CULTURAL PERCEPTIONS OF HEALTH AND DIABETES AMONG NATIVE AMERICAN MEN

A Thesis

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By

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ABSTRACT

The prevalence of diabetes continues to disproportionately affect minority populations, most specifically, Native Americans. Native Americans and Alaska Natives have the highest published prevalence of diabetes in the world. Culturally appropriate prevention programming has the potential to decrease the prevalence of diabetes, thus improving quality of life and reducing health care costs in this at-risk population. Identification of cultural definitions of health and diabetes is critically important in creating culturally relevant and effective diabetes prevention programs.

Methods: Qualitative interviews were conducted with 19 Native American men from 2 tribal clinics in northeast Oklahoma. Verbatim transcripts were analyzed utilizing grounded theory to identify cultural definitions of health and diabetes.

Results: The men interviewed defined health in terms of physical capabilities and presence of disease, with family members, people in the community, and Indian Health Service (IHS) clinic serving as significant sources of information regarding health promotion and treatment of disease. Conversely, the men described diabetes with a sense of fatalistic inevitability. The disease was viewed as an inexorable event that slowly manifests itself through various complications, including amputations, loss of eye sight, kidney disease, and ultimately results in death. Men feared for their own diagnosis as well as the diagnosis of family or community members whom they considered to be at-risk. Furthermore, the men indicated that diabetes could be

prevented or at least delayed through proper diet and exercise. Prevention barriers mentioned by the men were lack of motivation, lack of time, lack of money, and lack of ability.

Conclusions: Additional information allowing comprehension of the perceptions of health and diabetes in this at-risk population will significantly contribute to the development of effective diabetes prevention programs.

DEDICATION

Dedicated to my family.

Thank you for all of your love and support.

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CHAPTER 1

INTRODUCTION

Background of the Problem

Type 2 diabetes mellitus (diabetes) and its complications continue to disproportionately affect Native American (NA) communities, with a prevalence two to three times that among Non-Hispanic whites in the United States (1-3). During 1994-2002, the age-adjusted prevalence of diabetes increased 33.2% among NA adults, from 11.5% to 15.3% (4). In some NA communities, more than half the residents older than age 50 suffer from diabetes (5). More specifically, age-adjusted data show that approximately 50% of Pima, NAs in the Southwest, over 35 years of age are affected by diabetes (6). According to the National Institutes of Health, the diabetes rate among NAs is four times the national average, with some Arizona reservations exhibiting the highest known rates in the world (5). The progression of disease is exhibited by increasing incidence of diabetes complications such as retinopathy, amputations, and kidney disease in the Native American population (7). Thus, the chronic complications of diabetes are causing significant morbidity in NA communities.

The estimated two million Native Americans belong to groups with distinct social, cultural, political, and biomedical attributes (8). Additionally this population shares high rates of poverty, low educational attainment, increased susceptibility to certain disease,

and elevated mortality rates. Unfortunately, many aspects of NA life have stealthily contributed to the epidemic rise of diabetes (9). Limited access to basic resources such as healthy foods, adequate health services and safe environments for physical activity has contributed to high rates of obesity and diabetes.

Significance of the Problem

Indian tribes and Alaska Natives are eligible for health services provided by the Indian Health Services (IHS), an organization of the U.S. Public Health Service's Health Resources and Services Administration (10;11). Although Indian healthcare is provided by law, IHS budgets are discretionary and must be reauthorized every year by Congress. The effect of chronic insufficient funding has resulted in IHS not having the ability to meet even the immediate, primary care needs of its service population (2;5;12;13). Additionally, access to primary, specialty, and long-term care and emergency services is limited by geographic constraints (14-16).

Although diabetes is recognized as a major health concern among NA populations, the diet and physical activity has not been studied extensively and health intervention projects with NA populations are less well documented (17-20). Additionally, researchers tend to concentrate on populations on or near reservations; thereby overlooking the *urban Indian* population, even though census reports show that slightly more than one-half of NAs now live in urban areas. (8;14;21).

NAs are inadequately represented in national nutrition surveys such as the National Health and Nutrition Examination Surveys (NHANES) and the Nationwide Food Consumption Survey (NFCS), yet they are at high risk for the health consequences of poor dietary intake and impaired nutritional status (19). The nutrition status of the American Indian and Alaska Native population is still largely unknown (11).

Quality of life in this population has been affected by the tragic historical treatment of Native American people by the U.S. government. Warfare, forced relocation, and forced enrollment in boarding schools are all potential contributors to under nutrition and infectious diseases (22). The loss of quality of life for this population is reflected by the fact that all major social, physical, and mental health status indicators of the majority of NA are remarkably lower that of non-native American people (23).

Questionable studies for purposes such as anthropologic descriptive studies, studies of unusual occurrences of diseases and randomized trials to test new vaccines have made NAs wary of participation in research activities (22). Historically, NA's have been studied and written about by non-Natives, who have often drawn conclusions based on limited contacts and ethnocentric/Eurocentric views (24). In more recent years, IHS, in close collaboration with tribal governments, has established a system for more careful review of research conducted among NAs. Newer protocols have been developed regarding guidelines for community-based participatory research (CBPR) that will benefit both researchers and community members.

There is a critical need to develop an understanding of the NA population that so heavily bears a disproportionate burden of suffering from diabetes and its complications (22;24). Thus far, current assessment tools and interventions have been constructed around themes that are not commonly germane to this target group and/or other minority groups (25). Rates of chronic diseases, especially diabetes, continue to rapidly increase in the NA populations thereby suggesting that current health education and awareness is not effective. There is an urgent need to gain insight on Native American's feelings and perceptions toward diabetes in order to create culturally relevant nutrition

and health programs. Through gaining knowledge on perceptions of health and diabetes among the NA population, culturally relevant nutrition programs can be developed (26-28).

Objective and Research Approach

The objective of this project is to identify perceptions of health and diabetes among NA men in Oklahoma. Gaining insight on how these males view the condition of diabetes and its implications will allow researchers and healthcare providers to develop culturally appropriate disease-specific healthcare services that can reduce the risk factors for diabetes and prevent or delay the onset of disease. Analysis of verbatim transcripts from qualitative interviews will reveal specific themes related to health issues that may be useful in forming assessment tools, focusing on diabetes prevention (27;29).

Definition of Terms

Construct An abstract statement composed to merge several interrelated categories and concepts (30)

Category A group of similar concepts used to build constructs (31)

Concept Abstract statements that allow for classification of themes such as attitudes, beliefs or behaviors (30)

Code word An abbreviation used to code or identify a concept in the Ethnograph software (32)

Degree of Indian Blood The amount of Indian Blood that one possess. These are usually reported as a fraction and each tribe dictates rules as to how much blood one needs to be considered a member of that tribe (10)

Grounded Theory A set of interrelated concepts and constructs representing a systematic relationship of phenomena to explain or predict events or situations (33)

Native American A person who belongs to one of 564 federally recognized tribes in the United States. Native Americans inhabited what is now the United States, prior to Christopher Columbus's arrival (34)

Obesity Defined by a Body Mass Index (BMI) $\geq$ 30 (35)

Themes Labels for concepts used in thematic analysis (36)

Type 2 Diabetes Mellitus A condition that arises when the body develops a resistance to insulin, fails to utilize it properly, and develops a relative insulin deficiency (37). As classified by the World Health Organization (WHO) criteria for diabetes: FPG $\geq$140 mg/dL [1 mg/dL = 0.05551mmol/L] or FPG <140 mg/dL with a 2-h value $\geq$200 mg/dL (38). Serious health conditions that have been linked to diabetes are premature heart disease, stroke, blindness, kidney disease, and amputations.

CHAPTER 2

REVIEW OF LITERATURE

TRADITIONAL NATIVE AMERICAN DIETARY AND LIFESTYLE PRACTICES

Historically, Native American (NA) tribes existed in environments of limited and episodic energy supplies with an intense requirement for physical activity for sustenance activities (39). Periods of plentiful food were alternated with periods of famine (40). NAs were traditionally hunters and gathers and had not only experienced times of feast and famine, but often engaged in vigorous activities when hunting for wild game, such as deer and elk, fishing, and gathering foods such as pine nuts, wild berries and roots. Groups of NAs were comprised as tribes and bands, which nomadically moved from region to region to collect food (41). Often, the food attained through hunting and gathering was seasonal and specific to each region. When game was scarce, there was a dietary shift where hunting was supplemented by gathering and vice versa. Some tribes in the Southwest turned to farming, referred to as dry land agriculture, because of the nature of the region, when population growth threatened food supply.

The arrival of fur traders at contact (1700's) brought about alterations in subsistence activities; foods such as salted meat, flour, oatmeal, sugar, lard and tea were introduced to Native Americans (42). Before relocation to the reservation (prior to 1880), the Havasupai of Arizona were hunter-gatherers who practiced some irrigation

horticulture. Piñon seeds, sunflower seeds, prickly pear fruit, squash, corn, beans, cottontail rabbits, and bighorn sheep contributed to the traditional diets of the Havasupai (19).

About 2,000 years ago, Pima NAs in Arizona primarily used agricultural and irrigation for subsistence, and sometimes supplemented their diet with hunting and gathering activities. At the end of the 19th century, non-Hispanic immigrants diverted water supply from Pima farm land, consequently, disrupted their traditional forms of agriculture, forcing them to lose their traditional food practices. Today, Arizona Pima still engage in some traditional dietary customs, using wheat flour to make tortillas and making traditional dishes, such as *menudo* (35).

After contact with American settlers and the removal to reservation lands, many NA people's access to traditional food resources was compromised, often resulting in starvation and malnutrition (43). Traditional subsistence patterns were disrupted, natural resources were destroyed, and access to land was limited (26). To date, many tribes are still fighting for water and fishing rights guaranteed to them in treaties in exchange for land cessions (24).

Traditionally, diets of Southwestern NA tribes were dominated by corn, beans, and squash, all of which provided a broad-spectrum of nutrients, including high-quality protein, vitamin A, and dietary fiber (41). This Southwest agricultural diet was high in carbohydrates and fiber, moderate in protein and moderate to low in fat (44). Traditional foods of the Ojibwe tribe include deer meat, wild rice, and maple syrup, all good sources of protein, iron, zinc, folate, and sucrose (45). Traditional foods are low in fat and sugar and have relatively high nutritive value, but are consumed infrequently (17). Traditional foods of Inuit people, such as ringed seal, caribou, narwhal, walrus,

artic char, and mattock are reportedly significant sources of protein, iron, vitamin A, copper, phosphorus, magnesium, and zinc. Unfortunately the Inuit's natural food supply, in the Artic, is under rigorous examination because of concerns about contaminants (46). Now, many NAs limit traditional food consumption to special occasions and/or in ceremonies (45).

Energy-density is substantially greater in the Western foods than in traditional NA diets (6). A study comparing Anglo diets to traditional Pima diets showed that Anglo diets tended to be lower in complex carbohydrates (47). Among women, complex carbohydrates, dietary fiber, insoluble fiber, and vegetable proteins were significantly higher in the NA diet group when compared to the Anglo-diet group ($p<0.05$). Subjects reporting Anglo-diets were at 2.9 times more risk for diabetes than those reporting traditional NA diets. These data suggest that the adoption of an Anglo diet may increase the risk of developing diabetes in Pima Indians, with results pertaining primarily to women.

Traditionally speaking, diets of NA people are highly variable between tribes (11). Basiotis et al. (20), reported that the diets of NAs vary by tribe (Lakota vs. Navajo) and by personal characteristics (young vs. old). Murphy et al. (48), found that Eskimos $\leq$30 years old consumed significantly more non-indigenous protein and fat and low-nutrient-density carbohydrates than those $\geq$60 years old. Among Canadian Baffin Island Inuit, traditional food diet composition was at 51% for women, and 47% for men over the age of 60, and only 15% for young children.

Dakota reported that traditional foods could be divided into two sub-groups: "way back," and "Indian" (49). "Way back" traditional foods possess attributes of freshness, purity and strength as a sacred endowment of the Great Spirit. These "way

back" foods include wild game such as deer and buffalo or wild plants such as onions and turnips. "Indian" dishes were reportedly prepared in large quantities and include soups and stews that contain meat rich in fat with corn, potatoes, macaroni, tomatoes and onions, along with fry bread. These foods were present at occasions that involved the community, during Native American identity events—such as powwows social gatherings at schools or at locations off the reservation (49).

CONTEMPORARY NATIVE AMERICAN DIETARY AND LIFESTYLE PRACTICES

The food choices of the Pima reflect the influences of popular Mexican-style foods common in the Southwest—dishes such as tacos, tamales, chili stew, *menudo,* and chorizo sausage; however, young children and teenagers are consuming less of their energy intake as traditional foods (46). Furthermore, traditional food consumption, as reported by Native Americans today, more and more resembles a westernized American Diet. Among the Lumbee tribe of North Carolina, traditional foods reflect the typical southern diet (50).

The NA population has gone through a nutrition transition where increased energy intake from processed, energy-dense convenience foods has taken the place of traditional foods (40). This change has resulted in higher consumption of convenience foods such as soft drinks and snack foods, both of which are high in refined sugar, saturated fat, and sodium. Harnack et al. (17) found that Lakota adults frequently consumed high fat foods, including margarine and butter; eggs; whole milk; potato chips, corn chips and popcorn; bacon and sausage. Of the adults surveyed, most reported high consumption of soda pop and Kool-Aid, both of which contain high amounts of calories and carbohydrates.

Gittelsohn et al. (42) found that Native Canadian residents' diet was high in junk foods as well as bread and butter; these foods are high in simple sugars, low in fiber and high in fat. Several dietary practices that may contribute to obesity have been identified, including the wide use of butter, lard, whole milk, fry bread, and fried meats and vegetables, as well as generous use of fats in preparation of beans in NA diets (39). Using the Healthy Eating Index (HEI) as a measure of diet quality, only ten percent of NAs included in the Continuing Survey of Food Intakes by Individuals had a "good diet", while 74% have a diet that "needs improvement," and 16% had a "poor" diet (20). Only 21% of the NAs studies were found to meet the dietary recommendations for grains and milk products on any given day. The HEI indicated that NA particularly needed to improve their consumption of fruit and milk products.

With abundant high-energy foods and limited physical activity among Native people, the acculturated environment has resulted in obesity and increased mortality from chronic diseases (40). These dietary habits are related to the development of various chronic diseases, including heart disease, diabetes and cancer (39). The Strong Heart Dietary Study (SHDS) studied chronic risk factors and dietary behavior in ten NA tribes in Arizona, Oklahoma, and the Dakotas. Diets reported by all represented tribes reflected high risk with regard to cardiovascular disease (CVD), diabetes and some cancers. Among men , Oklahoma NAs consumed diets highest in β-carotene and vitamin C, while NA men in Arizona reported a higher intake of carbohydrates and dietary fiber, and the diets reported by NA men in the Dakotas were the most dense in total fat ($p \leq 0.01$). Overall, men consumed significantly more age-adjusted energy, macronutrients, and sodium than did women ($p \leq 0.001$) (51).

Twenty-four hour dietary recalls administered to NA women in California, indicated that 60% of those surveyed reported eating no fruit and 28% reported no vegetable consumption (52). A food survey of NA women's diets in Oklahoma reported the top ten core foods as soda, coffee, white bread, butter/margarine, tea, diet soda, chips, candies, sugar, and sugar substitutes. Most women consumed their vegetables in the form of French fries, and the leading source of carbohydrate intake (47%) was derived from soda (53). Vaughan et al. (19) found that among Havasupai adults, fried potatoes, soda and Kool-Aid accounted for 20% of the mean energy intake.

The Navajo Health and Nutrition Survey found that 41% of the Navajo diet was comprised of the following foods: Navajo tortilla and fry bread, home-fried potatoes, soft drinks, coffee, and tea, mutton and processed meats such as bacon, lunch meat and canned meat products. Fruit, vegetable and dairy intakes were lacking and most Navajo reported consuming less than one serving from the fruit, vegetable or dairy food groups, daily (54). Similarly, among the Catawba Indians, 47% ate less than one fruit a day, 18% ate less than one vegetable a day, and 98% consumed fewer than five fruits and vegetables a day (55).

These dietary habits have been related to issues with several nutrients. The Navajo diet seems to be lacking in adequate amounts of Vitamin A, E, B-6, folate, calcium and magnesium, when comparing intake to RDAs (54). In a study among Lumbee women in North Carolina, dietary intake of fiber, calcium, iron, and Vitamins A and C were low (50). Research by de Gonzague et al. (45) reported diets of Ojibwe men and women to be of lower quality than those of the general population; in particular, nutrient densities of vitamins A and C, folate, calcium, and fiber were lower

and fat and saturated fat were higher. Similarly, diets of Havasupai adults were deficient in calcium, zinc, folate, iron, and vitamins A and C (19). The food patterns of Havasupai adults typify those of other NAs groups (45;49;52;54;56).

The decreased availability and consumption of milk and dairy products may be the cause of calcium deficiency in diets of NA people. Dairy products are not widely consumed among the Navajo and other NA Tribes as there is a high incidence of lactose intolerance among NAs (54). Secondarily, dairy products are at an increased risk for perishability due to lack of use of appliances such as refrigerators and scarcity of resources such as grocery stores on reservations. Most Navajos live on remote reservations with limited food resources; therefore food is purchased infrequently, limiting the availability of fresh produce and dairy products. Three major limitations for food availability reported by IHS dietitians were cost, availability and shelf life, when assessing Native peoples' diets on the reservations. Some perceived barriers to changing diet and exercise habits found among Lakota adults were satisfaction with the taste of high fat foods, lack of availability to resources where healthy foods can be procured, and high expense of healthy foods (17).

The US Department of Agriculture's supplemental food program provides high-fat commodity foods such as canned meats, cheese, butter, shortening, and oil to poor people living on Indian reservations (39). In many communities, supplemental food programs have assisted needy recipients in obtaining daily energy requirements; however, fresh fruits, vegetables and fresh meats are not provided and many programs offer food including high-fat meats, highly sweetened canned fruits, and canned vegetables that are high in sodium (43;49). According to the Navajo Health and Nutrition Survey, approximately 14% of households on reservations participate in the

Food Distribution Program for Indian Reservations (PDPIR) program (57). Many families living on the reservation rely on food commodities provided by the Commodity Food Program for the majority of their energy intake (11;17;43;58). A dietary survey among Pima Indians reflected the use of commodity foods in typical dishes such as "cheese crisp" (melted cheese on tortilla), corn with squash and cheese, corned beef with gravy or potatoes, milk gravy, and refried beans (56). Commodities like canned pork, cheese, oil and other foods are high in fat and offer little nutritive value. The heavy reliance on USDA Food Commodities by Native American people raises several concerns for health and nutrition status.

In the last 50 years NA people have become less physically active and high fat, high caloric foods are increasingly more available (59). Social, economic and environmental changes experienced by NAs since the 1950s have been implicated as contributors to the development of obesity (18). Native people are the poorest of all Americans (13;34;60;61). The proportion of NAs living below the poverty level is 31% vs. 13% for all other races (61). One-quarter of Native Americans lived in poverty in 2002-2004. Most NAs have access to highly nutritious food but make dietary and/or lifestyle choices that adversely affect their health and well-being (62;63). Such choices are often exacerbated by economic, geographic, social, and cultural factors unique to Native Americans' existence (11).

OBESITY IN NATIVE AMERICANS

According to the CDC's Health Equity report, among the top ten causes of death for the NA population, at least five—diseases of the heart, malignant neoplasms, cerebrovascular disease, chronic liver disease/cirrhosis, and diabetes—are diet related (61;64). Obesity has become a major health problem in NAs only in the past one-two

generations and is believed to be associated with the relative abundance of high-fat foods and a rapid change from active to sedentary lifestyles (11;39;40). The most extensive tribe-specific estimates of obesity in adults are in Pima Indians (39). Studies show that Pima Indians are at a far greater risk for obesity than any other adult in the US population. Research has identified polymorphisms in β-3 adrenergic-receptor gene, which is believed to aid in the regulation of resting metabolic rate and lipolysis (65).

Among 120 Lumbee Indian women, surveyed in a recent study, 50% were either overweight or obese (50). In comparing Havasupai women to men, Vaughn et al. (19), found that the overall incidence of obesity was significantly higher in women. Additionally, Gittelsohn et al. (42) found that adult NA women tend to have higher body mass indices (BMI) and much higher percentages of body fat than men, as well as higher rates of impaired glucose tolerance. Among a Mohawk community in New York State, people with diabetes were found to be significantly heavier than those without disease (59).

According to Mendlein et al. (66), on average, Navajo Women have BMIs 2-5 kg/m2 higher than their male counterparts. However, men tended to have higher blood pressures, triglycerides (TC) and LDL cholesterol levels. A similar study, showed that women with diabetes or impaired glucose tolerance (IGT) were more likely to be overweight (BMI>30), than men with either of these conditions (38). Additionally, women were 27% more likely to have diabetes and 18% more likely to have IGT than men.

Kimball et al. (4) found the prevalence of substantial overweight among NAs in Washington State was 45% in men and 43% in women. Of 92 Havasupai adults, on the reservation in Arizona, 76 (83%) were found to be obese (19). Additionally, 90% of

women and 75 % of men exhibited obesity in the abdominal area. The recent upsurge of obesity in some NA populations makes them disproportionately susceptible to diabetes, hypertension, and CVD; all conditions that are aggravated by sedentary living and high-fat diets (4;67). Howard et al. (68) found that higher waist-to-hip ratios (WHR) (>0.98) were positively associated with diabetes in NA men in Oklahoma.

Throughout prehistory, NAs may have exhibited enhanced gluconeogenesis and hyperinsulinemia to meet metabolic demands within the constraints of a low carbohydrate diet (41). Neel (69) hypothesized that individuals predisposed to diabetes were able to store energy as fat, during periods when food was plentiful in order to utilize stored energy effectively during periods of food scarcity, this identified theory is known as the *thrifty gene*. The *thrifty gene* may once have provided a selective advantage during periods of fluctuating food availability by promoting fat deposition (70). Due to dramatic environmental changes in consistent availability of foods and convenience of attainment of food, sedentary lifestyles have made the "thrifty gene" more of a liability for obesity and development of disease such as diabetes and CVD, rather than a survival mechanism (35). The consequence of loss of energy balance can lead to excessive weight gain, reduction of physical activity, excess intake of fat and calories with subsequent development of diabetes and vascular disease, which poses a universal public health concern; however, the greatest burden at present is on Native people (59). NAs are disproportionately affected by obesity-related morbidities, due to their higher prevalence of obesity (39). Strauss et al. (71) found that 59% of Navajo women were overweight or obese, and approximately 30% were sedentary; both of these findings show that Navajo women are at high risk for heart disease, diabetes, and several other disorders.

INCIDENCE OF DIABETES IN NATIVE AMERICAN POPULATIONS

Type 2 diabetes has emerged as a leading cause of morbidity and mortality in NA communities throughout North America and constitutes the major chronic disease problem in many of these communities (42;63;72;73). In some Indian communities over one half of the adults have diabetes. Between 1994 and 2004, the number of NAs aged <35 years, with diabetes diagnosed thorough IHS health-care services, more than doubled from 6,001 to 12,313 (74). In fiscal year 1983, diabetes was the second leading cause of hospitalizations in IHS facilities (67). According to the Indian Health Service's (IHS) Clinical Reporting System (CRS), the overall prevalence of diabetes among the IHS direct and tribal population was 11% in 2005, an increase of one percent from the previous year (75). The prevalence of diabetes among the AI/AN population is approximately three times (3.5% versus 0.9%) the prevalence among non-Hispanic whites, and the death rate from diabetes has increased by 55 percent from 1972-1974 to 2000-2002, in this group (75-77). Approximately 15 percent of the IHS user population aged 45 or more years is diabetic, and half of the adults ages 45-64 in some southwestern tribes are diabetic (67). Diabetes continues to increase disproportionately among NA communities and across all age ranges (78).

The prevalence of disease varies according to degree of NA ancestry (72). A National Health Interview Survey (NHIS) found the prevalence of diabetes to be 12.7% among Plains tribes, 10.5% among the Southwestern tribes, 9.3% among the Woodland tribes, and 4.5% among the Pacific Coastal tribes (76). Full-blooded Pima Indians have been found to have higher prevalence of obesity and DM than non-Indians living in the

same environment (40). NA people are widely viewed as having a higher genetic risk for obesity than Caucasians, and the search for the specific genes conferring this risk continues, primarily in the Pima Indians.

Harris et al. (79) reported a 26.1% prevalence rate for NIDDM and a 13.6% prevalence rate for IGT among the Native community of Sandy Lake, Ontario, Canada. Native Canadians in Sandy Lake demonstrated increased rates of NIDDM with age (80). Moreover, rates in females were consistently higher when compared to males (80). Valencia et al. (35) reported a higher prevalence of diabetes in women than in men in the Mexican and Arizona Pima populations. The prevalence of diabetes in Oklahoman Indians (38% in men and 42% in women) is much higher than those reported for other US populations, but still not as high as those reported for the Pima of Arizona (81). The prevalence of diabetes among Navajo adults is 2.5 to four times higher than the general U.S. population (82). Present studies have suggested that the majority of Navajo adults either have diabetes or pre-diabetes. The increase in chronic diseases among the Navajo has been attributed to nutritional factors (22).

IMPACT OF DIABETES ON NATIVE AMERICANS

In a study looking at perceptions of diabetes among Dakota people, diabetes was not the only major life concern for most people (49). For a number of persons, diabetes had created significant personal incapacitation and suffering as a result of the long-term complications, such as Coronary Heart Disease (CHD), blindness, peripheral vascular disease, and kidney failure. Valdmanis et al. (83) found that persons with diabetes had higher burdens on multiple aspects of social function, which can affect

income and general well-being. Persons with diabetes were disadvantaged on all of the measures of well-being: general health status, days of disability and poor health, access to care, and economic burden.

The Strong Heart Study investigated risk factors of CVD in NAs, and found CHD to be strongly associated with diabetes (68). Patients with Type 2 Diabetes often present with risk factors for CVD, such as high blood pressure and cholesterol levels (84). Freedman et al. (82) observed a relation of relative weight to adverse levels of lipids, lipoproteins, and blood pressure that suggested the recent rates of increases in CHD and diabetes among the Navajo may continue to trend upward. The prevalence of CHD risk factors among the Navajo suggests that incidence and mortality are likely to increase in the future (66).

Native Americans have some of the nation's highest prevalence rates of major CVD risk factors such as smoking, diabetes and obesity (85). Moreover CVD is the leading cause of death in this population (67). Mendlein et al. (66) found adverse levels of several CHD factors including overweight, diabetes, HDL cholesterol and triglycerides, among Navajo adults. Rhoades et al. (85) reported a previously under-recognized disparity in CVD mortality for NA populations, particularly in middle aged adults.

In a survey of rural Indians of the Pacific Northwest, 81% of men and 77% of women who recognized that they weighed too much had neither reduced their food/caloric intake nor increased their physical activity (4). In contrast, Judkins (63) reported that among Seneca Indians with diabetes, there was an apparent good ability to lose and control weight. This weight may have been carried for years, but when necessary, individuals did prove capable of effective weight loss and dietary control.

In the Dakota Community of Devil's Lake, interviewed tribal members with diabetes were precise about their medications in terms of prescribed dosages and scheduling. They were also accurate about their weight, weight history, and doctor or dietician's recommendations from the most recent clinical appointment. The majority stated that they did not follow the dietary regimen, though they all indicated a familiarity with the basic "rules" they should follow in food selection and meal planning. Health workers at Devil's Lake perceived lack of success in patient control as a conflict between patients' understanding of disease or specific regiments, and a patient's lack of concern for their condition (49).

In the Mohawk Community of Akwesanse, the major identifiable barriers to healthy behavior were not lack of knowledge of healthy dietary practices and the value of exercise, but preferences for high-fat food, large servings and sedentary lifestyles (49;59). More importantly, factors such as lack of personal confidence, lack of skill and lack of social support for bringing about desired changes further impacted their risk for being overweight. Furthermore, Gregg et al. (86) found that Pima Indian Women with diabetes had a more external locus of control than those without the disease, indicating level of self-efficacy in management of disease.

Will et al. (38) discovered that more than 90% of Native Americans with diabetes mellitus had never checked their own blood sugar. This study also revealed that persons with diabetes rarely used insulin, and almost a third of women in this study used no medication to control their diabetes. According to the "Improving the Quality of Health Care-Measuring Successes and Challenges: 2005 IHS Executive Report," among patients with diabetes, 15% were found to have poor glycemic control, 30% maintained ideal Hemoglobin A1Cs (<7), 37% had maintained ideal blood pressure control

(<130/80), and 53% exhibited dyslipidemia, over the past year (75). There seems to be a lack of knowledge about diabetes and how to care for such a disease, among NA people.

OBESITY AND DIABETES IN NATIVE AMERICAN CHILDREN

The prevalence of obesity among youth living in the United States is continuously increasing and many studies have shown that some of the highest rates of obesity are found among Native American youth (87). Freedman et al, found a high prevalence of overweight among Navajo adolescents; the median BMI was 2 kg/m2 higher than that of the general population, and ~35% (boys) to 40% (girls) of the 12- to 19-y-olds had a BMI above the 85th percentile (82). Another study looking at growth and overweight in Navajo youth, reported that approximately 41% of youth, ages 6-12 years-of-age had BMI's $\geq$85th percentiles of US reference data (88).

A study assessing BMI's in Pima children, reported that BMI was higher than reference values with mean Z scores between 1.3 and 1.5 in males and 1.3 and 1.6 in females, at ages above 11 (89). After the age of 2 years, Pima children were significantly heavier and had higher BMI than reference values ($p<.0001$). Potvin et al. observed anthropometric characteristics of Mohawk children aged 6-11 years and found that comparisons with NHANES II mean values show that Mohawk children were generally heavier, had thicker skin folds, and had greater waist and hip circumferences (90). About twice as many Mohawk children had BMI values corresponding to the overweight threshold (i.e., the 85th percentile) when compared with the NHANES II distribution.

The Pathways study found that NA children were eating high fat foods at school meals. Children often chose whole milk over lower fat milks, menu items were often prepared with the addition of butter or fat, and food service workers and teachers commonly encouraged children to finish all of their food. NA children seemed to dislike fruits and vegetables, and plate waste was high for these items. In all the schools observed, children were allowed to have a second portion, mostly because tribal school policy stated that seconds should be offered (91).

According to the Navajo Health and Nutrition Survey, it was discovered that 35-40% of all adolescents examined were overweight (82). The Navajo Health and Nutrition Survey revealed that the prevalence of IGT and diabetes mellitus among 12- to 19-year-olds was 8%.

Diabetes has become more common in younger populations and is now appearing frequently in children and adolescents (72;92). If onset of disease continues to occur in younger populations, middle-aged Native Americans with diabetes will have more years of disease burden and a higher probability of developing serious or end-stage vascular complications by the ages of 35 or 40 years (72;78). There are numerous influences that could be contributing to the increasing rates of obesity in NA youth. Dillinger et al. proposed that federal food assistance programs may create unhealthy food preferences among NA youth, because food patterning is a learned behavior, and many children are raised almost exclusively on the Food Commodities Program (43).

NATIVE AMERICAN HEALTH

The diet and physical activity of NA people has not been studied extensively and health intervention projects with NA populations are less well documented (11;17;18;20). NAs are inadequately represented in national nutrition surveys such as the National Health and Nutrition Examination Surveys (NHANES) and the Nationwide Food Consumption Survey (NFCS), yet they are at an increased risk for the health consequences of poor dietary intake and impaired nutritional status (19).

Historically, NAs have been studied and written about by non-Natives, who have often drawn conclusions based on limited contacts and ethnocentric views (39). In the past, researchers have often benefited themselves and their academic communities more than the NA groups they purportedly served (24). Some researchers are unrelenting, neglecting to consider native beliefs and customs surrounding certain aspects in research efforts. Many researchers have yet to develop cultural sensitivity toward the NAs with whom they work (39). This history has naturally resulted in a varying sense of distrust and protectionism among Native Americans, thus having an impact on validity of results in studies.

A Harvard School of Public Health and Centers for Disease Control and Prevention study found that the lowest life expectancies in the United States exist in Native communities, at rates lower than those of any nation in this hemisphere, except Haiti (34). Furthermore, the National Center for Health Statistics reported remarkable rates of disproportional underestimation of NA total mortality rates compared to other races. According to the misclassification study of death certificate data for IHS user population, the NA race was misidentified on average 10.9%, with varying rates among

service units. Racial misclassification has resulted in decreased accuracy of incidence and prevalence rates of diseases and treatments among the NA populations (13;76;85;93).

Life expectancy for Native groups (71 years) is about five years less than that for the US general population (62). The NA population continues to experience significant disparities in health status compared with the general population and now are facing the new challenges of rising rates of chronic disease (13;15;17). Compared to the general population, NAs are 638% more likely to suffer from alcoholism, 400% more likely to contract tuberculosis, 291% more likely to suffer from diabetes, 67% more likely to have pneumonia and influenza, and 20% more likely to suffer from heart disease (94). According to another source, NAs are 950% more likely to suffer from alcoholism, 630% more likely to contract tuberculosis, 350% more likely to suffer from diabetes, and 61% more likely to suffer from pneumonia (34).

The statistics from the US Census Bureau reported that in 2004, 29% of NAs were without health insurance. Like other minorities, NAs are less likely to have health insurance coverage, see a provider on a regular basis, and receive preventative screenings or routine health care services; they are also more likely to be diagnosed at a later stage of disease. Racial and ethnic disparities are inevitable, due to a myriad of sources, including societal factors, environmental factors, and structural factors that may alienate people of color or discourage them from accessing needed health care (94).

NATIVE AMERICAN HEALTHCARE

Over the years, the U.S. government has not been a reliable partner in meeting its obligations to NA people in a variety of policy areas, including the use of health care. The federal government has a trust responsibility, rooted in the U. S. Constitution, to

provide healthcare for American Indians and Alaskan Natives, based on multiple treaties, court decisions, and legislative acts (10;13;15). Indian Health Service (IHS) has been an agency in the U.S. Department of Health and Human Services (DHHS) as a part of the U.S. Public Health Service since 1955, whose purpose is dedicated to serving the health care needs of Native Americans and Alaskan Natives in the United States. There are approximately 1.6 million active users of the Indian health system (15). In fiscal year (FY) 2005, IHS reported serving 1.4 million NA/AN peoples (75).

Unfortunately, IHS has been consistently inadequately funded. The current funding allocated for services represents 20% of estimated need (12). In FY 2002, the IHS budget was set at $2.8 billion; however, tribal leadership estimated a needs-based budget of $18 billion (13). Indian Health Service is not an entitlement program and its funds are obtained through an annual appropriations set by U.S. Congress. Between 1991 and 1995, appropriations increased by 2.5%, whereas IHS service population increased by 10.7% (14).

IHS beneficiaries do not pay premiums, deductibles, or co-payments for their IHS health coverage regardless of personal or family income (14). Health care eligibility criteria for IHS services are that one must be a member of a federally recognized tribe and be able to prove their claim with a tribal enrollment card or Certificate of Indian Blood (CIB) (10;16). At present, there are 562 federally recognized tribes spread across 35 states (15). The Indian health system is comprised of 49 hospitals, 247 health centers, 5 school health centers, 309 health stations, and 34 urban health clinics.

Many IHS eligible populations are located in the Western United States where there are many sparsely populated areas and vast distances that may separate residential communities from health care centers and transportation problems make it

difficult for IHS providers to reach all their patients who are eligible for IHS healthcare services (14;16). Travel times, to healthcare facilities, are dramatically longer for NAs living in rural areas, where there are few medical providers (15). Native Americans not living in the 33 reservation states must utilize alternative health resources or travel great distances to obtain services (93).

A National Medical Expenditure Survey (NMES) found that for persons living in shortage areas there was more than three times the travel time to non-IHS facilities than those living in nonshortage areas. The IHS user population may seek care outside of the IHS system; however, due to lack of private providers in many of the areas inhabited by IHS eligibles as well as their generally lower incomes and lack of private or public health care coverage, it is likely that non-IHS services are out of reach for most IHS eligibles. Access to primary, specialty, and long-term care and emergency services is limited by geographic constraints and by the historic and chronic under funding of the Indian health system.

The extent of the healthcare provided through IHS may be limited/hindered due to resource limitations. IHS's limited budget creates conflicts such as delayed clinical services provided under contracts and in some cases, patients may be denied care (14). Other repercussions of budget shortfalls include usage of outdated equipment, outdated facilities and specific service shortfalls, including the inability to provide some specific services, such as physical exams, mental health, decreases in dental services, now limited to only extractions and fillings, and a 79 percent increase in denial of health care referrals (16;34). Moreover, it is unlikely that IHS provides all needed services to its

eligible members; however, IHS direct care facilities will likely continue to be the sole or primary source of care for people living in some of the most remote and sparsely populated areas of the United States (14).

Understaffing is a result of IHS's limited budget; few Native healthcare facilities can afford to have adequate numbers of registered dietitians on staff (62). Laboratory instrumentation and technology to conduct appropriate nutrition assessments is available; however, its use is hindered, due to a lack of nutrition professionals, who might utilize them. For example, one hospital, equipped with an automated chemistry system that can screen prealbumin, does not do nutrition assessment testing because it does not currently have a dietician on staff. A significant element found on many NA reservations that negatively impacts good nutrition is an overall lack of awareness and poor provision of nutrition assessment by healthcare providers (62). A reported contributor to poor assessment is understaffing of nutrition professionals at Native medical centers throughout the US (11).

With limited access to healthcare through utilization of IHS, 40% of all Indian people continue to use only IHS health services year-round, with the proportion rising to 58% in areas with fewer than 10 persons per square mile (10). Roughly 20 percent of the IHS clinical services budget comes from Medicaid, while less than 0.5 percent of Medicaid expenditures go to Indian health (15). Furthermore, Medicaid reform issues have been problematic for NA health in that managed care channels NA people away from Indian health care system providers and toward providers who may not be sensitive to the cultural needs of Indian patients (95).

NATIVE AMERICAN PERCEPTIONS OF HEALTH

Native American cultural worldviews are vastly different from the dominant culture's worldviews, particularly in terms of concepts regarding health and wellness. NA belief systems perceive health not only as a physical state but also as a spiritual state (28). Native American healers believe that when one is in harmony with their surroundings, then they will be in good health (63;96;97). Dr. Lori Alviso Alvord, the first Navajo surgeon, refers to this way of life as "hozhó," the Navajo word for "walking in beauty." The notion of health meaning goodness is found in the interpretation of the Navajo Beautyway or Blessingway Healing Ceremony (97). Interestingly enough, the World Health Organization's defines health as a state of complete physical, mental, and social well-being and not merely absence of disease; this definition is very similar to many NAs definition of being in total harmony.

Illness and misfortune, for the Dakota, may occur when all is not "right" in the social and moral order; a state of well-being is more than physical bodily health, but a holism of mind, body and spirit (49). Elder NAs believe that sickness is brought on by ones actions, of being involved in something bad or hurtful, or by someone wishing it upon you (98). Older NAs often interpret sickness or disability as the result of a deliberate action against someone by means of "magic," "power," or "witchcraft (63;97)."

There is an expression of interactions between outside influences on health and other influential factors. NA people in Devil's Lake commonly expressed the idea that the "white man's food made us sick" (49). Implications were made that in a pre-reservation past, people were healthy, but have been afflicted with a series of ailments "coming in" from the outside European world. Dine' people (Navajo) have described

diabetes as a "white man's disease," that must be treated the "Anglo way," by following health care professional's instructions, rather than traditional Dine' prayer and offering (99). Furthermore, Seneca perception of the disease are traditionally-oriented, yet, the Senecas' expressed behavior with regard to the disease is just the opposite way—reliance on Western medicine and a determined individualistic approach to overcoming its effects (63).

Many Dine' are frustrated with having to deal with the influences of the white culture and are caught in the transition between cultures leaving them feeling powerless against the social changes that have occurred (99). Pressured for so many years to "be like the Anglos," now, NA are being told to go back to the ways of the "old days." Diabetes was viewed as the most recent instance of the white man's destruction of Indian society and culture, and is categorized with other introduced diseases such as tuberculosis and smallpox. In this contemporary society, some NA people continue to remain "traditional," living on reservations, speaking their native language, maintaining traditional healing practices, and having little contact with the dominant white or Anglo American culture. White et al. (57) found that among the Navajo, only half of the heads of household reported English was spoken in their households.

Health workers face challenges when patients are from a cultural and social background different from their own. Many times health professional's views of prescribed regimens and the patient's views are at odds, often leading to the provider labeling the patient as noncompliant (2;99). As experienced by the Dakota, clinical medicine is frequently considered part of the "outside" white or majority society;

therefore, treatment regiments may be questioned and/or disregarded (49). Patients and providers often hold different ideas about the meaning of illness in terms of its cause, as well as its meaning, or effect on individuals' lives (28).

Studies reflect that NAs tend to focus on the present rather than the future; therefore, preventative medicine is not compatible with the NA belief that one should not dwell on illness and negative events. Consequently, the notion of visiting a healthcare provider when one is not sick does not makes sense to many NAs. Furthermore, healthcare providers who do not understand that NAs tend to discourage assertiveness, may have a difficult time taking medical histories, because some NAs view asking and being asked too many questions as being disrespectful (26).

Pichette (28) reported that among IHS healthcare providers, very few have knowledge of the Navajo language or are familiar with the Navajo culture, traditions, or basic beliefs. Additionally, turnover rate in IHS clinicians is high, not allowing them to be accustomed to the Navajo culture and belief system and contributing to shortages in offered health services (16). Most members of the clinical staff have little interaction with the population they serve outside of their professional capacities, contributing to more misconceptions about the NA patients they serve (14).

Haffner (77) notes that there is some evidence that cultural influence may be one factor that increases the risk of disease development. For example, there is an increased incidence of obesity in these populations, which may, in turn, lead to insulin resistance. Teufel (44) proposed the theory that Southwest Native American's cultural memory of seasonal hunger places their cultural notions of appropriate body size in conflict with current Euro-Americans' ideals of thinness and intentional food restriction.

Huttlinger et al. (99) reported that Dine' subjects describe their experiences with diabetes metaphorically as "doing battle." The management of diabetes was thought of as a necessary ongoing surveillance that was needed to fight the disease or battle. The Dine' interviewed displayed a sense of hopelessness in that they didn't see a way to win the war or conquer the disease. Individual perceptions indicated the thought that one's own action will not greatly affect an outcome, and persons were doomed and powerless against the "war with diabetes," and "the system." The Dakota believe that diabetes is not necessarily treatable by traditional means because it is a "new" condition that came with the non NA way of life and, therefore, it is perceived that there is not an effective traditional remedy. (49).

Taylor et al. (27) conducted qualitative interviews to investigate perceptions of health and diabetes among Native American women. Health was predominantly defined in terms of lifestyle behaviors as well as in terms of presence or absence of disease. Individuals, even those diagnosed with disease, perceived themselves to be healthy in the absence of physical illness. Similarly, Navajo's refer to their health as either "Doo baah téé da," which literally translates into English as "not alongside or beside deep water," or "téé́h," meaning "into deep water (97)." Furthermore, the variation of health perceptions in a sample of Indian elders ranged from those who viewed their health as "pretty good" to those whose health was "not too good" (31). These elder NAs constructed their ideas of health on observed signs of illness, incorporated perceptions/ideas of others close to them, and their ability of "getting around," implying their ability to perform normal activities of daily living (ADL).

NA women in Oklahoma reported issues of denial and avoidance of diagnosis as challenges to diabetes prevention and treatment (27). In NA cultures, questions that

elicit negative thinking are inappropriate; thereby, asking a question about negative feelings or behaviors is believed to potentially cause those negative feelings and behaviors (100). Many NA tribes believe that speaking about a deformity or disability may give it power to manifest itself or express itself in human form (28). Taylor et al. (27) reported that when asking research participants about diabetes, researchers found that there was a sense of inevitability expressed by NA women.

In a study investigating perceptions of asthma among the Navajo, families were hesitant to use long-term controller medications, particularly in the absence of symptoms, because they consider asthma to be a series of acute episodes rather than a chronic disease. In addition, many parents were concerned that their child would become dependent on the medications, diminishing the body's ability to "grow out" of the disease. A number of parents also indicated that symptoms were something "one gets used to," and did not recognize or expect that treatment would create an asymptomatic state. The coping mechanism described by the Navajo, seems to be that of 'the deniers,' who reject the label of asthma, de-emphasize their symptoms, and never use anti-inflammatory medications that have been prescribed, in fear of addiction (101).

The Iroquoian-speaking Seneca Indians' perception of diabetes centers on a strong personalizing tendency. There is a distinct sense of there being an attack on Natives by the disease, and that this attack has a source that is conscious, malevolent, and calculatedly aggressive. Associated with these ideologies are highly fatalistic attitudes and verbalizations, as well as a distinct sense of awe and powerlessness. Judkins (63) explains this perception as a stereotypical way of perceiving disease that is

fully in tune with traditional cultural process, and apparently represents a major continuation or persistence of a basic set of Iroquoian cultural perceptions form ancient to modern times.

Sobralske (97) noted that behaviors demonstrated by the Navajo reflect values, attitudes, and beliefs that stress essential components of Navajo health: inseparability of religion and health, the need to be in harmony with the surrounding environment, family unity, importance of knowledge and education. The linkage between health and religion seems to exist whether it is between traditional religion and healing ceremonies or Christianity and modern health care (31;97). Similarly, in a study investigating influences on day-to-day self-management of Type 2 Diabetes among African American (AA) women, respondents indicated spirituality/religiosity to be a main theme in coping with disease (102). Women in the study mentioned "God" and related terms in the context of their health—thanking God for their health they have even with their diabetes and for taking care of their diabetes. Participants also reported asking God for help in controlling diabetes.

CULTURALLY EFFECTIVE NUTRITION EDUCATION PROGRAMING

Collection of dietary data from Native American populations may be beneficial in determining the cause(s) of disparity in the incidence of chronic diseases compared with whites (50). Despite a potentially genetic predisposition to obesity and chronic disease, a traditional lifestyle, characterized by a diet including less fat and more complex carbohydrates and by greater energy expenditure in physical activity, may protect NA from the development of obesity and the risk factors for CVD and DM (39).

In a survey study conducted by Dillinger et al. (43), Native American communities in California indicated a need for culturally sensitive nutritional counseling

and education modules to instruct supplemental food program recipients in the preparation of healthy meals and in managing obesity and diabetes. Complementary efforts in prevention and clinical treatment are required to reverse the trend of continuing increase in the rates of chronic disease among the Navajos (22). The key is joining together to seize an opportunity of a generation to assure that all the partners are meeting their obligations to promote and secure the health of Indian people (12). The success of intervention programs depends on an understanding and appreciation for cultural differences such as language, history, traditions, food preferences, and perceptions (39). Including native speakers as members of the research team becomes critical in fostering clear communication (24). Innovative approaches are needed to increase the accessibility of healthy foods, to educate communities on the need for dietary change and to reduce the chronic disease risk factors that are rapidly becoming more prevalent among NA (51;76;103).

As found in many NA cultures, the family has the most powerful influence over the shaping and maintaining of children's eating and exercise habits (18). Dietary and physical activity practices learned at a young age can be carried into adulthood; therefore, establishing healthful patterns at an early age is important (39). Parental involvement in weight control for children facilitates changes in the eating and exercise environment by providing a role model and social reinforcement for behavioral change (100). The school cafeteria can be a natural avenue for children to learn and practice healthful eating, because children on reservations generally eat two meals a day in school (39). Schools provide an excellent forum for prevention efforts, because of their potential to reach large numbers of children and to deliver structured risk-reduction programs (18;87).

A pertinent prerequisite for development of useful programs is an understanding of traditional NA cultures. Lack of understanding fundamental cultural differences handicaps research necessary for both program development and evaluation (26). Intervention programs that place emphasis on the need to integrate cultural issues have been indicated to be more cost-effective than cultralized programs.

Recent studies have explored approaches to conduct community based participatory research among Native Americans, creating a win-win situation for both the NA community and the research community (24;28;29).

CHAPTER 3

METHODS

OVERALL PLAN AND DESIGN

This descriptive study will be based on secondary data that was collected from Native American (NA) men in Oklahoma. During a face-to-face interview, demographic information, food perceptions and food intake pattern data were collected. Additionally, a semi-structured interview was conducted to obtain cultural perceptions of a healthy diet, health, obesity and diabetes among NA men. The questioning method was designed utilizing grounded theory as discussed by Corbin and Strauss in order to identify a cultural definition of health and diabetes (104). A description of the cultural perceptions of health and risk for diabetes and an explanation for these perceptions was developed based on interviewee's responses.

All portions of the research protocols were reviewed and approved by the Institutional Review Boards at Oklahoma State University and The Ohio State University. Data were collected in coordination with the Iowa (Perkins, OK) and Kaw (Newkirk, OK) tribal clinics.

PARTICIPANTS

Men of at least one-quarter NA blood, between the ages of 18 and 65 years of age, were eligible for inclusion in the study. A diagnosis of chronic disease, including

Type 2 Diabetes Mellitus, did not prevent inclusion. However, men diagnosed with chronic diseases that influence appetite, including those receiving cancer treatment, were excluded from the study. An effort was made to recruit approximately half of the sample with a previous medical diagnosis of Type 2 Diabetes Mellitus. All participants provided informed consent prior to participation and represented a convenience sample.

Key informants at each of two Northeastern Oklahoma tribal clinics: Kanza (Kaw) Health Clinic in Newkirk and Iowa Tribal Clinic in Perkins, and qualitative interviewers worked closely with research staff to recruit potential participants for the research study. Interviewers identified individuals from the community that were interested in participating, determined eligibility and scheduled the visits. Other participants were recruited from the tribal diabetes education programs and general health clinics of the two tribes. The snowball sampling technique resulted in a sample of 20 men that were recruited proportionately from the two clinics. One participant's responses were unusable due to the nature of the interview, resulting in 19 interviews for the current study.

MATERIALS AND METHODS

Interviewer Selection and Training- Job announcements were created to advertise the position and were distributed to the clinics. Application forms were drafted and distributed to the key informants at both of the two tribal health clinics. Five interviewers were selected to complete interviews with NA women for an earlier portion of the study. Each of the interviewers completed training on interview structure, data collection techniques, collecting food records and response recording.

The training consisted of a one-day meeting. The first session included instructing the interviewers on the use of the equipment and essential techniques of

qualitative interviewing, including listening and directive questioning skills. The second session focused on training the participants to complete the 4-day weighed food record and the logistics of the three qualitative interviews. Protocol for participant recruitment, completion of paperwork, and exchange of completed materials were explained during the training. The interviewers were compensated $100 upon completion of the training.

Two of the interviewers were retained to continue with the project to obtain data on men. An additional brief training was provided to reinforce interviewing techniques and to demonstrate the revised interview process. The protocol for the women's study included three interviews, while the men's study was trimmed to one interview.

Qualitative Interviews- The research team provided all materials necessary to complete the qualitative interviews. The interviews were conducted in the tribal health clinics or, if desired, in the participants' homes. Each participant completed one interview. The following narrative describes the details of the visits. Upon completion of the interviews, all materials were returned to the research team with the exception of the food portion kits, which were retained by the participants. After each interviewer conducted interviews on two participants, the data were examined and adjustments were made to adhere the protocol, before further interviewing took place.

Consent for the participation- The interviewers reviewed the informed consent form with the participants prior to beginning the interviews process. The interviewers read the complete consent form to each participant. The participants indicated full participation by signing two consent forms. One copy was returned to the research team and the participant retained the other.

Demographic form- After informed consent was acquired, a list of demographic questions was completed by each participant. Demographic information included marital status, tribal affiliation, education, employment, income, food sources, physical activity, age, self-reported weight and height, and how they found out about the study.

Cultural structure of health and diabetes- Each participant completed the Cultural Structure of Health and Diabetes questioning route. The questions were obtained and modified from previous research (92) to identify personal and cultural perceptions and definitions of health, perceptions of etiology, symptoms, severity, treatment, and complications of diabetes. Questions focused on areas of interest consistent with the objectives of the study. The method of constant comparisons allowed for the integration of key concepts or recurring themes derived from the qualitative interviews into the questioning route.

This part of the interview was audiotaped. The tape was labeled with the date, time, interviewer's name, and the participant number. At the completion of the interview, the interviewer broke out the tabs of the cassette to protect the recording. When the audiotapes were returned to the research team, the cassettes were duplicated and the originals were sent for verbatim transcription, to the Oklahoma State University Bureau for Social Research (BSR).

Food sort- Food image cards were made using the food images (National Dairy Council, Rosemont, IL.) for the 53 foods generated from The 1-day food lists that were obtained from NA Oklahoma women, mounted on yellow poster board (8" squares), and laminated (105;106). The cards were used during the food sorts to elicit perception regarding healthiness and fat and sugar content (107).

The interviewer introduced the cards containing images of the 53 most commonly consumed foods (107). The cards were randomly scattered face up on the table. Each participant grouped the foods under the following three subheadings: "healthy"; "not healthy"; or "not sure." The cards were mixed and sorted again, under the headings "high fat"; "low fat"; or "not sure" and then again for "high sugar"; "low sugar"; or "not sure." At the end of each sort, the numbers corresponding to foods were recorded on the form provided. This technique has been modified from previous research by Lieberman et al. (105;106) as the previous method sorted by fat, sugar and healthy.

Food frequency questionnaire- To describe the food intake patterns of men, the 100-item Block Food Frequency Questionnaire was administered.

DATA ANALYSIS

Demographic form- Data from the demographic forms were entered into SPSS for analysis. Age was computed from date of birth. Degree of NA blood (blood quantum) was entered as a percent. For example, if a participant was half-Kaw (offspring of a full blood Kaw and a non-Indian), they would be entered as 0.50. One participant had a blood quantum less than 25% (0.25); although stated criteria would exclude this participant from the study, he was included due to only a fractional difference from the criterion.

Frequency analysis was calculated for categorical variables in the total population and also stratified by health facility and prior diagnosis of diabetes. Means (± standard deviations) were computed for continuous variables for the total population and also stratified by health facility and prior diagnosis of diabetes.

Overview of transcript analysis- Upon receipt of the audiocassettes from the interviewers whom administered the Cultural Structure of Health and Diabetes interviews, the tapes were transcribed verbatim into Microsoft Word (version 2000, Microsoft Corporation, Redmond, WA) by the OSU Bureau for Social Research. The word processor files were converted into an Ethnograph editor file (version 5.04, Qualis Research, Denver, CO) in the "text editor" for coding and analysis.

Grounded theory as discussed by Corbin and Strauss, was used to guide the analysis of the transcripts (104). Open coding comprised the coding strategy for the early data analysis which employed the use of critical analysis of the transcripts to isolate and label incidents and text segments with a concept or theme label as described by Miles and Huberman (32). The preliminary coding scheme was identified through consensus of two researchers reviewing the transcripts; additional code words were added once agreement was achieved on the emerging content. Then text segments related to the concepts identified were appraised.

Secondarily, axial coding was used to process the related concepts into categories (104). Additionally, data was evaluated to identify the relationships among concepts within their individual categories. The final stage of analysis and selective coding assessed how relationships between concepts and categories were used to create constructs, or umbrella categories, drawing together all the related categories.

Thematic analysis- The transcripts for the Cultural Structure of Health and Diabetes interview were reviewed using two methods for improved analytical strength (108). Thematic analysis was used to identify recurring themes throughout the transcripts (36). After several reviews of the transcripts, key concepts were defined and

code words were developed to identify each concept in Ethnograph. A code word list was formulated, with descriptive definitions, for reliability of coding throughout the analysis of the transcripts.

Text segments within the transcripts served as the unit of analysis (32). Text linked with the code words or concepts vary in segment; some consisting of a few words and some consisting of full paragraphs of text. Coded segments were derived from direct statements, made by participants in the interview, or from abstract references in the text to a concept in context (32). The transcripts were coded using Ethnograph and the text segments were sorted by code word to aid in analysis and generation of code word frequency (32;108). Software was adaptable; thereby, allowing the ability to allow multiple and overlapping coded text segments when segments refer to multiple concepts. For ease of description of the code words, memo narratives were written to explain the content.

Content analysis- Content analysis encapsulated the themes from the interviews. After reviewing transcripts and coding concepts, as previously described, summative quotes were used to personify themes expressed in the qualitative interviews (36). Content analysis provided verbatim examples of the key concepts from the interviews to reinforce and demonstrate the results of thematic analysis.

Inter-rater reliability was established by two researchers who analyzed the transcripts. To establish an agreement between the two coders, a segment of ten central pages was selected for analysis by both coders, separately (32). Due to the length of the transcripts, when the verbatim transcripts were less than ten pages, reliability was assessed using the entire transcript. Reliability was assumed as the

number of agreements between the coders divided by the sum of the number of agreements and number of disagreements. Acceptable levels of variability were set at 75% (26).

CHAPTER 4

CULTURAL PERCEPTIONS OF HEALTH AND DIABETES AMONG NATIVE AMERICAN MEN

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ABSTRACT

The prevalence of diabetes continues to disproportionately affect minority populations, most specifically, Native Americans. Native Americans and Alaska Natives have the highest published prevalence of diabetes in the world. Culturally appropriate prevention programming has the potential to decrease the prevalence of diabetes, thus improving quality of life and reducing health care costs in this at-risk population. Identification of cultural definitions of health and diabetes is critically important in creating culturally relevant and effective diabetes prevention programs.

Methods: Qualitative interviews were conducted with 20 Native American men from 2 tribal clinics in northeast Oklahoma. Verbatim transcripts were analyzed utilizing grounded theory, to identify cultural definitions of health and diabetes.

Results: The men who were interviewed defined health in terms of physical capabilities and presence of disease, with family members, people in the community, and Indian

Health Service (IHS) facilities serving as significant sources of information regarding health promotion and treatment of disease. Conversely, the men described diabetes with a sense of fatalistic inevitability. The disease was viewed as an inexorable event that slowly manifests itself through various complications, including amputations, loss of eye sight, kidney disease, and ultimately results in death. Men feared for their own diagnosis as well as the diagnosis of family or community members whom they considered to be at-risk. Furthermore, the men indicated that diabetes could be prevented or at least delayed through proper diet and exercise. Prevention barriers mentioned by the men were lack of motivation, lack of time, lack of money, and a perceived lack of ability.

Conclusions: Additional information allowing comprehension of the perceptions of health and diabetes in this at-risk population will significantly contribute to the development of effective diabetes prevention programs.

BACKGROUND

The Native American (NA) people and culture have endured significant adversities over the past 2 centuries; however, their most threatening dilemma may be imminent. The prevalence of diabetes among the NA population is approximately three times (3.5% versus 0.9%) the prevalence among non-Hispanic whites. Moreover, the death rate from diabetes has increased by 55% from 1972-1974, when compared to data from 2000-2002 (75-77). Between 1994 and 2004, the number of NAs aged >35 years diagnosed with diabetes in an Indian Health Services (IHS) health-care facility more than doubled from 6,001 to 12,313 and age-adjusted prevalence increased from 8.5 to 17.1 per 1,000 population (74). Furthermore, data from the IHS Clinical

Reporting System indicated that the overall prevalence of diabetes among the IHS direct and tribal population was 11% in 2005, an increase of one percent from the previous year (75).

Although diabetes has been shown to affect the NA people, the trends differ across tribes and genders. Rates of diabetes have consistently been higher in females (80). Lee et al. (81) observed rates of diabetes of 38% among males and 42% among females in a sample of Oklahoman NAs. Additionally, prevalence of disease has been found to vary according to degree of NA ancestry (72). Prevalence rates of diabetes have been estimated at 12.7% among Plains tribes, 10.5% among the Southwestern tribes, 9.3% among the Woodland tribes and 4.5% among the Pacific Coastal tribes (76).

The progression of disease in NA communities is exhibited by increasing prevalence of diabetes outcomes and complications, such as retinopathy, amputations and kidney disease (7). The impact of diabetes in NA communities has been considerable. Diabetes has created significant personal incapacitation and suffering as a result of the long-term complications, such as blindness, peripheral vascular disease and kidney failure (49). Valdmanis et al. (83) found that persons in Oklahoma with diabetes were disadvantaged on all of the measures of well-being: general health status, days of disability and poor health, access to care, and economic burden. Furthermore, diabetes has become more common in younger populations and is now appearing frequently in NA children and adolescents (72;92). If the onset of disease continues to occur in younger populations, middle-aged NAs with diabetes will have more years of disease burden and a higher probability of developing serious or end-stage vascular complications by the ages of 35 or 40 years (72;78).

Rates of chronic diseases, especially diabetes, continue to rapidly increase in the NA populations thereby suggesting that current health education and awareness is not effective. Although diabetes is recognized as a major health concern among NA populations, data is lacking on how this multifaceted disease is perceived among members of the community. There is an urgent need to gain insight into NA's knowledge, feelings and perceptions regarding diabetes in order to create culturally relevant nutrition education and health promotion programs. The purpose of this study was to identify a cultural definition of health and diabetes using in-depth qualitative interviews from NA men residing outside a reservation setting. This formative data will allow researchers and health care providers to develop culturally appropriate disease-specific health care services that can reduce the risk factors for diabetes and prevent or delay the onset of disease in NA communities.

METHODS

The data was collected in one interview session at one of two Northeastern Oklahoma tribal clinics. The interview consisted of an informed consent, completion of a demographic questionnaire, food frequency questionnaire, an in-depth interview using questions from the *Cultural Structure of Health and Diabetes* questioning guide (Table 6.1), and a food sort of previously determined most-commonly consumed foods, where the participants sorted foods into groups based on their perception of health value and fat and sugar content. All portions of the research protocols were reviewed and approved by the Institutional Review Boards at Oklahoma State University and The Ohio State University.

Interviewer Training. Two female NA interviewers were hired to conduct the in-depth interviews. Each interviewer conducted interviews of NA women in a previous

study and completed a one-day course on subject recruitment, interview structure, data collection techniques, and response recording. The training consisted of equipment usage, essential techniques of qualitative interviewing, (e.g., listening and directive questioning skills) and the logistics of the qualitative interviews. The interviewers were compensated $100 for training and $75 for each participant that completed the interview.

Participants. Men of at least one-quarter degree NA blood, between the ages of 18 and 65 years, were eligible for participation in the study. A diagnosis of chronic disease, including Type 2 Diabetes Mellitus, did not prevent inclusion; however, men diagnosed with chronic diseases that influenced appetite, including those receiving cancer treatments, were excluded from the study. Men were recruited proportionately from the two tribal clinics in northeast Oklahoma using a non-probability sampling design. An effort was made to recruit approximately half of the sample with a previous medical diagnosis of diabetes. To increase participation, men who successfully completed the interview received $75. All participants provided informed consent prior to participation and represented a convenience sample.

Key informants at each of two tribal clinics and qualitative interviewers worked closely with research staff to recruit potential participants for the study. Interviewers identified individuals from the community that were interested in participating, determined eligibility and scheduled the visits to the clinics for the interviews. Other participants were recruited from the tribal diabetes education programs and general health clinics of the two tribes. The snowball sampling technique resulted in a sample of 20 men. All participants' responses were credible and usable, resulting in 20 interviews for the current study.

Data Collection and Analysis. The questions from the *Cultural Structure of Health and Diabetes* questioning guide (Table 6.1), were used to direct the semi-structured interview. Questions from previous research (92) were modified to identify cultural perceptions of health and diabetes, with the opportunity for the interviewers to probe on new or interesting topics that surfaced. Questions focused on areas of interest that were consistent with the objectives of the study, such as perceived causes, treatments, and efficacy of diabetes prevention behaviors. Key informants within each clinic setting reviewed the questions for cultural sensitivity prior to the beginning of the interviews.

Two researchers (CC, CT) analyzed the verbatim transcripts from the audiotapes. Grounded theory guided analysis of the transcripts (104). A list of initial code words was derived from recurring themes in the transcripts (Table 6.3). Then, key concepts or recurring themes that originated from the qualitative interviews were integrated into the questioning guide using the method of constant comparisons. Code word definitions were outlined to encompass the meaning of text segments throughout the transcripts. When new themes occurred in the transcripts, they were either assigned a new code word or a subcategory of an existing code word. Text segments were coded with the corresponding code words using Ethnograph (version 5.04, Qualis Research Associates, Denver, CO). After the initial open coding, axial coding was used to identify subcategories within the parental code words (104). The final step, selective coding, provided the means to determine the relationship among constructs and to identify how concepts are related to their constructs in order to establish an overall cultural perception of disease.

RESULTS

Twenty NA men completed the qualitative interviews. The men in the sample identified 18 tribal affiliations while the mean degree of NA blood was 58%. The mean age of the men was 40 ± 15 and 7 (35%) reported a previous clinical diagnosis of diabetes. Approximately 75% had an education level beyond high school; however, 58% indicated an annual household income of less than $25,000 (Table 6.2).

Utilizing grounded theory, unique code words were developed during the open coding of the transcripts (Table 6.3). Text segments coded for each code word were then analyzed to establish subcategories and relations among the primary 23 code words. The results of the analysis for code words associated with health and diabetes are presented below.

Cultural definition of health. The NA men most commonly defined health in terms of lifestyle behaviors. Individuals performing positive behaviors — such as consumption of a healthy diet, maintaining a healthy weight, exercising and refraining from unhealthy behaviors, including smoking and drinking alcohol — were considered healthier than those who did not.

Health was also defined in terms of the physiological presence or absence of disease. For example, when asked to define one's current health, responses concentrated on the signs and symptoms of diabetes, heart disease and other disease; many perceived themselves to be healthy if they didn't have an immediate, current pain or complication. Individuals who had been clinically diagnosed with disease did not express concerns regarding diminished health until there was a physical manifestation of illness. This was particularly true of diabetes, as many men did not express concern

over the disease until it was complicated by severe comorbidities. One participant stated, *"That's the biggest problem with the Indian People...we don't take care of ourselves, 'til we get sick, (then) we get aware of our bodies."*

Another indicator of health status was defined through physical functionality. Poor health was considered to limit one's ability to perform activities of daily living. One man reported his health in terms of limitations, *"I can't hardly do the work I used to do. My back, it bothers me quite a bit, you know, I can't do a lot of lifting."* Conversely, being healthy was defined as one having the ability and energy to perform these tasks. One man indicated, *"I can get around good, so I assume I'm healthy."* Thus, health was having the energy and ability to perform daily activities.

Additionally, these men expressed reservations about increasing age. They expected their health status to decline with age, and disease concerns to become more apparent. One man suggested, *"I guess like anybody else at 52 years old, you start worrying that diabetes is entering the picture among Indian People."* Many defined their health status compared to their personal expectations for their current age.

Cultural definition of diabetes. Diabetes was defined, primarily, in terms of long-term complications, which were often tied to fear and concern. These complications included blindness, kidney disease, dialysis treatments, transplants, and amputations. The most commonly mentioned complication was amputation, which invariably were enveloped in gruesome overtones. For example, when asked about his greatest fear regarding diabetes, one man noted, "*Getting something cut. Getting my ankle cut off, my leg, toes, or something. I like my body parts.*" Another said, "*Getting things whacked off.*" Furthermore, when asked what comes to mind, when the word 'diabetes' is mentioned, one participant replied, *"People with no legs."*

The majority of the men reported their source of information regarding diabetes as a family member or a person in the community, whom they had heard had the disease. One man stated, *"I knew a guy that had diabetes, but I didn't want to be rude and ask, so I just kind of heard stories, hearsay, like from people talking about it, his whole diabetes thing. You know, (I learned about diabetes) just through his stories."* Additionally, many of the men reported IHS clinics as a source of learning about the disease. They mentioned that they had picked up fliers, talked to public health nurses, and saw posters on diabetes at the IHS clinic.

Some men expressed fear towards diabetes, calling it a "*crazy disease.*" Diabetes was portrayed as troublesome. One participant expressed an irresolute view toward the disease: "*It's kind of scary to think of diabetes as an actual disease, but it is. It causes malfunction in your body and you don't know what it may flair into."* Diabetes was defined as a cruel, devastating disease that causes declination of overall health status and malfunction of the various body systems, leading to complications such as blindness, amputations, kidney disease, etc. One man described diabetes as an ailment that, *"Make's your heart work faster, harder. Makes your body have to work more than it should. Stuff gets clogged up. Next thing you know, you're getting something cut off."*

"Fatalism" (27) was a main sentiment expressed toward diabetes and its complications. Many of the men in the sample recalled how the disease had taken the lives of family members or someone in their community. One man suggested, *"(Diabetes is) just one death sentence as far as I'm concerned."* Most of the participants mentioned that being of NA descent was a significant risk for onset of diabetes. This belief was expressed through the feelings of increased susceptibility and

inevitability toward the development of diabetes. On noting the high prevalence among NAs, one man stated, "*Yeah, you're going to get it anyway.*" Moreover, these men acknowledged that they have a hereditary/genetic predisposition to diabetes. One participant acknowledged, "*With Indians, it usually runs in their families.*" Another man defined diabetes as, *"It's an ailment that most Indians got, not all, but most."* Other characteristics thought to put someone at risk for diabetes were laziness, lack of exercise, unhealthy weight, and old age.

Furthermore, many of the men in the study feared that they, themselves, were at risk for diagnosis, because they were of NA descent, or because they knew of family members who had suffered from the disease. When questioned about his biggest fear regarding diabetes, one subject responded "*probably just not knowing that you have diabetes and not treating it.*" Moreover, some of the men feared that diabetes would disable them to the point that they would become forced to depend on other people. Additionally, the respondents feared the potential of a diagnosis of diabetes in family members who they considered to be at-risk for diabetes. The participants were especially worried about the younger generation, including their children and grandchildren; "*I worry about the little kids, you know. I worry about a lot of little kids, not just mine, but everybody's.*"

Some men seemed to be coping with their disease through denial. "*I try to just ignore it and act like I don't even have it. But it'll stay there unless the good Lord heals me.*" This respondent states his sense of denial, then his acceptance of disease, followed by a hope for a miracle remedy. Another man admitted that he had been in

denial about getting screened, for fear of diagnosis: "*I was in denial. You know, I didn't want to know. I didn't even want them to test my blood or anything like that because I didn't want to know, you know, if it was true or not.*"

Many of those interviewed reported symptoms of diabetes as episodic states of disorientation where one becomes shaky, dizzy, and sometimes, irritable. Other symptoms were weakness, sleepiness and lethargy. Some men noted excessive urination, excessive thirst and depression as symptoms of diabetes. Men with diabetes admitted that they didn't know the symptoms until they had been diagnosed. One man said, "*I think I had diabetes maybe five or six years before I understood what the symptoms were,*" while another respondent reported, "*I really couldn't tell that I had diabetes. I didn't know any of the symptoms or anything. I had severe headaches...pressure headaches, way down. Felt like my head would explode. Blurred vision. I had pretty awful eyesight.*" Still, other men had other thoughts about the signs of diabetes. One man indicated that a person could tell if they have diabetes, "*If they start fainting when they walk,*" another stated that people with diabetes, "*have, like, a fruity smell to their breath.*" Having a fruity smell to one's breath is not necessarily a sign of diabetes, but a sign of ketosis, indicating 'out of control' diabetes.

The men felt that individuals diagnosed with diabetes, should alter his or her lifestyle behaviors to maintain their health and control their condition. Diabetes was thought to require thorough, demanding care. One respondent expressed his condition as an "*endless job*," with "*odd hours*," when referring to diabetes care. Another stated, "*People are weak in many ways (but) their spirit is healthy. They're scared you know? Battling everyday against the darkness.*" Appropriate care involved eating a healthy diet, engaging in physical activity, taking medicine and following the advice of

healthcare professionals. Still, some of the men were unsure of the full scope of diabetes treatment, one man stated, *"People have to take insulin, and I think that insulin is a sugar, isn't it?"*

The men in the study seemed to express a sense of social responsibility and an effort to uphold their image in the community, regardless of their diagnosed diabetes. One man expressed social responsibility for rearing his grandkids; "*You got grandkids and kids and families sometimes, makes you want to change yourself for them. 'Cause if you go and don't take care of yourself, you know...*" Furthermore, some men expressed guilt for passing on the disease to their younger generations. One man stated, "*I don't want them to say, look what I got from old daddy. Look what he left us, his diabetes.*" Moreover, some men recalled not wanting to reveal their disease in efforts to avoid questioning about their food selections at potlucks and other community events where food is involved. One man mentioned how his mother was always nagging him about what food he did or didn't '*need.*' Another man hid his diabetes from his mother, for fear of worrying her about his condition.

Most men indicated that diet was the primary cause of diabetes; many thought that having a diet poor in nutrient value put one at the highest risk for getting diabetes. Men explained that today's diet was comprised of fast, processed, greasy food and felt that a traditional NA diet could aid in prevention. One man reported, "*I believe it'd help. I mean, cause a lot of that, it takes energy to catch a fish or hunt or grow your garden, you're not pulling up to the take-out window and telling them what you want.*" There were conflicting views regarding the composition of a 'traditional diet.' Some men thought that a traditional diet, *"More than a hundred years back,"* would help to prevent or delay onset of diabetes. Foods named as 'very' traditional were corn, beans, red

meat, wild game, fish, berries, and garden vegetables. Furthermore, men who reported a more contemporary 'traditional diet' named high fat, high sugar foods, such as corn soup, fried potatoes, fry bread, meat and gravy, and grape dumplings.

Many of the men thought that performing healthy lifestyle behaviors was the most effective way to prevent diabetes. Many mentioned that by consuming a good, nutritious diet, and maintaining a healthy weight, chances of being at-risk for disease could decrease. A diet full of candy bars and sugars was indicated as a "bad diet" or a diet that may put one at risk for disease. Many respondents defined prevention as exercise. Many thought that by exercising, one could decrease their chances of getting diabetes. Furthermore, the men who suggested exercise also suggested diet as a means of preventing diabetes.

The men felt that diabetes could be prevented by education and awareness of disease. Screening was mentioned as a means of educational prevention, especially during regular preventative health maintenance check-ups. Culturally appropriate interventions were mentioned. The men indicated that parents acting as positive role models would aid in prevention of disease. Community/Tribal interventions were also indicated as means of educating the young about the disease and playing a significant role in prevention. The most noted barrier to prevention behavior was lack of motivation or "laziness." Furthermore, many men reported that lack of money and economic hardship was a barrier when attempting to eat a healthy diet. One respondent stated, *"I try to eat healthy, but it just costs a lot,"* while another man stated *"(Indians) don't have much money to eat and that's why they eat like that, cause they're poor."* Other barriers mentioned were busy lifestyles, lack of ability, and fear of change.

DISCUSSION

The qualitative approach used in this study demonstrates an effort to develop a cultural definition of health and diabetes among NA men. The invasive nature of diabetes in these NA communities was readily evident as most participants knew of people in their communities who had diabetes or who had diabetes related fatalities. Although one-third of the participants had diabetes, the responses received from those without diabetes mirrored the responses of those with diabetes. Stratification of responses by diagnosis of diabetes would provide little additional information.

NAs are affected by both American Indian culture and the dominant white or Anglo American culture. Numerous factors, including historical, political, geographical, and sociocultural affect the perceptions of health among NAs (98). Many challenges are presented in an effort to define perceptions among NAs, especially through the scope of Western medicine. Previous research reports that NA belief systems perceive health not only as a physical state but also as a spiritual state (28). Furthermore, Native American healers believe that when one is in harmony with their surroundings, then they will be in good health (63;96;97). Little mention of spiritual treatment or the use of traditional healing methods were discussed by the men in this study.

The perception of being healthy or well, when signs or symptoms are not apparent was of particular concern, in this current study. Other studies have reported a reliance on symptomology for disease recognition and treatment. A qualitative study among NA women from the same communities as this study revealed that health was defined by the presence or absence of physical symptoms of disease (27). In a study of Dine (Navajo) families with asthmatic children, parents were hesitant to administer medications to children, particularly in the absence of symptoms or complications (101).

Additionally, Hatton found that NA elders discerned their health status in relationship to immediate presence or absence of disease (98). Some men in our study reported severe symptoms of diabetes, but didn't know how to deal with them, or what they had, therefore, they ignored these symptoms and tried to carry on their daily routines. They mentioned how they suffered from headaches, blurred vision and disruptive sleeping patterns, not knowing what was wrong with them. In fact, one man admitted that he thought that he was experiencing an everlasting hangover. There is a disparity that exists between the discernment of a biologically defined chronic disease and the more culturally-relevant presence of physical symptoms among NAs groups (27).

An assumption of good health standing, when able to perform activities of daily living was a prominent view expressed by the men in our study. Moreover, men who did not express their health as an ability, expressed it as a lack of ability to perform daily activities. This phenomenon has been observed in previous research among other NA groups (27;97;98). Similarly, elderly NAs viewed health as the ability to "get around" (98), where the men in this study were concerned about performing the duties related to their societal roles. Women in the same communities framed their health around their physical ability to care for their families (27). Another pertinent gender difference surrounds the role obesity plays in health and the overall concern. Very few men raised obesity as a major health concern, while it was perceived as a major determinant of health status for the women.

A strong sense of inevitability toward the acquisition of diabetes and its accompanying complications pervaded the various ideas involving prevention and treatment of disease among this NA sample. Many participants held the belief that diabetes is unavoidable and eventually leads to fatality, especially for those who are of

NA descent and have a family history of disease. Similarly, Judkins (63) reported fatalistic attitudes and verbalizations, as well as a distinct sense of awe and powerlessness among the Seneca, when faced with the topic of diabetes. Furthermore, fatalistic viewpoints of the disease prevented some NAs with diabetes from actively managing their disease in a sample of inner city NAs (109). Garrett et al. reported that the NA worldview allows acceptance of whatever has gone awry as simply a part of nature and as a part of the world as it is (28). This approach to coping and acceptance that leads to beliefs of inevitability and lack of ability to change was observed in this study. These perceptions should be considered and incorporated into diabetes prevention activities among NA populations. Programs focused on instilling self-efficacy in the ability to change and the ability to prevent diabetes may encourage this population to take a more active, engaging role in healthy, preventative behavior.

Huttlinger et al. (99) reported that Dine' subjects describe their experiences with diabetes metaphorically as "doing battle;" where the management of diabetes was thought of as a necessary ongoing surveillance that was needed to fight the disease or battle. Likewise, men in our study defined diabetes as an "ongoing job" with "odd hours." Monitoring diet and blood sugar, and engaging in physical activity was considered tedious and inconvenient. Furthermore, many of the men without diabetes expressed fear regarding diagnosis, and felt that they were at-risk because they were of NA descent or had a family member afflicted with the disease. Overall, there was a sense of impending doom and ongoing fear regarding the disease.

Due to the high prevalence of diabetes in NA populations, many men seemed to down-play the significance of the disease. Throughout the interviews the men joked about various aspects of diabetes and its complications. This is similar to what Taylor et

al. (27) found among NA women; one woman referred to amputees as "becoming a member of the stub club". Additionally, some men coped with their disease through denial, while others admitted that they often avoided screenings in fear of diagnosis. This behavior was exhibited in an asthma study, where Navajo parents often denied or rejected their child's ailment and avoided utilizing medication, when their child experienced acute episodes (101).

There are several limitations of the current study; one of which is that NA women were hired from local NA communities to conduct the interviews, regardless of experience in qualitative interviewing technique. Training aside, the women employed utilized different questioning approaches during interviews and varied in the amount they probed participants. To address this concern, transcript reviewers attained tapes immediately after interviews then provided feedback to interviewers as additional training and support. Furthermore, transcript reviewers functioned as the research instrument, thereby introducing bias in the lens through which reviewers read and interpreted the transcript data. To address this concern, transcripts were read separately and independently, and later, discussed until consensus was reached on coding. We achieved an inter-rater reliability of >85%. Furthermore, the lack of responses related to traditional healing practices and the role of spirituality commonly linked to NA culture may be a result of recruitment location. Participants who utilize the services of tribal health clinics are likely not representative of all NA cultures. Finally, the sample was derived through snowball sampling, which is recognized as a non-probability method. Though these methods may decrease the generalizability of the findings, they are often essential in identifying individuals from an at-risk population (27;110).

Regardless of these limitations, the data revealed are similar to data reporting perceptions of diabetes among other NA groups; providing support for our findings (63;98;109). Most of these studies were conducted with reservation-living NA groups; we have identified perceptions of health and diabetes among NA men, residing in a non-reservation setting. Previous reports have not addressed the relationships of perceptions of health and issues regarding diabetes prevention. We have attempted to address some of these issues; however, each new issue raises several questions, indicating a need for further investigation of the cultural definitions of health and diabetes.

There is a critical need to develop a deeper understanding of the NA population that so heavily bears a disproportionate burden of suffering from diabetes and its complications (22;24) while illuminating several gender differences. Identification of health perceptions and worldviews are paramount in the attempt to develop culturally appropriate interventions (26-28). Previous research and multi-site programs, like *Awakening the Spirit: Pathways to Diabetes Prevention & Control* (American Diabetes Association) have proved to aid in diabetes prevention and treatment by targeting specific lifestyle behaviors within the environment of NA communities (91). Furthermore, Huttlinger et al (99) reports that promotion of patient's worldviews and perceptions of illness can promote understanding among health care professionals. NA communities vary largely in tribal affiliation and location; future researchers should identify the distinctiveness of each tribe's population and culture, to ensure that they meet the community's specific needs (28). Moreover, the degree to which the

perceptions held by NA men in Northeast Oklahoma match other NAs within and outside of Oklahoma should to be observed in order to assist in designing valuable intervention and education programs.

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Describe your current health to me.

1. Describe how you feel about your health.
2. What, if any, health concerns do you have?
3. What are the major health concerns of other Indian men you know?
4. What do you think is the leading cause of death for Indian men in the United States?
5. What comes to mind when I mention diabetes?
6. Let's discuss diabetes a bit.
   What do you think causes a person to get diabetes?
   Why do you think these things (mentioned above) cause diabetes?
   If eating right, describe how people should eat.
   What keeps people from eating right?
   If exercise, what should they do and how often?
   What keeps people from getting exercise?
   How did you find the information that you just told me?
7. What do you think happens to a man once he develops diabetes?
8. Can you think of anyone who is at risk for developing diabetes? (Is he or she Indian?)
9. How can a person tell if he or she has diabetes? How do they feel?
10. Tell me about anything that you know of that might keep a man from developing diabetes.
    Why do you think these things (mentioned above) prevent diabetes?
    Where did you find this information?
    If read, where? Books, magazines (which ones)?
    If heard, where? From whom?
11. What may prevent a man from doing the things that may prevent diabetes?
12. What treatments are there for diabetes that you know about?
    If diet, describe the diet.
13. Who are you concerned about developing diabetes?
    What are the reasons that you are concerned about this person(s)?
14. What can parents or family do to help prevent this person/child from developing diabetes?
15. What can the tribe or community do to help prevent this person/child from developing diabetes?
16. How do you feel about diabetes?
17. What is your greatest fear about diabetes?
18. What control do you think a person has over diabetes?
19. Can you prevent diabetes?
    When can a person begin to do these things to prevent diabetes?
20. How would you describe a traditional (Indian) diet (the old way of eating)?
    What would you think of shifting the diet back toward the old ways Indians used to eat?
    Do you think eating a more traditional diet would help Indians prevent diabetes?
22. Is there anything else would you like to tell me about diabetes?

Table 4.1. Cultural Structure of Health and Diabetes: Questioning guide for interviewing Oklahoma American Indian men about cultural perceptions of health and diabetes

Characteristic	Mean ± SD	
Age (years)	40.7 ± 14.8	
Degree of Indian blood (%)	57.7 ± 0.3	
Body mass index[a] (kg/m^2)	30.6 ± 6.3	
	N	**%**
Marital status[b]		
Married	13	68.4
Not married	6	31.6
Education		
High school or less	5	25.0
Some college	13	65.0
College degree	2	10.0
Employment[b]		
Employed	14	73.7
Not employed	5	26.3
Annual household income[b]		
< $10,000	4	21.1
$15,000-$24,000	7	36.8
>$25,000	8	42.1
BMI categories (kg/m^2)[a]		
Healthy (18.5-24.9)	3	15
Overweight (25.0-29.9)	7	35
Obese (>30)	10	50
Diagnosed Diabetes		
Yes	7	35
No	13	65

[a]Based on self-reported height and weight.
[b]Does not sum to n=20 due to missing data

Table 4.2 Demographic characteristics of Oklahoma American Indian men interviewed about cultural perceptions of health and diabetes

Code Word	Definition
AT RISK	Characteristics of those at-risk for developing diabetes
AVOIDANCE	Avoiding screening or seeking treatment for ailment for fear of diabetes diagnosis and acknowledgement of complications
COMPLICATE	Perception of medical complications caused by diabetes
CONTROL	Perceived capability to control diabetes
DEF DM	Definition of diabetes
DEF EXER	Definition of exercise
DEF HEALTH	Definition of health
DENIAL	Denial experienced post-diagnosis of diabetes
DIET BAR	Perceived barriers to eating a healthy diet
DM CAUSES	Perceived causes of diabetes
DM CONCERN	Concerns and fear about diabetes
DM DIET	Perceived diabetic diet, followed after diagnosis, in order to control disease
DM SYMPTOM	Perceived symptoms of diabetes onset
DM TREAT	Perceived treatments for diabetes
EXERCISE BAR	Perceived barriers to exercising
GOOD DIET	Definition of a healthy diet
INEVITABLE	Perceived feeling of inevitability toward diagnosis of disease
NA DEATH	Perceived leading causes of death for American Indian men
NA MEN	Perceived health issues of other American Indian men
PREVENTIONBAR	Perceived barriers to prevention behaviors
PREVENTION	Methods to prevent or delay onset of diabetes
SOURCE	Sources of health and nutrition knowledge
TRAD DIET	Cultural definition of a "traditional diet"

Table 4.3. Parent code words used in initial coding of verbatim transcripts of interviews of Oklahoma American Indian men about cultural perceptions of health and diabetes

CHAPTER 5

DISCUSSION AND CONCLUSIONS

Numerous adversities exist in the attempt to define health and wellness in the eyes of Native American people. It is especially trying when making distinctions about a culture whose values and norms differ from that of Western society. Moreover, health intervention projects with Native American populations are less well documented (18). This study was an effort to fill the vacuous void of information on definitions and perceptions of health and diabetes among Native Americans (NA) living outside of the reservation setting. Additional research is needed to verify the findings presented herein within Oklahoma and among other NA non-reservation communities.

Preceding research suggests that dietary intakes of Native Americans has shifted from a historical, traditional hunter and gatherer diet to a more Westernized diet. According to Compher (40), the typical dietary pattern associated with the nutrition transition is increased energy intake as traditional foods are substituted for processed, energy-dense convenience foods. Men in our study reported a history of dietary intake exhibiting a nutrition transition; foods named as 'way back traditional' were venison, corn and garden vegetables, whereas foods referred to as 'contemporary traditional' were corn soup, fry bread, and grape dumplings, and foods named, most presently illustrated an Americanized diet of fast-food, candy bars, and pop. Men also reported

that the more traditional, 'way back' food took more time to obtain and required physical activity through gardening, hunting, or fishing. Previous research has demonstrated that these traditional foods do not significantly contribute to overall intakes due to the infrequency of consumption (53). Previous research also suggests that 'way back' traditional foods are low in sugar and fat and are relatively high in nutritive value (6;17). In 2002, the Tribal Chairman of three tribes (Mandan, Hidatsa, and Arikara) developed a Foodways nutrition model and intervention that could increase the intake of healthy traditional foods, as a way to fight the "war on diabetes" (111). Programs such as Foodways should be implemented into the 300 various tribal communities around the U.S. as a way to educate youth on historical diets and to increase the intake of these healthier traditional foods. Further research is needed to better depict the dietary patterns of NAs as well as the variables linked to food choice behaviors.

Several barriers that hampered the ability of NA men to participate in diabetes prevention activities were identified through our study. Some barriers noted in regards to healthy diet included the perceived higher cost of "healthy" foods and time needed for preparation of a healthy meal. This finding agrees with the findings of Story et al. (112), who reported that poverty is pervasive in NA communities, and access to healthful food supply is often limited. Additionally, the men didn't want to sacrifice taste and convenience to eat a healthy meal. Barriers noted in regards of physical activity were lack of motivation or "laziness," time constraints and the inability or fear of changing behaviors. Other barriers and resolutions regarding dietary intakes should be evaluated in order to identify approaches that can help promote intake of high nutrient-valuable foods in Native American populations. Furthermore, Native Americans have

been shown to present with an elevated prevalence of lactose intolerance; however, little scientific data exists to support this claim. Identifying these barriers will aid in public nutrition education efforts for health promotion and diabetes prevention.

The increase in childhood obesity and associated obesity-related morbidities such as diabetes point out the urgent need for primary prevention of obesity in Native American communities (112). School and community-based approaches addressing a wide range of contributing factors are needed to effectively reduce the prevalence of obesity among Native American youth (87). There is an urgent need for the development and dissemination of interventions that are both culturally appropriate and clinically comprehensive (113). Moreover, immediate interventions should be put in place by IHS, tribal, and community establishments in order to interrupt the perpetual climbing rates of obesity, diabetes, and diabetes complications among Native American people.

Huttlinger, et al. found that the advice of health professionals fell on deaf ears, among Dine' patients, on part of their strong beliefs regarding "Hohzoni," meaning balance, for only when one is in balance with their surroundings, are they perceived to be healthy (99). In the Dine (Navajo) culture, it is often rude to ask questions, especially to health care professionals, because of their perceived elevated status; it is suggested as a sign of disrespect when one questions an expert (99). Oftentimes, this behavior contributes to what health care professionals refer to as non-compliance. One of the men in our study indicated that perhaps health professionals should learn more about the disease, "I think we need to have health professionals that know about it and can tell the right information." This man didn't seem to think that the current health professionals that he was interacting with understood him, or the disease, most likely

due to cultural differences. Furthermore, health care professionals should encourage positive behavioral changes, rather than dooming NA patients with the at-risk factor. One of the men in our study reported, "My mom had it, then a nurse friend told me that I would probably get it, which I did."

Many of the men reported sources of information concerning diabetes as their friends and families or people in the community whom they had known to have diabetes. Similarly, Taylor et al. (27) reported that Native American women utilized community and family members as a considerable source of both information and misinformation regarding diabetes. It is critical that educational programs are developed and offered to NA communities in regards to diabetes, so that if community members are looking to other community members for information, the right information will be shared. Furthermore, it is important that parents become educated about diabetes prevention in order to educate their children, because diabetes is becoming so prevalent in youth populations. Teufel et al. (18) reported that parental and familial involvement in weight control for NA children facilitates changes in the eating and exercise environment by providing a role model and social reinforcement for behavioral change.

The men in our study indicated that diabetes and alcoholism are the two major leading causes of death among Native American men. Moreover, previous DHHS reports state that NAs have the highest frequency of drinking-associated problems of any ethnic group (67). Other men in the study mentioned how they had 'learned' to consume alcohol, as a diabetic. One man stated, "You have to be awfully careful, if you take insulin, especially if you are drinking hard alcohol." More research is needed to explore

the associations between these two diseases. Additionally, diabetes prevention programs should implement alcohol education into the curriculum, and vice versa in Native American communities.

Aspects of Native American culture and ideals vastly differ from that of mainstream society. Oftentimes it is thought that acknowledging negative feelings or thoughts will bring them to come. A previous study that assessed beliefs among Native Americans, reported that asking a question about negative feelings or behavior is believed to potentially cause those negative feelings and behaviors (100). Some of the men in our study admitted to their feelings of denial when dealing with their condition, while others expressed avoidance in getting screened for diabetes, for fear that they might have it. Furthermore, Taylor et al. (27) reported a demonstrated negative social environment affecting diabetes prevention and treatment, when commenting on how one woman's family didn't want her to be screened for fear that she may be diagnosed. This negative air toward diabetes in NA communities has contributed to a 'hush-hush' tendency toward the disease, where if it is not mentioned then it may not come about. Furthermore, Pichette et al. (28) reported that many NA tribes believe that speaking about a deformity or disability may give it power to manifest itself or express itself in human form. More research is needed to look at the beliefs of NA people and how their beliefs can affect prevention and treatment of disease. NA populations can no longer avoid and ignore the diabetes epidemic, because it elicits negative feelings. Proactive approaches need to be taken to recognize diabetes as a real threat that can be prevented, rather than a negative condition, that can brought about by thoughts of doom.

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