture.

Application of the four topics listed above help identify the oppressive nature of T2DM in conjunction with Leininger's theory of culture care. Together, the two theories help to frame the Native American perspective of T2DM within the community. Critical theory supports the need for further attention to T2DM in Native Americans. Leininger and McFarland (2006) suggest that qualitative research methods offer important ways to discover embedded or covert knowledge of a specific culture. The authors also suggest that worldview, lifeways, values, and beliefs of a culture are powerful aspects to understand in order to apply health care principals within a specific culture. These theoretical ideas are reflected in the case of the lived experience of Native Americans diagnosed with T2DM by the statements of the participants. The understanding of Leininger's theory in conjunction with critical theory reveals an obvious path for which to follow when seeking an understanding of the Native American cultural beliefs. This must be understood in order to formulate a plan to treat and reduce the effects of T2DM within

the Native American population. Recognition of the oppressive nature of T2DM within the Native American community via study results provides support for the need of community awareness regarding the daily battles, coping mechanisms, and needs for a culturally competent and understanding providers. Additional understanding regarding Leininger's cultural theory and critical theory allows for researchers to understand barriers between healthcare providers and specific patient populations. This fundamental understanding allows for cultural stereotypes, misinformation, and biases to be marginalized in order to give quality cultural care. Understanding cultural patterns aids in the application of care which is the fundamental essence and central focus of nursing (Leininger & McFarland, 2006). Coupling the two theories allows the results to be focused, purposeful, and unbiased by providing evidence that supports actions that produce culturally competent care.

Implications for Practice

Implications for practice regarding the results of this study consisted of what was learned that may be beneficial, how this can be applied to what is already in place, and who is the beneficiary of the knowledge discovered. Mentioned earlier, it was discovered that Native Americans affected by T2DM have a desire to effectively manage the diabetes within their own lives with assistance from their support system and healthcare provider. Additionally, they expressed desires to further educate the population in regards to T2DM. It is imperative to understand that the feelings and desires of the patients affected by T2DM are true manifestations of emotion and cultural beliefs. Providers can use this knowledge to apply to their personal interactions with patients and to the development of, or modification of, current programs that aid in the

awareness of T2DM. Community involvement is necessary to educate future generations about the importance of healthy lifestyles that can potentially suppress the effects of T2DM on the Native American populations. This study was able to add to the knowledge base for the understanding of living with T2DM as a Native American. This was achieved by gaining actual opinions and feelings from real life situations and experiences. Native American populations can directly benefit from the findings of this study, if providers take in to account the desires of the population as suggested in this study.

Future Research Recommendations

Long after this study is finished there will be needs for researchers to continue to probe the depths of this topic to further understand how to benefit the Native American culture affected by T2DM. Currently T2DM continues to rise in native populations across the country. It is concerning that T2DM is becoming more prevalent. Future research will aid in increasing the effectiveness of the health care approach to combat T2DM.

Future research suggestions are as follows:

1. Quantitative analysis of current and perceived coping mechanisms.
2. Needs for further cultural understanding in clinics outside of Native American reservations.
3. Identifying effective educational opportunities what work and those that need improvement.
4. Which programs are having the most success regarding prevention of T2DM?

Chapter Summary

Type 2 diabetes mellitus is a disease process that has grown increasingly prevalent among the Native American people in northeast Wisconsin. This study offers a glimpse into the lived experience of Native Americans plagued by T2DM. Serious matters involving recognition of disease, personal affliction, constant battles, ups and downs, emotional support, and a desire for community awareness were unearthed. Future research is needed in this area to aid in the prevention and early detection to alleviate the effects of T2DM. Expanding the knowledge of those affected will aid in the prevention. Understanding that T2DM is a lifelong battle for Native Americans is essential. Assisting in providing adequate resources and support systems to Native Americans will only increase their chances of successful approaches to dealing with T2DM.

Nurse practitioners have the advantage to approaching treatment of Native Americans with T2DM through their unique patient-provider relationship. Nurse practitioners are known for their caring and holistic approach to providing quality healthcare to patients with chronic disease. Nursing education has given nurse practitioners the tools they need regarding research and practice to effectively approach the fundamental needs of disparaged groups of people. Nurse practitioners provide the personal, professional, and social support needed to aid Native Americans in the continued fight against T2DM.

APPENDIX A
QUALIFICATION QUESTIONNAIRE

Inclusion and Exclusion Questionnaire

- 1) Do you have type 2 diabetes? Yes No
- 2) How long have you had type 2 diabetes?
- 0-5 years 5-10 Years 10-20 Years More than 20 Years
- 3) Are you over the age of 21 years? Yes No
- 4) Are you recognized as recognized as Native American by the federal government by a
Certified Indian Blood Card? Yes No
- 5) Are you willing to participate in a one hour interview to discuss your experiences of
living with type 2 diabetes? Yes No

If you answered Yes to #4 & #5 please fill out below:

Name: _____

Phone Number where you can be reached: _____

APPENDIX B
DEMOGRAPHIC QUESTIONNAIRE

Demographic Questionnaire

- 1) What is your age? _____
- 2) What is your gender? Male Female
- 3) What is your marital status? Single Married Divorced
- 4) What is your Native American tribal name? _____
- 5) How long have you had diabetes?

 0-5 year 5-10 years 10-15 years 15-20 years More than 20 years
- 6) Do you take pills to control your diabetes? Yes No
- 7) Do you use insulin to control your diabetes? Yes No
- 8) Do you feel your diabetes is under control? Yes No
- 9) How many times do you visit you doctor in a year?

 1 2 3 4 5 More than 5
- 10) What is your highest level of education completed?

 Grade School High School College Graduate School
- 11) Do you reside on a Native American Reservation? Yes No
- 12) What is your annual household income?

 \$0-10,000

 \$10,001-20,000

 \$20,001-30,000

 \$30,001-40,000

 More than \$40,001

APPENDIX C
INFORMED CONSENT

Travis R. Novy, RN BSN

Principal Investigator

INFORMED CONSENT LETTER

I, Travis Novy, am a graduate student at the University of Wisconsin-Oshkosh. As fulfillment of my graduate studies I am studying Native Americans diagnosed with type 2 diabetes. The purpose of this study is to gain an understanding of what it is like for Native Americans to live with type 2 diabetes. By participating and providing information about your experience with diabetes, healthcare professionals will be able to apply your knowledge to future research, and improve upon what is already known as to provide higher quality care to Native Americans living with type 2 diabetes in the future.

This study will take place at the Oneida Nation Tribal Clinic. The interview is expected to last approximately 45 – 60 minutes.

As the participant:

You have the right to refuse participation in the study and can withdraw at any time during the process. If you so wish you can choose not to answer any question you are uncomfortable with. Any information you provide will be kept confidential and in a lock file cabinet in a locked office. No one other than the interviewer will have access to documentation linking you to the study.

By signing this document you acknowledge that you may review your statements and the results of the study after the information has been prepared.

If you have any questions after the interview process you may contact Travis R. Novy RN via email (novyt47@uwosh.edu) or Suzanne K. Marnocha PhD RN CCNR, chairperson for this study, at the University of Wisconsin, Oshkosh via email (marnocha@uwosh.edu).

By signing below you, _____, accept participation and give permission for Travis R. Novy to ask questions related to your experience of living with type 2 diabetes. In addition you consent to be the interview being audio-taped.

Participant's signature

Date

Witness

Date

APPENDIX E
UNIVERSITY OF WISCONSIN OSHKOSH IRB LETTER



December 3, 2010

Mr. Travis Novy
UWOSH
CON

Dear Mr. Novy:

On behalf of the UW Oshkosh Institutional Review Board for Protection of Human Participants (IRB), I am pleased to inform you that your application has been approved for the following research: The Lived Experience of Native American Diagnosed with Type 2 Diabetes Mellitus?

Your research has been categorized as NON-EXEMPT, which means it is subject to compliance with federal regulations and University policy regarding the use of human participants as described in the IRB application material. Your protocol is approved for a period of 12 months from the date of this letter. A new application must be submitted to continue this research beyond the period of approval. In addition, you must retain all records relating to this research for at least three years after the project's completion.

Please note that it is the principal investigator's responsibility to promptly report to the IRB Committee any changes in the research project, whether these changes occur prior to undertaking, or during the research. In addition, if harm or discomfort to anyone becomes apparent during the research, the principal investigator must contact the IRB Committee Chairperson. Harm or discomfort includes, but is not limited to, adverse reactions to psychology experiments, biologics, radioisotopes, labeled drugs, or to medical or other devices used. Please contact me if you have any questions (PH# 920/424-7172 or e-mail:rauscher@uwosh.edu).

Sincerely,

A handwritten signature in black ink, appearing to read "Frances Rauscher".

Dr. Frances Rauscher
IRB Chair

cc: Dr. Suzanne Marnocha
1899

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