AN APPROACH TO DIABETES PREVENTION

AMONG NATIVE AMERICANS

IN OKLAHOMA

By

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CHAPTER I

INTRODUCTION

Type 2 diabetes mellitus (diabetes) is a major public health concern among the Native American (NA) population in the United States. This disease is the fourth leading cause of death in this population (1) while the comorbidities, including blindness, kidney failure, lower-limb amputation and cardiovascular disease are consequences of the increased prevalence of diabetes in this population (2). However, not all tribes are affected equally; Southwestern tribes present an age-adjusted prevalence of 10.5% while Woodland and Pacific tribes have a reported prevalence of 9.3% and 4.5%, respectively (3). Despite the differences in prevalence among tribal groups, Native Americans as a whole exhibit a four- to eight-fold higher risk of developing diabetes than the general US population.

In addition to the increased rate of diabetes in this population, little is known about the dietary practices and cultural beliefs about health and diabetes in NAs in Oklahoma. Research tends to gravitate toward reservation living NAs, leaving those living in non-reservation settings not well understood. And despite the availability of Indian Health Service (IHS) healthcare, reports indicate an underlying concern for quality and continuity of healthcare for patients drawing services from a system running with less-than-optimal resources (4-7).

Analysis of the current research literature demonstrated that only a small proportion of the published research involves non-reservation living NAs (8); however, 60% reside in non-reservation urban areas, many outside IHS service areas (9). Oklahoma did not enact a reservation system despite a large NA population resulting in the integration of NA communities into the dominant culture (10). Originally, the various

NA tribes and bands were located throughout the US; however, westward expansion of white settlement triggered the development of treaties, beginning with the Dawes Severalty Act of 1887, designed to relocate tribes to other portions of the country (10-12). Many groups were relocated in the late 19th century to Indian Territory, an area that was to become an "Indian state" (10). This territory, *okla-hhoma* (meaning "red people" in Choctaw) later became the state of Oklahoma in 1907 (10). The dissolution of the reservation system and the cohabitation that followed created a diverse mix of cultures and backgrounds.

The social and economic climates vary greatly between reservations and NA communities integrated into Western society (13). A majority of IHS services are positioned within close proximity of reservation lands making services more readily available than for those in urban settings. Thus, this structure provides a substantial gap in the ability to serve those NAs living outside the confines of reservations.

Although diabetes is reaching epidemic proportions in several NA populations, limited data related to the perceptions towards health and diabetes impede efforts to assess health-related quality of life. As with other minority populations, the current assessment instruments have been constructed around issues not always germane to the target group (14). In a previous report, issues pertinent to a group of elderly African American women were not fully addressed in any existing tools developed with predominantly Caucasian populations (14). By using concepts ascertained during several focus group sessions, the researchers were able to identify valid items to create a specialized health-related quality of life diabetes assessment tool for African Americans.

Cooperative research efforts with NA tribes have become increasingly difficult because of a bitter history of misuse and abuse (15). These efforts, ranging from ethnographic descriptive designs to vaccination testing, have not always translated

directly into programs of benefit to the group of interest (16). Despite the perceived benefits to humanity, often little regard was paid to the desires and values of the NA population, fostering a sense of exploitation by the NAs (15). As a result of previous practices, the Indian Health Service (IHS) developed a more intensive review of studies with NAs (16). Thus, these previous issues were addressed during the development and completion of the present research project to generate a win-win situation for both the researchers and the tribal health clinics.

This project addresses the prevention of human disease in Oklahoma by continuing to identify health concerns, specifically related to diabetes and healthy eating issues of Oklahoma NA adults. The purpose of this study was to explore the dietary habits and cultural perceptions of health, obesity and risk for diabetes among NAs in Northeast Oklahoma. The information learned from the present study will be used to plan culturally appropriate nutrition and health programs for Native Americans in Oklahoma that can reduce the risk factors of diabetes and prevent or delay the onset of diabetes. Analysis of verbatim transcripts from the qualitative interviews unveiled specific themes related to health issues that were included in the formation of an assessment tool focusing on diabetes prevention. Such a tool will aid in the clinical assessment of NA clientele in the health care setting and provide an individualized approach to disease prevention and/or treatment. It may also be used in the formative assessment of the Native American groups for the development of culturally appropriate tailored nutrition education and health promotion programming.

CHAPTER II

REVIEW OF THE LITERATURE

ETHNOHISTORY OF PLAINS TRIBES

Area of origin

Prior to the arrival of Europeans, Native American (NA) tribes were scattered across the vast North American continent. Tracing the lineage and regional origins of many groups is aided by the history of the linguistic groups from which they originate (10). Siouan ancestry links the Iowa and Kansa (Kaw) tribes to the northern Great Plains regions (10). After migrating south and west from the Great Lakes region, the Iowa began settlements in what is now known as Missouri, Iowa and Minnesota. Similarly, the Kansa ("Wind People") occupied the northern plains in areas of Nebraska and northern Kansas.

The Pawnee people descend from the Caddoan linguistic group of the Great Plains (10;13). Four distinct bands make up the Pawnee tribe: the *Chaui* ("Grand"); *Kikehahki* ("Republican"); *Pitahauerat* ("Tappage"); and *Skidi* ("Wolf") (10). Tribes of this linguistic group were historically thought to originate from the lower Mississippi River valley (10). Early contact documented by the Spanish explorer, Coronado, primarily in regards to the raiding of goods passing through the region toward settlements in New Mexico, placed them near northeastern and central Kansas (10).

Previous economic and agricultural practices

Early accounts from French explorers remarked on the domestic, agricultural lifestyle of the Iowa (Bah-Kho-Je) tribe while occupying the northern Plains (10). The early bartering of their embellished buffalo hides and pelts with local tribes proved a valuable skill to French explorers, who befriended the Iowa for the purposes of local

trade (10). The Kansa were a semi-nomadic group of the Plains, cultivating some crops near villages while relying heavily on buffalo hunting. Warfare, often with the Pawnee, comprised much of the lifestyle of the early Kansa.

Much of Pawnee life was impacted by religious beliefs, including but not limited to marriage, agriculture, warfare, hunting, building earth-lodge homes and government (10). Their reputation as a people (respect for authority, courage and loyalty) was based on the values instilled through their religious convictions. This carried forward into future relations with the US government as many Pawnee faithfully served as scouts for the US military in many Indian wars as well as in both World Wars. Pawnee men were of good stature and possessed great physical endurance while the women were known for their vivacity and efficiency in affairs of the home and community.

Period of relocation to Oklahoma

Settlements of small bands of the Iowa were spread along the line of migration from the Great Lakes to the northern Plains (10). Treaties for the ceding of land began in 1815 between the Iowa and the US government; by 1824, they had given up all lands in present-day Missouri and Iowa and shared the northern portion of a reserve with the Sauk and Fox in northern Kansas. New federal Indian policy urged further land acquisition in 1876 that triggered the formation of bands within the tribe for those in opposition to the division of tribal land to allotments (13) . Any remaining unclaimed land from the allocation to tribal members was opened for white settlement. Many of these bands left for the Indian Territory to reestablish their communities, which they shared with the Sauk and Fox (10;13). Due to a lack of a permanent location on which to build their homes, the Iowa in Indian Territory petitioned the federal government for reservation land. In 1883, this request was answered, providing land in present day Payne County, between the Cimarron and Deep Fork rivers where they reside today (13).

In 1846, the Kansa ceded approximately 2 million acres of land west of the Big Blue River in Kansas to the US government to make room for newly arriving tribes being relocated (10;13). The Kansa were subsequently moved onto approximately 30 miles of land near present day Topeka, Kansas (10). Soon thereafter, they moved their villages near the Neosho River to Council Grove where they remained until another treaty relocated them to Indian Territory in 1872 (10;13). A 100,000 acre piece in the northwest corner of the Osage reservation in Oklahoma was provided and was placed under supervision of the Osage Indian Agency in Pawhuska (13). This relocation did not come without hardship as the population declined drastically from approximately 533 members after relocation to 194 after 16 years of life on their new reservation land (10).

Despite the loss of their homelands through the Louisiana Purchase, the Pawnee never engaged in warfare with the US (10). Three treaties (1833, 1848 and 1857) served to transfer all of their lands, less a small plot in Nebraska, to the federal government in exchange for land in Indian Territory. Removal of the Pawnee was taken with much eagerness. Leaders of the Chaui and Kitkehaki bands traveled to the Wichita Agency in 1873 to arrange for cohabitation with the Wichita tribe until arrangements for their promised reservation lands were completed. In 1874, the Pawnee were relocated to their current location in present day Pawnee County, Oklahoma.

Further change in federal administration brought about further changes in policy and ultimately the dismantling of a reservation state (13). An increased demand for land for white settlement (and the ensuing land run at noon on September 16, 1893) served as the impetus for the scavenging of “unused” lands held through reservation allotments (10). The Dawes Act of 1887 was approved to make NAs in Oklahoma citizens of the US with sovereignty with hopes to assimilate the tribes into American society (12;13). The lands formerly held by tribes were divided equally in severalty to eligible members of the tribe and the remaining land was redistributed for white settlement. This served as

the movement toward the current structure of proximity and cohabitation of “tribal” and public lands in Oklahoma (10).

NATIVE AMERICAN FOOD INTAKE BEHAVIORS

Little comprehensive data is available to describe the historically traditional diets of NA. Various ethnographic accounts have been collected using bands inhabiting Alaska and northern Canada that have been subject to minimal Western contact until relatively recently (17-22). Reviews of ecological reforms resulting from Western presence have been compiled, indicative of dramatic lifestyle modifications (23-26). Tribes residing outside these regions of interest present little available data about pre-contact diets. The following review describes the traditional Native diet and the extrinsic changes moderating the shifts in dietary intake behaviors, followed by a summary of current knowledge about contemporary dietary intake trends of NAs.

Historical intakes by Native Americans from other regions

Early evidence has been gathered to support the hunting and gathering sustenance used by early NA tribes (27). Molecular and microscopic analyses of fecal samples attributed to three archaic Native Americans indicated the presence of indigenous plants and animals in Hinds Cave, TX. DNA amplification identified seven different animals (pronghorn antelope, cottontail rabbit, packrat, squirrel, bighorn sheep, cotton rat and fish) from the digestive remains. Local fauna were also revealed in the diet including agave and yucca (Lillaes), sunflower (Asteraceae), elm and hackberry (Ulmaceae), acorns (Fagaceae), ocotillo (Fouquieriaceae) and candalia (Rhamnaceae). These findings demonstrate a degree of variety in meats and vegetation consumed by a hunting and gathering band within a brief period of time.

Similarly, NAs of the Northwest Pacific Coastal region used related means to identify historically significant native foods (28). Springbank clover (*trifolium*

wormskioldii) and Pacific silverweed (*Potentilla anseria ssp. pacifica*) are two historic edible roots linked to the diets and social culture of NAs in the British Columbian corridor of the Pacific Ocean. Similar uses for these crops have been found for Pomo and Yuki groups of present-day California. The leaves and roots of these two varieties were harvested twice a year. When the leaves darkened in response to an approaching winter, the crops were harvested and either consumed or dried for storage. In the following spring, the same sites were revisited to collect more roots. Gathering the crops was labor-intensive, as five hours of physical digging yielded three adequate servings of prepared product. Despite the effort and care required for harvest and preparation, these roots were important in terms of nutritive value, dietary diversity and overall palatability of the meal. Furthermore, the harvesting activities themselves served a social aspect for members of the tribe.

Comparable patterns of intakes have been noted in Native Canadian populations (18). High-protein, moderate-fat and low-carbohydrate diets were a result of fishing and hunting practices for survival. Seasonal conditions and wild game availability precipitated several bouts of famine for a group enduring harsh winters and great levels of physical exertion for daily tasks. Despite the arrival of fur traders, who introduced salted meat, flour, lard, sugar, tea and oatmeal, historical dietary practices remained strong until the 1940s.

Zawadiuk (29) reported traditional feeding practices for Northern Alberta Cree in the early twentieth century. Hunting and harvesting provided the necessary nourishment. Wild game (moose, deer, bear, beaver, lynx, groundhog, rabbit and skunk) and fish (pike, perch, walleye, whitefish and sturgeon) provided protein and fat while wild berries (blueberries, Saskatoon, cranberries, raspberries, chokecherries, strawberries, gooseberries and red and black currants) and nuts (particularly hazelnuts) provided carbohydrates and sundry nutrients. Preparation and preservation was

primarily performed by the females of the tribe. Meats and fish were boiled, fried, barbecued, baked, smoked or dried and ground to pemmican. Fats, entrails, blood and bones were also utilized for various purposes.

The Southwest also possessed hunting and gathering groups. Animal products provided the cornerstone of Diné (commonly known as the Navajo) and Apache high-protein diets prior to migration to the Southwest (25). Conservationalist ideals were used as all parts of the animals were utilized. For example, blood was used to make blood sausage, bones were boiled in stews to extract the marrow and organ meats provided iron and vitamin A. Upon arrival in the Southwest, these Athabascan tribes adopted the aforementioned Pueblo farming and Spanish-derived animal husbandry practices.

In the late 1920s, staple foods of Native peoples were identified through survey of half of the federal jurisdictions (30). Meats, fish, bread and beans served a primary role while fruits and vegetables supplemented intake through either farming or gathering of wild species. Eggs and milk products were, at this time, non-existent in Native diets. Current and traditional Diné diets are usually void of dairy products resulting in a compromised intake of calcium (31). Integrating Native foods into dietary habits has been shown to aid in nutritional adequacy (31;32). Traditional use of the juniper ash, baked into breads, improved the calcium, iron and magnesium intakes of seniors at a congregate feeding program in the Diné Nation.

Historical intakes by Great Plains tribes

Lowie (11) described accounts of the large game hunting practices of tribes of the Great Plains. Nomadic tribes typically relied on buffalo, deer, antelope and elk for food. Collective hunting practices, involving all community members, were more prevalent than smaller hunting parties. Four major tactics were used for the collective hunt – surrounding the game, diverting a group down a cliff, corralling and grass fire

surrounding. Horses were advantageous but not critical in the surrounding method, as the party would encircle a congregation of game. Once surrounded, the game would be shot, usually with bows and arrows. The grass fire technique shared similarities with the surround technique, substituting fire as the means of entrapment of the animals, driving them toward the anticipatory hunting party. Similarly, the driving method coerced the herd over a hill toward a group of waiting marksmen.

Interestingly, the impounding technique required greater preparation and insight (11). A field was prepared with strategically placed obstacles or individuals, channeling the game toward a corral. Once within the system, the animals would be driven into the corral by a grass fire or frightening by the hunters. Furthermore, a hunter dressed in calfskin, imitating a calf's cry, lured buffalo into the corral. The success of the hunt was contingent upon the ability to complete the system; therefore, a hierarchical, strict chain of command was often instituted. Fishing comprised a lesser percent of Plains Indians hunting practices, often reserved for when meat was scarce. Spearing was often used; some Iowa elders denied fish were caught any other way but by spearing. Crude basket nets or weirs were created to harness fish from streams and rivers for some groups.

Gathering practices were not isolated to agronomic tribes. Farming and hunting tribes (11) used the collection of berries, chokecherries and wild turnips, a prized food among several groups. Wild turnips were often dug up in the early summer by the women of the tribes, which required a great deal of physical labor. Once obtained, much of the harvest was peeled, dried and stored for winter. For the non-farming bands, non-meat products were obtained from nearby farming communities, as part of the bartering network, swapped for horses, pelts or goods acquired from Europeans.

Beans, squash, pumpkins, sunflowers and maize were the most common agricultural goods produced with maize being the most prominent (11). To the Pawnee, corn and buffalo were equally important cornerstones of the diet. Often fertile fields

were not available near encampments, requiring the women to travel as much as eight miles to harvest the crops, requiring warrior escorts for protection from enemy attack. Crops were harvested twice during the year. In early August, green corn was gathered, boiled, shelled and stored for future use. The last harvest occurred in late fall when fully-grown corn and other crops were retrieved. In addition to the preparation used in the earlier harvest, some of the crops were stored in eight-foot deep pits.

Transformation from traditional diets

Diets of Southwestern NA tribes have also undergone considerable change from historical intakes (8;25;26). Arid land adaptation and irrigation agriculture accurately depict the food procurement habits of Pueblo tribes of Arizona and New Mexico (25). Farming practices focused on raising corn, beans and squash, while sunflower seeds, onions, garlic and chilies were gathered to augment intakes. Consumption of corn and beans facilitate adequate nutriture, as they exist as complementary proteins, while the remainder of the diet was high in fiber, moderate in protein and low in fat.

Furthermore, relocation of many Native peoples from their homelands to ecologically dissimilar regions beginning in the mid-19th century triggered dramatic changes in food intake behaviors (25;26). Survival required the adoption of new foods and agronomic practices. For tribes that were removed from the homelands, dietary modifications were either a reliance on small game or the utilization of military rations of white flour, baking powder and lard (25). These were used by soldiers to make biscuits but were used by Natives to produce fry bread. Other foods provided included salt pork bacon, potatoes, beans, sugar, coffee and tea. For those tribes allowed to return to a portion of their native land, a return to traditional sustenance activities were impossible due to an altered physical environment.

Concerns have been expressed about the transition from a traditional diet, which is often perceived to be healthier, to a Westernized diet (17;32;33). Examinations of the

perceived ideal diets in three Yukon communities reported a two-fold greater number of traditional foods in the ideal diets as compared to actual intakes (17). Mothers and children from the Tallcree band in Northern Alberta had mixed perceptions about the health quality of traditional and non-traditional foods (33). Bannock and moose were traditional foods perceived to be most healthy while some store-bought foods (milk, carrots, apple) were also rated most healthful. Availability, taste and harvest time were found to be significant predictors of traditional food consumption in Nuxalk adults (32). For some groups, Native foods have been reduced to use during ceremonies or other special occasions (34).

The potential of traditional foods to contribute to daily nutrient intakes today is moderated by many factors. Political and economic factors dictate the specific foods that can comprise intake behaviors (17;25;26;32;34). Federal limitations on hunting and gathering practices restrict reliance on fishing and wild game (17;32). Seasonal variation and availability of plants and animals directly impact the food use of some Native groups (35). Furthermore, taste preferences were significantly correlated with the integration of traditional seafood, berries, wild game and plant roots in contemporary Nuxalk diets (32).

Wein (17) conducted an investigation of perceived ideal and reported intakes to be used in negotiations with Yukon and Canadian governments in fishing and gaming rights for Yukon Indian people. Hunting and fishing practices of the Ojibwa were confined to reservation allotments, with additional concerns regarding the transportation of food across state or reservation borders (34). In addition to the resultant reliance on federal food assistance, social interaction and cultural heritage have been crippled by the loss of traditional food harvesting and preparation practices (28;34).

An evaluation of Alaska Native women indicated a decreased reliance on traditional foods (22). Less than one-third of the 74 women recruited reported use of at

least one of the listed traditional Alaskan foods. The most commonly reported traditional food was salmon, as consumed by six women. Similarly, an isolated band of Cherokee retained a large proportion of their food procurement practices, with more than 80% of households using gardening, gathering wild foods and fishing methodologies; however, all households reported purchasing some foods from an external source (36). Despite the retention of traditional food procurement, preparation and preservation methods, Native foods were consumed less frequently. Some of the traditional foods, like pumpkin, chestnut bread, bean bread, hominy and black walnuts, have diminished to consumption only at special occasions or ceremonies.

Limitations on the use of non-traditional foods for groups living in isolated, remote areas also exist, resulting in a greater reliance on traditional foods, if available, for survival (17;37). Accessibility of communities to food and the costs incurred in transporting foods are critical factors in the amount and types of food available. An examination of the feasibility of food assistance programs in First Nations communities in Canada exhibited mixed abilities to meet needs with standard provisions (37). Program recipients in Vancouver could purchase foods for an adequate diet at a little less than 100% of the benefits, while the more isolated communities required costs at 130-180% of federal provisions.

Similarly, Native Miwok families in California as well as participants of the Food Distribution Program on Indian Reservations (FDPIR) indicated they would eat healthier if they had the necessary resources (38;39). Participants expressed an inability to procure food from the land due to federal restrictions on hunting and fishing coupled with a low level of awareness of local food assistance programs (38). Furthermore, the foods recommended by healthcare professionals were considered to be too expensive on a limited budget (39). Dillinger (23) found that underutilization of food assistance programs by eligible NA adults was attributed to a variety of factors, including the lack of

palatable or culturally appropriate foods, lack of knowledge about eligibility criteria, long waits for service, social stigma associated with assistance programs and physical impairments limiting ability to wait for disbursement.

Limited access to wild game and a greater reliance on store-bought foods precipitated a loss of traditional Miwok foods from contemporary diets (38;39). Many of the traditional foods, including acorns, venison, Indian tacos, salmon, pine nuts, beans and fry bread, were now associated with powwows and social gatherings. Therefore, lifestyle changes recommended by healthcare professionals, especially dietary modifications, must overcome the ingrained cultural centrality of food in social functions (39). Powwows and social gatherings are often centered on feasts that often include fried and high-sugar foods. Environmental changes, such as the restrictions on hunting and fishing and the feasibility and availability of foods, serve as formidable barriers to both individual lifestyle changes as well as improving the health status of NAs.

Various studies have indicated a transition from reliance on traditional foods to Westernized diets (19;20;32). Wolever (19) indicated that adolescents of an Ojibwa-Cree community in Northern Ontario reported a greater consumption of Western foods, including soda, pizza, french fries, hamburgers and potato chips, than their adult counterparts. Several Native foods were reported in the most commonly reported foods for those greater than 49 years of age while these foods were essentially absent in the list from adolescent intakes. Kuhnlein (32) reported that time constraints as well as the increased availability of market foods have moderated the transition from traditional foods in the last half-century. Cherokee youth surveyed in North Carolina reported little use of traditional plants or game (36;40). These findings are further supported by Murphy et al. (21) who reported an greater consumption of non-traditional protein and low nutrient-dense carbohydrates among Alaskan Eskimos and Athabascan Indians less than 30 years of age compared to those older than 60 years.

Interviews conducted with Native adults in the Yosemite-Mariposa region of California resulted in similar amounts of soda consumption with the Ojibwa-Cree and Cherokee (38). Soda consumption was on the rise with one-third of adults and one-quarter of children indicating drinking soda with meals. More than half of NA women surveyed in Minnesota reported frequent consumption of sugared beverages, including regular soda and sweetened fruit ades (41); younger, less-educated women were more likely to consume these beverages than their older, more educated counterparts.

Nutritional adequacy of Native American diets

Few comprehensive diet studies of contemporary NAs focus on regional or community specific data (18;42) and food intake of NAs is not well represented in national nutrition monitoring studies (43). The few recent studies that have been conducted reported that the diets of NAs are high in fat, saturated fat, sugar, and calories, low in fruits and vegetables, dairy products, fiber, complex carbohydrates, calcium, vitamin C, vitamin A, iron and zinc (16;42;44;45).

A few studies of Alaska Natives have been conducted that provided nutrient intake data (17;22;35). Nobmann et al. (35) found intakes of all nutrients but calcium significantly higher than Canadian national average intakes; however, diets of only half of the Native sample met the 1989 RDA for most nutrients. More than one-fourth of Native women had iron intakes <70% of the 1989 RDA. A considerable portion of men and women had inadequate intakes of vitamins A, C, thiamin and riboflavin. Dietary intakes from multiple 24-hour recalls from women with cervical neoplasms in Anchorage, Alaska indicated similar results (22). Mean intakes of calcium, magnesium, iron, zinc, folate and vitamin E did not meet the RDA, with less than one-fifth of the women consuming the RDA for folate. Though the mean energy derived from total fat was 31%, only 34% of the sample had total fat intakes contributing <30% of energy. More than

70% of the women had intakes of calcium, magnesium, zinc and vitamin E below the RDA

DeGonzague et al. (34) examined dietary intakes of two Northern Ojibwe communities in Minnesota and Wisconsin. Total fat and saturated fat provided 37% and 13% of total energy intakes for the pooled sample, respectively. Mean vitamin A intakes were inadequate to meet the RDA for men, while women consumed below recommendations for vitamin A, folate, calcium, iron and zinc. Nutrient intakes were compared for obese and non-obese participants as well as against mean intakes reported in the Second National Health and Nutrition Examination Survey (NHANES II). Overweight Ojibwa women had significantly higher intakes of total and saturated fat and significantly lower total carbohydrate, sucrose and calcium intakes than non-obese women. No significant differences existed between overweight and normal weight males. Compared to NHANES II participants, Ojibwa males had less desirable intakes of saturated fat, vitamin C, folate and dietary fiber. Ojibwa women had significantly lower intakes of carbohydrates and dietary fiber and greater intakes of total and saturated fats and protein. Furthermore, Ojibwa women also had less desirable intakes of vitamins A and C, folate and calcium for compared to national data.

Dietary intakes of 107 Lumbee Native women in Robeson County, North Carolina were reported by Bell et al. (46). Analysis of three-day food records indicated that 36% and 12% of total energy intakes were derived from fat and saturated fat, respectively, though mean cholesterol intakes were 207 mg per day. Intakes of total energy (1,500 kcals), calcium, dietary fiber, vitamin E, magnesium, zinc and iron were low.

To compare the impact of influence of Westernized diets on NA food intake behaviors, dietary intakes of 165 non-diabetic Pima were evaluated based on their self-reported adherence to a traditional diet (47). Protein and fat intakes were similar among women consuming traditional, Westernized and mixed diets; however, women

consuming a Westernized diet had significantly lower complex carbohydrates, insoluble fiber and vegetable protein than those consuming a traditional diet. No differences existed for men across the three intake patterns. Interestingly, Pima consuming an Anglo diet were 2.9 times more likely to develop diabetes within one year of follow-up than those consuming a traditional diet.

Ikeda et al. (42) found that 61% of NA women had "less adequately nourished" diets, which meant the diets provided less than the Recommended Dietary Allowance (RDA) for three or more nutrients. The mean energy intake of these NA women was 1,412 kcal and was lacking in vitamins A, C, E, and B_6; calcium; iron; magnesium; and zinc. Food assistance did not improve nutrient intake. Fruit intake was low with 60% of the women reporting not eating any fruit in the previous 24 hours. Vaughan et al. (45) reported similar results in Havasupai adults. Diets were similar between gender groups and provided 35% of total energy from fat, 12% of energy from saturated fat, and 14% of energy from sugar. Calcium, zinc and vitamin B_6 intakes were below the RDA for both genders.

Evaluations of dietary intakes by Diné participating in food assistance programs indicated inadequate intakes of energy, calcium, phosphorus, iron and vitamins A and C (48). Ballew et al. (44) supported these findings with a report of median intakes below the RDA for calcium, vitamins A, E, B_6, and folate in a group of reservation-living Diné women and men. Fruit, vegetable, and milk intakes were low with each being consumed less than once per person per day.

Assessment of Hualupai women's dietary intakes exhibited significant differences in energy and carbohydrate intakes between obese and non-obese women (49). Mean contribution of fat to total energy intake was 35% among all women, with obese women consuming 37% of energy as fat. Alcohol intake also significantly increased energy

intakes for Hualupai women (50). Despite the additional 41.2 g of alcohol per day, residual dietary intakes of drinkers and non-drinkers were relatively similar.

In all of these studies, the majority of subjects lived on a reservation. The only recent publication involving Oklahoma NAs was a result of the Strong Heart Study (SHS) conducted in southwest Oklahoma during 1988-1991 (51). Zephier et al. (51) reported that nutrient intakes of 892 NAs 45- to 74-years of age in southwestern Oklahoma were significantly lower than NHANES III data for energy, protein, carbohydrate, sodium, fiber and higher for percents of energy from total fat and saturated fat using 24-hour recall methodology. Mean energy intakes were estimated at 1,831 and 1,431 kcals for males and females, respectively. Dietary habits were considered to be a risk factor for heart disease and other chronic diseases with 37% of energy for males and 36% of energy for females derived from total fat. The SHS did not publish actual foods consumed. The present study will fill the void of missing recent data on nutrient intakes and core food consumption representing the non-reservation NA population in northeast Oklahoma.

Minorities are at increased risk for many diseases, including osteoporosis (35;52). Contributing to this tendency is an inadequate intake of calcium, which has been documented in various studies. Results of 24-hour recalls with Alaska Native adults indicated that nearly half of Native men and two-thirds of Native women had intakes < 70% of the RDA for calcium (35). Twenty-four hour recall data indicated that only 12% of Alaska Native women met the RDA for calcium (22). Lumbee women reported a mean intake of less than 500 mg of calcium per day from three-day food records (46). In addition to inadequate intakes, food selection habits further exacerbate risk in NAs (22;35;38;48;53;54). Low intakes of calcium are often linked to low intakes of milk products commonly attributed to lactose intolerance (22;48;49;53).

Food group intakes for Native Americans

Limited data are also available on comparisons of current NA food intakes to recommended Food Guide Pyramid servings nor are there data on comprehensive diet quality. Dietary assessments of Alaska Natives resulted in mean intakes below minimum recommended servings from all Food Guide Pyramid groups except the meat group (22). Fruit and vegetable intakes were low at 2.0 and 1.2 servings, respectively, with much of the fruit intake resulting from juice. Fruit and vegetable intakes were also inadequate for members of the Catawba Indian Nation in North and South Carolina (55). Nearly half of the sample consumed less than one serving of fruit per day and 98% consumed less than five servings of fruit and vegetables per day. Similarly, major sources of vitamins A and C for Diné participants receiving food assistance were fruits and vegetables (48); however, 68% had intakes of less than two servings per day.

Food patterning in Native American populations

Little is known about the perceptions, attitudes or beliefs of NAs in Oklahoma towards lifestyle behaviors, such as consuming a low fat diet, eating more vegetables and fruits, or healthy eating (56). Dietary habits and perception regarding what is healthy eating are influenced by cultural and social functions and need to be understood prior to development of programs attempting to improve dietary intake (28;57-60). One method of studying overall food habits is the food-patterning method by interviewing the target group and studying the beliefs and practices of interest. The foods that people typically eat are categorized based on frequency of consumption into core, secondary, and peripheral diet components (59;61-63). When designing a nutrition education intervention, core and secondary foods should be emphasized (64). The core foods, beliefs, and practices are categorized into neutral, healthy, less healthy, or uncertain, with healthy foods and beliefs being encouraged and the less healthy foods or beliefs being improved or dissuaded.

Food patterning has not been widely studied in NAs even though it is very important to know food patterns in order to plan nutrition education interventions (17;30;46;65). What has been discussed in the research literature is that traditional NA food consumption has decreased to peripheral food status but might be a more healthy alternative than Western foods (65;66). Koehler et al. (65) observed that the following were core foods in Diné and Jemez Indian children's diets: eggs, whole milk, tortillas, bread, cereal, pancakes, potatoes, bananas, citrus fruit, other fresh fruit, fruit juice, pop, fruit ade drinks, and chips and salty snacks. Ballew et al. (44) reported core foods for Diné including: Diné tortillas and fry bread; home-fried potatoes; soft drinks; coffee and tea; mutton and mixed dishes containing mutton; and bacon, sausage; lunch and canned meats.

Nobmann et al. (35) collected 24-hour recalls from 873 Alaska Native adults to identify a list of the most commonly consumed foods. Dietary intakes were remarkably similar to common foods reported in NHANES II. Coffee, tea, white bread, fish and margarine were the five most commonly reported foods, in descending order.

CULTURAL PERCEPTIONS OF HEALTH AMONG NATIVE AMERICANS

Economically disadvantaged and cultural minorities represent an underserved population in US healthcare (67). Gaps in health status between NAs and the general US populations are becoming increasingly wider as rates of various chronic diseases, including diabetes, are reaching epidemic levels (68;69). Over the last 3 decades, the rate of diabetes has increased 5.5 times and 2.5 times for NA women and men, respectively (23). Diabetes rates have risen to 40-50% of adults in some Southwest tribes (70;71). Attempts at ameliorating these health disparities may suffer setbacks as a result of varying worldviews between Native cultures and Western medicine (72).

Understanding cross-cultural differences in health perceptions is crucial to successful health promotion efforts in the NA population.

Cultural perceptions of health have been difficult to ascertain, especially when derived through the lens of Western ideology (67), as the need to alter a causative variable that precipitates disease is the cornerstone of Western medicine. Conversely, a NA patient may perceive a clinical condition as part of the natural progression of life (73). For example, to the Diné, deviation from *hohzoni* (internal balance) or witchcraft may be the source of an impeding illness (72). Therefore, in NA worldviews, personal health extends beyond physiology to an interaction of the individual with family, community and the environment (74). Cultural beliefs will also dictate the healthcare services sought. Utilization of biomedical services may occur secondary to traditional treatment modalities (67). Traditional ceremonies exist to relieve an individual from the disease or condition; however, symptoms are often left to other means of healing, often biomedical treatment. With this duality in mind, it is essential to approach health with respect to underlying traditional beliefs, values, attitudes and behaviors.

A multitude of interrelated factors play a synergistic role in the development of personal health perspectives in NAs (73;75;76). Judkins (76) reported several key determinants of lifestyle behaviors in the Seneca living on the Allegany Reservation in New York. In addition to the minority status of NAs, other attributes impart a synergistic bearing on health perceptions including geographic location, education, socioeconomic status, traditional beliefs and values, culture, and individual personality (76). Similarly, previous research identified certain characteristics considered to transcend tribal affiliation (73). Of particular interest in relation to health were several *commonalities* across tribes: individuals are responsible for their own state of health and they possess the ability to self-impose good health or unwellness. Additionally, an interrelation between unwellness and the mind, body and spirit is strong in the NA culture.

Understanding these key components and their subsequent impact on health perception is critical to understanding worldview differing from those of mainstream Western society, especially with regard to diabetes.

Indigenous approaches to health maintenance expand beyond the Western doctrine of the freedom from disease. Many common attributes typically exhibited through NA spirituality contradict mainstream culture and account for much of the divergence of health perceptions from Western pedagogy (73). These elements include the intense interrelation between spiritual forces and personal wellness. Balance and harmony of mind, body and spirit with one's family and environment are key determinants of wellness or unwellness in some NA groups.

Cultural perceptions of health and supported behaviors impact the identification, treatment and health care seeking behaviors for numerous diseases. To gain a better understanding of the role of cultural beliefs in asthma treatment in households with asthmatic children, qualitative interviews were conducted with 22 Diné families (77). Despite the chronic nature of asthma, respondents defined asthma as a series of discrete bouts of triggered reactions instead of the prolonged inflammatory state. Many families relied on emergency room visits for the most severe cases, indicating a delay of treatment until physical symptomology became severe. In the extreme cases, medication use was often delayed until extreme symptoms, such as physical discoloration (cyanosis), were evident. Therefore, a condition is not deemed significant unless there are physical signs of illness.

When trying to grasp a cultural perception of health, certain cultural attitudes are crucial to understanding the origins of these perceptions. The Diné culture perceives their world in constant motion (67). Thus, the resulting definition of health may likely be tied to one's interaction with their dynamic environment. These thoughts may also extend to deal specifically with the individual; one may express health in terms of things

being good or bad with them. In the event of a sense of disharmony, a traditional Diné may turn to a ceremonial intervention to return the cycle toward harmony with one's body, mind and surrounding environment.

Gender differences have also been identified when defining one's own health (78). Female Alaska Natives receiving treatment for alcohol dependency were more likely to rate their health as fair or poor while the men were more likely to consider themselves in very good or excellent health.

Methods of traditional healing practices among NAs have received scrutiny from practitioners of Western medicine (67). The strong interdependence of health and religion in the Diné may further complicate the matter of defining health. As mentioned earlier, many traditional Diné attribute disease or unwellness to witchcraft or other spiritual forces. Because biomedical science defines the same condition in physiological terms, institutional rejection of witchcraft may serve as impedance to care (67;72). This clash in worldviews may decrease the likelihood that prescribed lifestyle or therapeutic behaviors are fulfilled, resulting in the labeling of the client as non-compliant. NAs seeking services through the Indian Health Service (IHS) have been labeled as lazy and uncooperative (72). The underlying issue may be that the patient and provider are not communicating effectively to address specific cultural norms and values in care.

This disjoint in perspectives of health is also true in terms of adherence to a medication regimen for treatment of disease. Many Diné asthma patients rejected certain medication treatments for fear of side effects or development of a dependency for the medicine (77). There was a generalized distrust of the medication; many parents discouraged asthmatic children from medication during less severe episodes or in the absence of symptoms to "*teach*" the body to adjust to the condition and react to the symptoms. Through such behaviors, it was assumed that the disease would "*go away*" or they would "*grow out of it*." Consequently, for the NA population to be served

effectively in the prevention or treatment of disease, a thorough understanding of the cultural norms and values and their implications to care are needed to achieve effective communication and achievement of desired outcomes (67;72-74).

Furthermore, the responsibility for an individual's health lies solely on that person (73). An individual's needs should not be placed above the needs of the whole, which is in disagreement with Anglo culture. The consequences of this point are further exacerbated by the family structure inherent in NA culture. The health of an individual may further suffer when conflict arises between self-care behaviors and family responsibilities or the desires of the family. It is this competition between individual requirements for health promotion and conflicting needs for the family or community that introduce a considerable barrier to health promotion behaviors.

SUSCEPTIBILITY TO DIABETES AMONG NATIVE AMERICANS

Diabetes was not as serious a problem among the NA people in the early parts of the 20th century (21;79). Few cases were reported among the Diné before the 1940's (79). Indian Health Service (IHS) data from 1955 showed that 17 out 100,000 NAs had diabetes, which was only slightly higher than that of the general US population (13/100,000). This disparity became more pronounced by 1982, with a rise to 19.9/100,000 NAs diagnosed with diabetes (21) to become a significant health problem among NAs (30;80;81). Prevalence rates have become higher in NAs than in the general US population (71;81-83).

Based on IHS national outpatient data from 1998-1999, the age-adjusted prevalence rate of diabetes among NAs was estimated at 88.7/1,000 for people over the age of 15 years (81). Results from the Strong Heart Study reported rates between 33% and 72% from samples collected in Arizona, the Dakotas and Oklahoma (1). Rates vary among the different tribes and also by region. In Oklahoma, the age-adjusted rate for

diabetes was 60/1000 in 1987 (82). This means NAs in the Oklahoma City area, the largest area of the IHS (81), are 2.43 times more likely to have diabetes than the rest of the population (82). Lee et al. (70) observed in an Oklahoma sample of 1,449 NAs that 38% of NA men had diabetes compared to 42% of NA women. Diabetes was the fifth leading cause of death and accounted for 7% of all clinical impressions for ambulatory medical visits in the Oklahoma IHS Area (81). The number of deaths due to diabetes may actually be greater because Oklahoma underreports deaths of the Indian race (81).

National trends from 1990-1997 demonstrated that NA women (6.3%) were 1.4 times more like than NA men (4.5%) to have diabetes (84). Prevalence rates in Oklahoma in the Strong Heart Study were higher for NA women (42%) than for NA men (38%) over the age of 45 years (1). Zuni men younger than 45 years presented slightly higher rates than Zuni women, but rates among Zuni women over 45 years-old were nearly two-fold higher than their Zuni male counterparts (85). Furthermore, diabetes rates rise with increasing age. Rates for tribes in New Mexico ranged from 14% to 32% for adults over the age of 35 years (86) . Age-adjusted rates of diabetes have been reported as high as one-half of Pima adults in Arizona for adults over 35 years old (87;88).

CULTURAL PERCEPTIONS OF DIABETES AMONG NATIVE AMERICANS

Because of the pervasiveness of diabetes in the NA population, specific attitudes and beliefs have surfaced. Of these is the feeling of hopelessness or inevitability to developing diabetes (89,90,91). Lang (89) described the role of the social experiences of Dakota Sioux in the development of cultural perceptions of illness; the experiences of individuals within the tribe were used to collectively describe the experiences of the community and ultimately the cultural perceptions of health. Experiences and personal history have also been linked to beliefs about health and illness in Mexican Americans

(90); these experiences were ultimately manifested through social functioning and physical and mental health.

Kozak (91) conducted in-depth interviews with Pima Indians from the Gila River Indian Community (GRIC). The Pima present with the highest rate of type 2 diabetes in the world, with more than half of the population over the age of 35 years having diabetes. Forty of 44 participants indicated a feeling of inevitability of diabetes. One individual stated:

"Oh well, I'm going to get it anyway, so why bother [trying to prevent it]." (91, pg) Many addressed the futility of prevention, indicating prevention behaviors were a waste of time. These feelings have been described as "surrender" to diabetes; however, caution should be used in applying this terminology because it implies a passive approach to health. Though "surrender" would likely impair an individual's drive to take preventative steps toward diabetes, this surrender response was theorized to serve as an emotional defense mechanism against a disease that has inevitably become an everyday reality.

Similarly, Judkins (76) reported a fatalistic approach among the Seneca with a feeling of powerlessness in developing diabetes. Respondents from the GRIC expressed a fear of the morbidity associated with diabetes (91). Many perceived diabetes to produce a demeaning, painful death. Focus groups with NAs receiving benefits from the Food Distribution Program on Indian Reservations expressed a helplessness in their ability to modify lifestyle behaviors thought to be associated with diabetes (39). To these participants, guidance would be required on improving stress management, modifying negative lifestyle behaviors and invoking family support for healthy eating patterns if diabetes was to be prevented. Conversely, Womack (92) surveyed NAs in northern Minnesota in regards to their beliefs about the seriousness of

diabetes and impact of diabetes on their lives. Only 50% of the respondents felt diabetes was a very serious disease.

Differences in knowledge, beliefs and values towards health and diabetes are exacerbated by ineffective communication between the healthcare provider and the patient. As previously mentioned, these dissimilarities are often manifested during healthcare visits. Many NAs with diabetes communicate with many different providers throughout their treatment experience (72). The healthcare provider is considered the expert and often is not questioned, even if treatment regimens are difficult to understand or contrary to cultural beliefs. This lack of agreement typically precipitates a lack of following the treatment regimen, leading to a perception that the patient is passive or non-compliant.

Additionally, the difference between a biologically defined *disease* as opposed to an *illness*, with social and personal ramifications, may be an important mediating variable in diabetes treatment (67;72;77). In the absence of symptomology and long-term complications, diabetes exists as a fairly benign condition. On a positive note, Diné families reported use of several over-the-counter medications (including antihistamines, vitamins and acetaminophen) in the prevention or control of asthma symptoms (77). As asthma was defined as several distinct episodes, preventative methods were adopted to deal with a chronic condition, shedding hope for diabetes treatment and prevention.

Research with Mexican Americans reported that women judged the severity of diabetes by extent of physiological damage it caused (90). Diabetes then became a "scary" disease "because of all the damage." While measuring the cultural relevance of several diabetes education materials, concerns about diabetes for African American adults were strongly linked to emotional factors including fears about diabetes, denial, insulin therapy and required lifestyle changes (93). In African American women, diabetes manifested itself as physical fatigue (94). In 1981, Hopper (95) reported that

African American women felt that diabetes was not a serious disease and that medication alone would “cure” the disease. Most of the African American women believed that the lack of symptoms of diabetes indicated they no longer had diabetes.

Elevated blood sugar levels do not exert a physical feeling of discomfort; episodic occurrences of the physical symptoms are therefore not attributed to an underlying physiological state. Huttlinger et al. (72) developed a treatment strategy for the Diné to bridge these perceptions by discussing diabetes treatment as a metaphor of “*Doing Battle*.” The use of the metaphor provides an ability to distance oneself from the emotional aspects of a disease that holds one “prisoner.” The continuous surveillance of diabetes and experiences within the healthcare system were expressed as a series of battles in the war against diabetes. Available *weapons* in the fight against diabetes were religious devotion and adherence to diabetes treatment protocols. Introducing such coping strategies was key in helping a group feeling *powerless* to control their diabetes.

As culture plays a considerable role in determination of worldviews and perceptions of health and diabetes, understanding the level of subscription to cultural traditions is important in diabetes prevention and health promotion efforts (73;96). Varying beliefs and practices within and among tribal groups contradict a universal approach to healthcare with NAs, commonly attributed to varying levels of the adoption of mainstream culture (97). To address this continuum of acculturation, five levels independent of degree of Native blood have been described (97). These levels include:

- **Traditional** – strongly holds traditional thoughts and values
- **Marginal** – does not fully adopt traditional values while also not fully accepting mainstream culture
- **Bicultural** – accepted and function in both the mainstream and cultural societies
- **Assimilated** – complete adoption of mainstream values

- **Pantraditional** – an assimilated Native American making a conscious commitment to lost traditional values

Garrett and Pichette (97) developed and validated the NA Acculturation Scale to identify the degree of acculturation. Understanding one's position in this continuum provides insight into the worldviews and self-perception, which are key to providing appropriate and efficacious rehabilitation services.

CHALLENGES TO NATIVE AMERICAN HEALTH CARE

The Indian Health Service (IHS) from the US Public Health Service, Department of Health and Human Services (DHHS) was formed to provide health services to the greater than 550 federally recognized NA tribes in the US as a result of the cession of land, less the reserved tracts retained for NA habitation (4). Presently, IHS serves approximately 1.5 million of the 2 million NA and Alaska Native population (5). Services are rendered either directly from the service units, IHS hospitals, health centers, and health stations or from tribally run programs that receive contractual support from the federal level. Furthermore, all IHS and tribal hospitals are fully accredited by the Joint Commission on Accreditation of Health Care Organizations (JCAHO).

Upon its establishment in 1955, the IHS was charged to provide health care services to eligible NAs in the US (9). Criterion for eligibility were established as those of NA descent residing within an Indian community or those possessing evidence of certified enrollment with a federally-recognized tribe or other relevant criteria as established by the Bureau of Indian Affairs (BIA) (4). The lines of ambiguity for eligibility have surfaced, as the criterion for tribal enrollment has become more diverse (5).

As an act of assertive commitment, in 1976 Congress amended its previous obligation to NA health care in a statement of legal responsibility to promote optimal health via provisions to meet all necessary resources to achieve this goal (4). However,

twenty-five years later, Congressional appropriations are failing to meet the calculated needs by 25-50% (5). Despite a 10.7% increase in the service population in the early 1990's, the appropriated budget for this period increased a disproportionate 2.5%. This creates a great disparity between established goals and functional outcomes due to financial limitations.

The Indian Health Service was not designed to be the sole source of funding for health care services (4;5;98). Clientele are encouraged to seek support from appropriate programs for which they are eligible, including private insurance, Medicare and Medicaid. Regulations require the exhaustion of third-party funds prior to the procurement of IHS funds to cover the costs of care. Furthermore, the increasing service population and the complexity and diversity of health care needs place further strain on a scant budget (99). With limited funds, IHS must prioritize which services will be delivered internally and which will be provided contractually from the private sector, mimicking issues in managed care organizations. Tribal clinics are often reluctant to unite with existing provider networks in fear of loss of tribal sovereignty in health care arenas (98).

Much of the recent health care reform has involved changes in federal programs, such as Medicare, Medicaid and welfare occurring at the national and state level (5;99). Heretofore, tribal relations have been manifested as nation-to-nation interactions with the federal government, leaving relations with state government untested or adversarial (4). NA populations express concern that access to existing health care services may be threatened as a result of state-based Medicare reform (5). State level reform has focused on increasing the level of managed care that is incongruous with the current IHS decentralized health care system (9). These efforts may weaken NA access to health care from existing sites if the criterion for inclusion into the Medicare system is not revisited (5).

To illustrate this point, the proposed criterion for managed care source providers include specified levels of dollar reserves for the care of patients, 24-hour availability of services rendered and hospital privileges for staff physicians (5). A required movement of clientele from the IHS network to managed care may unnecessarily circumvent the availability of culturally appropriate care (98). An enduring strength of the IHS system is its ability to provide services in close proximity to non-urban populations (99), which may not sustain appropriate funding for either the cash reserves criterion or the hours of operation (98). It has been suggested that Joint Commission accreditation could serve as an indicator of quality care at an acceptable level for inclusion into state Medicare coverage (5;98).

As a result of the challenges required of service providers designated through the Medicaid system, Washington state implemented programs that automatically exempted and Oregon automatically enrolled NA clients into managed care programs (5;98). For individuals expressing intent to opt-out of assigned care, services may resume within the IHS network. Efforts such as these permit delivery of optimal, culturally sensitive care to the target population while lessening the burden of a taxed fiscal budget by increasing third-party reimbursement for services rendered.

An additional challenge faced by IHS is the provision of services through the Urban Indian Health Program (UIHP). Sixty percent of the NA population resides in non-reservation urban areas but accounts for only 22% of the IHS operating budget (8;99). The existing focus on reservation-based health centers indicates a need to revisit the commitment made to NA health care. The barriers experienced in outreach to the urban population are similar to those of reservation-based programs, including availability of specialty services, eligibility disputes, state health care reform and culturally sensitive and appropriate health care. This concern is perpetuated by the historically

disproportionate level of funding each region receives which only recently has been shifted toward a need-based formula for disbursement.

ECONOMIC IMPACT OF DIABETES.

Rhoades et al. (100) estimated 882 years of productive life lost among NAs due to diabetes mellitus itself. Besides the decreased longevity and quality of life due to diabetes, there are fiscal ramifications to increased rates of diabetes. Total health care costs of diabetes treatment have been estimated at $44.1 billion in 1997 (101) and up to $100 billion when including direct costs of diabetes treatment plus the indirect costs of diabetes, including lost productivity due to morbidity and lost years of life (102;103). In a 1994 study, healthcare costs for treatment of patients with diabetes was 2.4 times greater than control subjects, with 38% of the expenditures going toward long-term complications (102). A Monte Carlo study of patients with diabetes indicated that intensive control of blood sugar levels could result in an annual 3% reduction in healthcare costs for treatment of complications (101). The Oklahoma Behavioral Risk Factor Surveillance Survey (BRFSS) data demonstrated significantly greater number of days of disability and poor physical health for patients with diabetes compared to controls that did not have diabetes (103). This has ramifications for productivity at work. Therefore, success at delaying or preventing the onset of diabetes will delay the rising costs of diabetes treatment and prolong one's potential to be a contributing member of the economy.

RISK FACTORS RELATED TO DIABETES

A critical review completed by the American Diabetes Association (104) explored the potential of diabetes prevention efforts to successfully curb the rising rates seen in the US and worldwide. The report cited the inability of early, poorly designed studies to

precipitate appreciable improvements in glucose control or resultant macrovascular complications to cloud the potential for lifestyle interventions and drug treatment in diabetes prevention programs. Recent larger clinical trials, including the Diabetes Prevention Program (105-107), Finnish men's study (108), Troglitazone in Prevention of Diabetes (TRIPOD) (109) and the STOP-NIDDM trial (110;111) provide solid evidence for the role of lifestyle interventions and medication in diabetes prevention efforts.

Blood sugar levels below the cut-point used for the diagnosis of diabetes (now called pre-diabetes) have been shown to be related to increased risk for cardiovascular disease (104). The Finnish men's study randomized middle-aged, obese men with pre-diabetes into either the brief diet instruction (control) group or an intensive lifestyle intervention group (108). Lifestyles targeted through intensive counseling included achieving a healthy weight, improving dietary intake and increasing physical activity levels. Similarly, the Diabetes Prevention Program enrolled slightly younger obese adults with pre-diabetes for either a lifestyle intervention (nutrition and physical activity counseling), metformin or placebo group (105-107). Both of these interventions included the use of time-intensive and cost-intensive interventions in measuring the impact of modifying lifestyle behaviors to prevent or delay the onset of diabetes. Therefore, the extent to which these interventions can precipitate an appreciable change in diabetes risk in the general population is yet to be determined.

Similarly, a technical review by the American Diabetes Association investigated the lifestyle behaviors related to the development of diabetes that should be considered in diabetes prevention programs (112), including weight loss, physical activity and dietary intake. Though obesity reduction efforts have presented a challenge in health promotion research, a decrease in body weight has produced decreases in diabetes risk. Lifestyle interventions should target sustained weight loss efforts, with a goal of body mass indices (BMI) of 25 or less. In addition to the role of obesity in diabetes risk,

moderate physical activity produced a protective effect against diabetes risk and mortality from hyperglycemic complications. Performance of regular physical activity appears to impact diabetes separate from that of energy balance (112).

Specific dietary components may also play a role in the prevention of diabetes though not all are fully understood (108). Current evidence suggests a direct relationship between total fat and saturated fat intakes in insulin sensitivity may be accounted for by their contribution to overall energy intake. An inverse relationship has been proposed between regular consumption of whole grains and dietary fiber and incidence of diabetes. Limited and equivocal data are available linking alcohol consumption, cow's milk and many micronutrients to diabetes. Additional research is needed to further elicit the impact of dietary fat, whole grain intakes, micronutrient intakes, alcohol and cow's milks on diabetes risk.

Extensive investigations have explored the relationships between various lifestyle behaviors and the increasing rate of diabetes in NAs, which provides valuable information for diabetes prevention programming (24;113-119). Haffner (113) reviewed various epidemiological investigations of diabetes in NAs to summarize several key risk factors, including ethnicity, obesity and insulin insensitivity as risk factors for diabetes. Others have suggested that genetic, familial and other lifestyle factors, such as lack of physical activity and high-fat intakes are associated with the rate of obesity and diabetes in the NA population (24;114-119).

Lifestyle behaviors, including decreased exercise and elevated energy and fat intakes, have led to an increase in obesity (24;114). Obesity is a risk factor for diabetes (114) and today many NAs are obese (16;24;83;119;120). Obesity rates have been classified as an epidemic among the NA people (24;121). Nationally, Behavioral Risk Factor Surveillance Survey (BRFSS) data suggest rates of obesity around 34.4% in NA adults (120). Obesity rates have been reported to be in excess of 70% in NA women

between the ages of 35 and 64 years in three communities in northwestern Ontario (122). Kimball et al. (123) reported rates of obesity at 45% and 43%, for NA men and women, respectively over the age of 15 years in Washington state. Despite the fact that 85% of those who were overweight had considered themselves to be overweight, only one-third of these individuals said a health professional had suggested they should try to lose weight. In Oklahoma, Lee et al. (70) found that 70% of NA adults were obese and that the rate of diabetes increased as the body mass index (BMI) increased.

Birth weight and the intrauterine growth environment have also been related to insulin resistance and rates of diabetes in NAs (115;116). Periods of feast and famine coupled with transformation to a high-carbohydrate, high-fat diet – as a result of the reliance on US commodities – were experienced by NA during the last century, as previously discussed. In an attempt to replicate the physiological ramifications of past US public policy, Martin et al. (115) employed a rat model to simulate the changes in dietary intake as a result of movement of the NA groups to reservation lands. Rats in the experimental group were malnourished during pregnancy; the offspring were fed either normal, isocaloric (N) or high-energy, high-fat (HF) diets. A third generation of rats was raised on either N diets or the HF diets. Second generation rats demonstrated depressed insulin responses to a glucose challenge; however, third generation rats presented with a significantly greater insulin response to a glucose challenge and significantly elevated body weight. Exacerbation in insulin response was 30% greater in third generation rats fed the HF diets than in third generation rats fed N diets. Similarly, studies with the Pima demonstrated significant U-shaped relationships for insulin resistance with birth rates; rates of diabetes were higher among adolescents and young adults who were low birth-weight (<2.5 kg) and high birth-weight (>4.5 kg) than normal weight (2.5-4.5 kg), supporting an assumption that *in utero* deprivation could result in alterations later in life (116).

Several theories have circulated regarding the rise in the rates of obesity and its resultant increase in chronic diseases. The term “Comod Bod” was termed to describe the changes in body weight thought to result from the federal food assistance programs that provided high-fat, energy-dense, low-fiber foods to NAs in the US (24). Consumption of commodities in conjunction with decreases in physical activity may have accounted for the rapid rise in obesity rates (24). Significantly higher protein (OR=1.38, 95% CI: 1.04-1.83) and significantly lower fiber intakes (OR=0.61, 95% CI: 0.39-0.94) were found for newly diagnosed NA adults than adults without diabetes from the Sandy Lake region of Canada (124). A chart review of NAs with diabetes revealed that consumption of high-fat, high-sugar diets were significantly related to elevated glycated hemoglobin (Hb_{A1c}) values (125). Additional research is needed to identify the role of contemporary dietary trends in chronic disease prevention and treatment in NAs.

Physical activity and diet are two lifestyle behaviors that play a role in the development of obesity (126). If in fact the epidemiological transitions from historic lifestyles to more Westernized diet and physical inactivity patterns have precipitated increased rates of obesity and diabetes, research with groups experiencing this transformation may provide valuable information to understanding this phenomenon (118). Kriska et al. (118) reported significant negative relations between physical activity levels (occupational and leisure) and physical fitness with insulin concentrations in men from an isolated Native Canadian community while controlling for age, BMI and waist circumference. Similarly, comparisons of Mexican Pima and Arizona Pima, which historically were one group, showed four-fold greater amounts (and intensity) of occupational physical activity in Mexican Pima in the past year than for Arizona Pima (127). Increased rates of physical activity in the absence of remarkable differences in food intake resulted in obesity rates below 20% for Mexican Pima as compared to 69% among the Arizona Pima. More than half of urban NA women in Minnesota reported no

strenuous physical activity during a typical week and only a third indicated mild exercise at least 6 days a week (41). Barriers to increasing physical activity included impairments in health status, lack of available child care, concerns regarding safety and lack of will power to initiate regular activity.

Furthermore, heredity has been linked to increased rates of obesity and diabetes in NAs (119;128). Rates of diabetes among NAs in southwest Oklahoma were significantly related to parental diabetes status (119); rates increased two-fold for individuals with two parents (17.9%) with diabetes as compared to those whose parents did not have diabetes (9.9%). Independent of weight status, individuals with siblings that had diabetes were twice as likely to have diabetes as those who had no sibling with diabetes. With regards to the degree of "Indianness," the percent of NA blood was positively related ($P<0.0001$) to both rates of obesity and diabetes. The varied rates of diabetes among different tribes, especially among those from the East compared to the Southwest, was considered a result of the mixing of the gene pool with non-Native blood (69)

Another theory for the rise in obesity and subsequent chronic diseases was proposed in 1962 (117). Neel advocated the role of the "Thrifty Genotype Theory" in the development of the milieu of physiological changes causing diabetes in those with a "diabetic genotype." Periods of "feast" and "famine" experienced by NAs during periods before contact with whites resulted in a metabolic adaptation to overcome periods of food shortages. This adaptation primarily involved an increase in the quantity and effectiveness of insulin during times of "feasting" to produce greater reserves — in the form of glycogen and adipose tissue — for times of famine (69;117). Furthermore, the levels of insulin released during feeding have been considered to exceed the threshold concentrations capable of inducing cellular insulin receptor down regulation in muscle and adipose tissue (69;129). This "quick insulin trigger" in conjunction with depressed

receptor availability suggests that the inhibition of fatty acid release from adipose tissue may be a resultant change from the enhanced insulin response which accounts for the rising rates of obesity in the NA population (69). Despite the various theories presented, a great deal of controversy exists regarding the merit of the "thrifty genotype theory" (88;129;130).

In light of the mounting literature, the question of the potential for diabetes prevention efforts to alter the rising rates of diabetes in NAs needs to be addressed. Five specific criteria have been proposed to determine if disease prevention efforts are merited and likely to provide laudable results (104). First, the disease must exhibit a considerable burden to public health for consideration; diabetes has reached epidemic proportions in many NA communities therefore it warrants prevention interventions (30;80;81). Substantial information surrounding the etiology and risk for disease should be available. Epidemiological and intervention studies have identified risk factors related to diabetes risk, which will be discussed further below (112). Further, ample means to monitor pre-disease states must be available. In terms of screening, the use of fasting and 2-hr glucose values serve as credible sources of progression toward diabetes (104).

Finally, the safety and effectiveness of intervention methods required for disease prevention should outweigh the risks assumed in participation. The aforementioned clinical trials (105-111) achieved at least a delay in diabetes onset in as little as 3 years (105-107). Lastly, preventive interventions need to involve a non-cumbersome, cost-efficient manner of identifying at risk subjects that could include diabetes screenings (104)

DIABETES QUALITY OF LIFE ISSUES

Uncontrolled diabetes can cause inordinate damage to body tissues, leading to a compromised quality of life (125). The elevated risk for diabetes among the NA

population has also precipitated an increased rate of its long term complications (2;125;131). Data from the mid-1980s demonstrate a four-fold greater age-adjusted mortality rate for NAs than for US adults (132). Mortality rates from diabetes varied greatly for NAs in various regions with Alaska possessing the lowest (10 per 100,000) and Arizona (Tucson and Phoenix – 93 and 78 per 100,000, respectively) presenting the highest rates. The Oklahoma IHS service unit fell in the middle with an age-adjusted mortality rate of 34 per 100,000. IHS data from 1996 indicate similar trends; however, the age-adjusted rate in Oklahoma rose to 38.1 per 100,000, though it remained below the nation IHS rate of 46.4 (133).

Data are accumulating on the rising rates of long-term complications of diabetes among NAs. Freeman (131) reported prevalence rates of retinopathy (1.7%) and end-stage renal disease (ESRD – 1.1%) among NA adults with diabetes in 10 reservations in Washington, Oregon and Idaho. Men were twice as likely to develop ESRD or require amputation while women were more likely to develop diabetic retinopathy. In Oklahoma, incidence of diabetic retinopathy was 72.1% and 72.7%, respectively, for females and males after follow-up (134); rates were significantly related to fasting plasma glucose, presence of hypertension, initial treatment (oral agents), age and duration of diabetes.

Rates of lower extremity amputations (LEA) not related to physical trauma were directly related to age in a cross-sectional examination of four IHS areas in the southwestern US (135). Phoenix (203 per 10,000) and Tucson (240.8 per 10,000) IHS services areas had consistently higher age-adjusted rates of LEA's among patients with diabetes than the Oklahoma (87.3 per 10,000) or Navajo (74.0 per 10,000) service areas. Annual age-adjusted rates of all LEAs were slightly higher in Oklahoma than in the entire US (73.1). A similar report estimated prevalence rates of 400 per 10,000 among NA adults with diabetes in 10 reservations in the Pacific Northwest (131).

Based on a concerted effort between the Centers for Disease Control and Prevention (CDC) and IHS (2), a two-fold increase in the number of NAs beginning ESRD treatment was found between 1990 and 1996. Age-adjusted rates of ESRD increased 24% over this period, with a greater incidence in women (32%) than in men (14%). Native Americans presented with higher age-adjusted incidence rates (584 per 100,000) than for the US population (278 per 100,000) for ESRD. Risk for macrovascular complications (ischemic heart disease, cerebrovascular disease and peripheral vascular disease) was significantly associated with diagnosis of diabetes among Canadian Mohawks, with a six-fold greater risk among those with diabetes (136).

TOOLS TO ASSESS DIABETES RISK AND QUALITY OF LIFE

The use of qualitative measures as the foundation for quantitative measures has been documented and successfully implemented (137-139). Various tools have been created to assess knowledge and attitudes about diabetes (14;92;94;139-145); however, the primary focus for each of these tools has been those who already have diabetes. Other tools have focused on the locus of control issues for diabetes control, including the Diabetes Locus of Control (DLC) (146), Confidence in Diabetes (CID) Scale (147) for those with type 1 diabetes and the Diabetes Activities Questionnaire (TDAQ) (148). Garcia et al. (143) developed a diabetes knowledge questionnaire in Spanish for Mexican Americans with type 2 diabetes with a focus on self-management of disease. Similarly, the Insulin Management Diabetes Self-Efficacy Scale (IMEDSES) was developed to address self-management scales in Hispanic adults (149). Many instruments have been developed to address care and support for patients with diabetes (150-153) but a recent literature search indicated existence of no such assessment tool focused on diabetes prevention and healthy lifestyles in NA adults.

Womak (92) revised an existing questionnaire to target NA adults, but, like the other existing tools, it measured the attitudes of individuals with diabetes. This instrument measures attitudes regarding special training for diabetes care, patient compliance with care plan, seriousness of diabetes, correlates with care and long-term complications, impact of diabetes on the individual, autonomy of the patient and team care practices. Half of the participants perceived diabetes to be a serious disease while 10% felt long-term complications would prevail despite well controlled blood glucose levels.

The proposed research targets an underserved population in an attempt to identify cultural beliefs that can be addressed in interventions to modify lifestyle behaviors to lower the risk of developing diabetes.

CULTURALLY EFFECTIVE NUTRITION EDUCATION PROGRAMMING

Epidemiological data have demonstrated several notable changes in NA health over the last few generations (18;23;25;51). Previously negligible rates of obesity and diabetes have dramatically swelled into an emerging epidemic for Native peoples. Due to the multifactorial nature of diabetes, the increased prevalence of diabetes in Native peoples has been attributed to modifications in food intake behaviors, food selection and decreased energy expenditure with a concomitant genetic predisposition (27;47). Many historical and political forces have precipitated the aforementioned lifestyle behaviors (33;51;154).

Ingenuity and resilience has been a cornerstone of Native culture in the Americas (26;32). Survival is hinged upon lifestyle changes compensatory to the environmental conditions requiring accurate assessment of dietary behaviors for successful programs (155). Understanding community dynamics and food use practices based in culture will aid in successful education interventions (32;33;155;156). Formative research

endeavors can provide valid data that examine all the contexts surrounding food availability and intake particular to the community of interest to promote personal and environmental changes (156). For programming efforts to be successful, several issues, including legislation, changing demographics, employment trends, acceptance of traditional foods and cultural and social traditions linked to procurement and preparation, must be factored into the equation (34;156).

Nutrition education interventions must be targeted toward a specific group and built around the variables or mediators that influence behavior change (157-159). Steps to identifying disparities in health perceptions and worldviews are essential in health promotion and diabetes prevention programs. As found within this discussion of health and diabetes, a predominantly Diné-based explanation has shaped the current knowledge of health perceptions among NAs. Research exploring NA health and wellness needs to branch beyond the few tribes to represent the many. Furthermore, we must step past the reliance on the "captive-audience" of reservation-living people and address those living in non-reservation or urban areas.

Programs targeting specific dietary intake behaviors have been successful at achieving better health outcomes (160-164). An intensive, interactive training of newly diagnosed diabetic patients precipitated less weight gain at 12 month follow-up (160); however, blood glucose levels improved from a mean 258 mg/dL to 170 mg/dL following dietary counseling. Specific dietary behaviors were targeted, including sugary-beverage consumption, food selection, portion-size control and the consumption of fat, fiber and starch, using positive messages and hands-on practice with foods. As well, Pelican (161) reported positive, yet non-significant, improvements in meals served in the elderly nutrition, Head Start and school lunch programs after an intensive lecture series with program cooks. Guidance in preparing culturally appropriate foods in a healthy manner precipitated a feeling of service to their people.

Data from a pilot study for lifestyle intervention in obese Arizona Pima adults without diabetes demonstrated better outcomes from less-rigid program guidelines (165). Volunteers were randomized into the structured physical activity and nutrition intervention program (Pima Action, n=47) or a self-directed lifestyle program (Pima Pride, n=48); volunteers (n=35) not willing to undergo randomization into groups served as observational controls. Improvements in amounts of physical activity were found for both groups at 6 and 12 months of follow-up, while the Pima Pride group achieved significantly improved energy, carbohydrate and fat intakes by 6 months; only reductions in starch intake persisted to the 12 month follow up. After one year, significant increases in body weight, BMI, and 2-hr insulin and glucose were found in the Pima Action group; Pima Pride participants presented significantly lower waist circumferences at 12 months. Participants in the Pima Action group reported that adherence to program protocol was improved with the support of peers, the provision of cooking classes and nutrition education concerning the fat content of foods. Less structured health promotion and nutrition education programs that foster social support may provide more desirable results among NA groups when trying to improve lifestyle behaviors.

In addition to the identification of the key factors related to diabetes, researchers must assess the impact of the research process on the target population. A storied history of misuse and abuse from outsiders has spurred many tribes to enact various forms of guidelines and restrictions on research efforts with the tribes (15). When cultural differences are not appreciated, efforts produce ineffective results for both parties. Because of previous issues in NA research, the Indian Health Service has developed stringent guidelines for the scrutiny of research protocols within their jurisdiction (16).

Recent reports have explored approaches in cooperative research efforts to facilitate a win-win situation (3;15;73;74;96;166-169). Davis et al. (15) promote a

participatory research approach when working with NA groups to foster involvement in the process and key decisions about how to proceed. A multi-site obesity prevention program, Pathways, was founded upon this principle; open lines of communication with the tribes were used before, during and after collection to better facilitate a reciprocal relationship. Similar approaches have been used with a Mohawk community (170) which resulted in the development of a Research Code of Ethics (171). Within these guidelines were strategies to address the extent of incorporation of cultural values and norms, collaborative partnerships and obligations for the researchers and the stakeholders and descriptions of control and dissemination of the data. Paramount to this procedural guide is the informed status and active participation of the communities in data interpretation. Scientific research publication is completed only after final approval is provided by the advisory committee of the participating community; disagreements in content and interpretation must be resolved prior to submission. An in-depth review of published works regarding various health promotion and diabetes prevention efforts (3;59;172-175), in addition to the descriptions of participatory research, should be conducted prior to the development and implementation of such programs within NA communities.

CHAPTER III

METHODS

OVERALL PLAN AND DESIGN

This descriptive study was divided into three phases. Phase I involved the collection of food intake data for the generation of the most frequently consumed foods in Native American (NA) women. Phase II involved qualitative inquiry of NA women to obtain a cultural perception of health, diabetes and a healthy diet. The questioning route was drafted to identify a cultural definition of health and diabetes utilizing grounded theory as discussed by Corbin and Strauss (176). A description of the cultural perceptions of health and risk for diabetes and an explanation for these perceptions was developed. Phase III involved the generation of a theory from the qualitative interviews that was used to develop a diabetes prevention assessment tool. The assessment tool was then judged by a panel of experts. Once appropriate revisions were made, the assessment tool was administered to NA in Oklahoma to evaluate the validity and reliability of the instrument.

All portions of the research protocols were reviewed and approved by the Institutional Review Board at Oklahoma State University (Appendix A). Data were collected in coordination with the Iowa (Perkins, OK), Pawnee (Pawnee, OK) and Kaw (Newkirk, OK) tribal clinics. Letters of cooperation are included in Appendix B. All participants in each phase represented a convenience sample and provided informed consent prior to participation.

PHASE I

Participants

Women of at least one-quarter NA (NA) blood, between the ages of 25 and 65 years of age, who were not pregnant or lactating, were eligible for inclusion in this portion of the study. A diagnosis of chronic disease, including type 2 diabetes mellitus, did not prevent inclusion. However, individuals diagnosed with other chronic diseases that impact dietary habits, including those receiving cancer treatment, were excluded from participation.

Methods and Materials

Collection of the 1-day food list Seventy-four women were recruited from three Northeastern Oklahoma tribal clinics: Kanza (Kaw) Health Clinic in Newkirk; Pawnee Tribal Clinic in Pawnee; and Iowa Tribal Clinic in Perkins to complete a 1-d food list, a non-quantitative 24-hour dietary recall.

Potential participants were identified through and interviewed at congregate meal sites, tribal health center activities and mobile exam screenings. Advertisement of Phase I activities was conducted by the tribes, including fliers and articles in tribal newsletters (Appendix C). After the potential participants were screened for the aforementioned criteria, they were read a verbal script identifying the interviewer and the purpose of the interview. The initials of the participant on the recording form demonstrated informed consent (Appendix D). Demographic information collected included age and prior diagnosis of type 2 diabetes mellitus.

Three trained research dietitians completed the interviews. The coordinating dietitian was a PhD, RD who trains students to conduct food intake recalls. All interviewers were registered dietitians with one dietitian being trained by the National Institutes of Health to conduct food recall interviews with another NA population. Twenty-five women from Iowa and Pawnee tribal health clinics and twenty-four women

from the Kaw tribal clinics were recruited to complete a modified multiple-pass 24-hour recall (43), less the quantification of portion sizes. Twenty-four hour recalls are less reliable for estimating individual nutrient intake but are useful for group analyses (177). Identifying the foods most commonly consumed was the primary goal of the exercise and nutrient analysis was not an objective; therefore, portion sizes were not collected.

Data from the Pawnee tribal congregate meal site was conducted on a Monday to ascertain foods from a weekend day as well as avoid bias in recording foods received from the same meal program. The food lists obtained from the other tribal clinics were obtained mid-week. Each woman was asked about all foods and beverages consumed in the past 24-hr period. Probes were used to elicit condiments and additional foods commonly forgotten consistent with the protocol of the multiple-pass method (43;178). Upon successful completion of the 1-day food list, participants received $15 incentive.

For a cross-referenced evaluation of the list of commonly consumed foods reported by NA women in Oklahoma, an analysis of the 1994-96 Continuing Survey of Food Intakes by Individuals (CSFII) was conducted using NA women between 25- and 65-years of age. The CSFII data set contains data for only 108 NA with only 28 being women in the same age classification as used in the Oklahoma study (178). Food data in the CSFII was provided using two non-consecutive multiple-pass 24-hour recalls for all but two participants. These two women provided only one day, resulting in a total of 54 days of food intake for the CSFII analysis.

Data Analysis

Generation of the most commonly consumed foods of NA in Oklahoma

Data from the 1-d food lists were entered into Microsoft Excel (Microsoft Corporation, Redmond, WA) and imported into SPSS (version 10.0, SPSS Inc., Chicago, IL) for frequency analysis to generate a list of the most commonly consumed foods among NA women. This list was used in Phases II and III of the study. To better understand food

consumption patterns, foods of similar nutritional content and food type were grouped; however, foods differing in fat and sugar content were left separate for frequency analysis. Two of the three interviewers evaluated the congregate list of foods from all three tribes, identifying foods with similar composition in regards to fat and sugar content. Combination foods (i.e. green salad, sandwiches and stews) were analyzed as whole foods and not as individual components.

Discrete food groups were created after consensus was reached. For example, all artificial sweeteners (i.e. Equal and Sweet 'n Low) were combined into an artificial sweeteners category. Chicken intake was divided into a fried chicken category (i.e. fried chicken and chicken wings) and a chicken category (i.e. baked or boiled chicken). Butter and margarine were combined to table fats while sour cream and mayonnaise were also grouped together as a "mayonnaise and sour cream" group.

Frequency analysis was completed with the pooled sampled from all three tribal clinics and were displayed in order of descending count using previous research as a guide (179;180). The incidence of food consumption was counted for each eating occasion, without regard to quantity. For example, if coffee was consumed with breakfast, lunch and dinner, coffee would provide a frequency of three. In an attempt to identify the fifty most commonly consumed foods, a threshold of the food being consumed by the Oklahoma NA women five times resulted in a list of 53 commonly consumed foods. Therefore, foods reported at least five times from the total sample were considered among the most frequently consumed foods from the 74 days of food intake.

Creation of the food image cards Food image cards were made using the food images (National Dairy Council, Rosemont, IL.) for the 53 foods generated from the 1-d foodlists from the Oklahoma NA women, mounted on yellow poster board (8" squares), and laminated (181;182). The cards were used during the food sorts during Phases II,

to elicit perception regarding healthiness and fat and sugar content.

Generation of the most commonly consumed foods of NA from the CSFII

For comparative purposes, frequency analysis was completed to identify the most commonly consumed foods of NA from the CSFII using the same methods as described for the Oklahoma sample. Each food in the USDA database is denoted by an eight-digit survey food code (food code). For example, different food codes were assigned to each of several types of green beans due to differences in processing and/or preparation. We concluded that the grouping of foods of similar fat and sugar content in the USDA database would not provide additional benefit compared to time required to group foods. All codes for green beans were not collapsed into a category of green beans. Therefore, frequency analysis was ascertained from the frequency of raw food codes as presented in the CSFII and not by discrete food groups as used in the Oklahoma sample.

Unlike the Oklahoma sample, participants in the CSFII provided two days of food intake through two non-consecutive multiple pass 24-hour recalls. A threshold of 3 reports provided a list of the 56 most commonly consumed foods for the CSFII sample.

PHASE II

Participants

Women of at least one-quarter NA blood, between the ages of 18 and 65 years of age, who are not pregnant or lactating, were eligible for inclusion in the study. A diagnosis of chronic disease, including type 2 diabetes mellitus, did not prevent inclusion. However, women diagnosed with chronic diseases that impact appetite, including those receiving cancer treatment, were excluded from the study. An attempt was made to recruit approximately half of the sample of women with a previous medical diagnosis of type 2 diabetes mellitus.

The sample of 79 women was recruited proportionately from three Northeastern

Oklahoma tribal clinics: Kanza (Kaw) Health Clinic in New Kirk; Pawnee Tribal Clinic in Pawnee; and Iowa Tribal Clinic in Perkins. Letters of cooperation are in Appendix B. Key informants at the three clinics and the hired qualitative interviewers worked closely with the graduate students to recruit potential participants for the research study. Articles were published in the Pawnee and Iowa tribal newsletters to promote the study (Appendix C). Those interested in participating were referred to one of the interviewers to determine eligibility, receive more information and to schedule visits. Additional participants were recruited from the tribal diabetes education programs and general health clinics of the three tribes. The sample derived for the 1-d food list was independent of the sample derived for Phase II of the study.

Methods and Materials

Interviewer Selection and Training Job announcements were created to advertise the position and were distributed to the clinics (Appendix E). Application forms were drafted and distributed to the key informants at each of the three tribal health clinics (Appendix F). The key informants distributed the applications to potential candidates; they were encouraged to screen applications as received to generate a list of viable candidates.

Upon receipt of all applications, the research team reviewed the applicant pool and selected two candidates per clinic. Two female interviewers from the Pawnee and Kaw tribal health clinics were hired to complete the qualitative interviews. At the insistence of the administration, only one interviewer from the Iowa tribal health clinic was hired to conduct the interviews. Interviewers were at least one-quarter NA blood with a valid driver's license and reliable transportation. No previous interviewing experience was necessary. Letters were drafted representing a formal offer of hire as an independent contractor to complete the interviews. A formal acceptance letter was requested from the candidate for acknowledgement of hiring. The interviewers were not

considered employees of Oklahoma State University (OSU) but were bound by contract (Appendix G) to complete services as independent contractors.

Each of the five interviewers completed training on interview structure, data collection techniques, collecting 4-day weighed food records and response recording. The training consisted of a 1-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. Upon completion of the training, the interviewers received a check for $100.

Qualitative Interviews The research team provided all materials necessary to complete the qualitative interviews. The interviews were conducted in the clinics or, if desired, in the participants' homes. Each participant completed a total of three visits. 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 completed two participants, the data were examined and adjustments were made to the protocol.

Visit 1

Consent form The interviewers reviewed the informed consent forms with the participants prior to beginning the qualitative interviews (Appendix H). The interviewers read the consent form fully and if the participant agreed to participate, signed 2 copies. One copy was returned to the research team and the participant retained the other.

Demographic form After informed consent was received, a list of demographic questions was completed by all participants (Appendix I). Demographic information

included marital status, tribal affiliation, education, employment, income, food sources, physical activity, age, self-reported weight and height, and how they learned about the study.

Rank order of life concerns Participants then completed the Rank Order of Life Concerns portion of the interview by writing their concerns in life on individual index cards. Instructions for this exercise are found in Appendix J. They were then asked to order their perceived life concerns from most important to least important in a ladder-like fashion, with the least important concern at the bottom and the most important concern at the top. Once the cards were sorted, a card with "body weight" was given to the participant unless they already had expressed body weight as a concern. The interviewer asked the participant to rank body weight in the list of concerns according to their perceived importance of weight management. The cards were collected by the interviewer and numbered in accordance to their ranked importance, with one being the least important and the highest number for the most important concern.

Training for 4-day weighed food record At the conclusion of the first visit, the interviewer trained the participant how to conduct and record the 4-day weighed food record. An Ohaus CS 2000 or 5000 dietetic scale (Ohaus, Pine Brook, NJ), Styrofoam plates and recording booklet (Appendix K) were provided for food record completion. Styrofoam plates were provided to lessen the burden of multiple dish use when weighing leftovers. At this time, the participant practiced weighing multiple food items and was instructed how to record foods consumed outside of the home. A portion size estimation kit was provided to aid in portion size estimation when eating away from home. The kits contained measuring cups, measuring spoons, bean bags representing quarter-cup, half-cup and one-cup servings; and a box resembling a three-ounce portion of meat.

Visit 2

The second visit was not conducted until the 4-day weighed food record had

been completed to prevent biasing the food record with the foods from the first food sort.

Cultural structure of health and diabetes During visit 2, the participant completed the Cultural Structure of Health and Diabetes questioning route (Appendix L). The questions were modified from previous research (183) 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 portion of the interview was audiotaped. The tape was labeled with the date, time, interviewer's name, and the participant number. At the conclusion 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 I Following the completion of the Cultural Structure of Health and Diabetes questions, the interviewer introduced cards containing pictures of the 53 most commonly consumed foods developed in Phase I of the study (184). The cards were randomly placed face up on the table. The participants were asked to sort the cards into groups of their choice and give names to the groups. Once the participants completed the sort, the interviewer recorded the participant-assigned group names on the Food Sort I recording form (Appendix M) and recorded the food numbers from the back of the cards on the same form. Each food card contained its own discrete number for analysis.

Visit 3

Weight valuation and cultural definition of obesity During the third and final visit, the participant completed the Questions for Weight Valuation (Appendix N). Nine body image cards were created displaying images used in previous research (185) modified for appropriateness to the target population. The cards were used during the questioning phase (Appendix O) to ascertain a cultural definition of obesity. The questions used were modified from previous research (183) to better suit the target population.

Initially, the participant was asked to freely describe each of the somatic drawings. The images were then displayed face-up for the participant to rank from the most healthy to least healthy and next most attractive to least attractive. This exercise was followed by questions to address several perceptions of attractiveness, body size, and the importance and challenges of weight maintenance.

This portion of the interview was audiotaped and the tapes were labeled with the date, time, interviewer's name, and the participant's name. At the conclusion of the questioning route, the tabs of the cassette were broken out to protect the contents of the recording. The weight valuation questions were written to address the issues of body perception; grounded theory provided the basis for modifying the questions in the presence or absence of specific topics or recurring themes. Only one revision was made to the questioning route; one questions was deleted to eliminate redundancy.

Food sort II The interviewer reintroduced the cards containing images of the 53 most commonly consumed foods used in Food Sort I. The cards were randomly scattered face up on the table. Each participant was asked to group the foods under three subheadings: healthy; not healthy; or not sure. The cards were mixed and displayed again for a sort as 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 (Appendix P). This technique has been modified from previous research by Lieberman et al. (181;182) as the previous method sorted by fat, sugar and healthy.

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-Pawnee (offspring of a full blood Pawnee and a non-Indian), they would be entered as 0.50. One participant had a blood quantum less than 25% (0.25) but was not excluded from analysis due to a fractional difference from the criterion.

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

Rank-order life concerns Data from the life concerns sort were entered into SPSS for analysis. Variables were entered in descending rank, from most important to the least important concern. Once all concerns were entered, similar responses were recoded to more general categories. Two members of the research team discussed the trends and agreed on the categories. For example, the data “child”, “children,” “kid,” “kids,” “son,” “daughter,” “grandchildren” were collapsed to create the category “children.” Additionally, the data “finances,” “money,” “bills,” “money management” and “income” were reduced to a single code of “finances.”

Life concerns data were analyzed using three different methods. First, to determine the life concern most frequently reported as the most important concern, frequency analysis was conducted for the most important concern. Frequency analysis was then conducted on each of the subsequent concerns. Further analysis was

conducted without regard to the rank order. All recoded data were pooled to establish the raw frequency of each concern among all participants. To remove the artifact of forcing all participants to rank body weight among their life concerns, the body weight responses were recoded. In the instance that body weight was indicated to be a life concern of the participant without the introduction of the card by the interviewer, the data was recoded as "body weight by subject". Otherwise, body weight was recoded as "body weight by interviewer". The concern with the highest frequency was considered the most common life concern.

The third method of examination used a calculation to determine the relative position of a concern to the total number of concerns presented. Data were recoded to indicate the total number of concerns indicated for each participant. New variables were created to denote each category of concern that indicated the rank it was given. Variables deemed most important were coded as 1 and the subsequent concerns were coded in descending rank in their respective variables. A life concerns score was imputed by dividing the rank of a concern by the total number of concerns for that participant. A score closer to zero indicated a more important concern. For example, if body weight was the most important of eight concerns, the life concerns score for body weight would be 0.125. Means scores were computed for each concern are provided in ascending value, indicative of descending rank.

4-d weighed food record After completion of the 4-day weighed food record, the food recording booklets were returned to the research team for examination. Questions regarding individual or combination foods recorded were conveyed to the interviewer for clarification. Following any necessary clarifications, the food records were entered into the Food Processor (version 7.8, Esha Research, Salem, OR) nutrient analysis program for analysis. Nine participants were excluded from entry and subsequent analysis due to the incompleteness of the food record or failure to weigh any

items across the four days.

Intake records created in Food Processor were exported to a tab-delimited file to be tabulated in Excel. Because of the concerns for the accuracy of Food Guide Pyramid servings generated by Food Processor to be used in examinations of diet quality, the decision was made to use USDA data for nutrient and Food Guide Pyramid serving intakes. Individual foods were matched to eight-digit food codes in the USDA's Pyramid Search Tool. Food codes were added to the delimited files and matched to USDA databases to compute nutrient and Food Guide Pyramid serving intakes per food. Servings and nutrients required calculation as the USDA provides data based on a 100 g serving for each food. Estimated nutrient consumption was computed for each day and as a four-day average.

The foods consumed were used for triangulation of the food perception data and also for further comparisons to the most commonly consumed foods derived from Phase I. For comparison to the 1-day food lists and the CSFII data, foods from the food records were recoded based on the methods discussed in Phase I. Foods were recoded into categories and frequency analysis was conducted to identify the most commonly consumed foods based on four days of food intake. Results specific to the nutrient intake, Food Guide Pyramid servings and diet quality will not be discussed herein.

Identifying core, secondary and peripheral foods The individual foods listed in the 4-day food records were recoded into discrete food groups for analysis of core foods. For example, all similar types of American cheese were recoded as American cheese. Foods such as fried chicken nuggets and cheeseburgers from various fast food establishments were recoded as fast food fried chicken and fast food hamburgers, respectively.

The frequency of foods reported during the 4-day weighed food record and the proportion of people consuming these foods were used to identify and verify core,

secondary and peripheral foods using a modification of a method previously developed (62;63). Fanelli et al. (62) assessed three days of intake derived from 24-hour recalls from the CSFII; our data provided four days of intake using weighed food records.

Initially, a raw frequency of the recoded foods was conducted to identify the top 150 foods reported (62). A raw frequency of 4 provided 152 foods to be used for core foods analysis. Data were then trimmed to incorporate only reports of the top 152 foods from the raw frequency. The data was stratified by food and frequency analysis was conducted to establish the number of days across the four days of recorded food intake for each participant consumed each food using the participant-day variable.

A food use frequency score was tabulated using the proportions of the population consuming the item on none (R_1), one, two, three and each day (R_5) of record. Also, a scale weighting of one was included for foods not consumed on any of the four days in record (S_1) and a scale weighting of five for foods consumed on all four days (S_5). The food use frequency score was computed using the following formula:

$$\text{Score} = [(R_1S_1 + R_2S_2 + R_3S_3 + R_4S_4 + R_5S_5) / 5]$$

where:

R_1 = % of respondents not eating food on any of 4 days

R_2 = % of respondents eating food 1 of 4 days

R_3 = % of respondents eating food 2 of 4 days

R_4 = % of respondents eating food 3 of 4 days

R_5 = % of respondents eating food daily

S_1 = 1 = scale weighting for foods not eaten on any of 4 days

S_2 = 2 = scale weighting for foods eaten 1 of 4 days

S_3 = 3 = scale weighting for foods eaten 2 of 4 days

S_4 = 4 = scale weighting for foods eaten 3 of 4 days

S_5 = 5 = scale weighting for foods eaten daily

The lowest possible score is 0.2 with only one person consuming a food on one day of

recorded food intake and the remainder not consuming the specified food on any day of record. The highest possible score is 100 if all participants consumed the food on all four days of record.

For example, the most frequently reported food was soda. Soda was not consumed by 32.4% of the sample on any days of recorded food intake, while 12.7%, 9.9%, 21.1% and 23.9% consumed soda on one, two, three and four days, respectively. Using the aforementioned formula, the food use frequency score for soda was computed as 58.3.

A cut off of thirty foods was used to determine the list of core foods. The list of core and secondary foods was used to support or contradict the list of most commonly consumed foods derived from the 1-day food lists during Phase I and the most commonly consumed foods from the 4-day weighed food records.

Food sort I Data from Food Sort I was entered into SPSS for analysis. Responses of a similar nature were recoded into discrete categories. For example, “drink,” “drinks,” “beverage,” and “beverages” were recoded to “beverages” category. Also, responses of “what patient eats,” what she eats” and “what others eat” were recoded to a “what others eat” category. Questionable responses, such as “potato and bread” for coffee and tea, were confirmed from the recording forms and, if consistent with the data files, were left as is. Frequency analysis was conducted on the recoded categories for each of the 53 most commonly consumed foods presented on the food cards.

Food sort II Data from the trichotomous food sorts were entered into separate files in SPSS for each of the sorts. Frequency analysis was conducted to identify the proportion of participants classifying each discrete food group on each of the facets of the trichotomous sort.

For triangulation of data, the responses on Food Sort II were compared to food

intake data. Two research dietitians recoded the foods from the 4-d weighed food records according to the aforementioned protocol used with the 1-day food lists in Phase I. The frequency of consumption of the most commonly consumed foods from Phase I was used for the analysis of food perception data. Frequency of consumption of each of the most commonly consumed foods was achieved by splitting the data file by the recoded foods. Frequency of consumption was generated for each participant. This elicited the frequency of consumption for each food by each participant over the four days of record and was entered into a new SPSS file for analysis.

The responses from Food Sort II for each food were correlated with the frequency of consumption for that food using Spearman's rank order correlation coefficient. Individuals responding "not sure" were not used for the comparison to the 4-d weighed food record for the corresponding food. Relationships between the perceptions and the frequency of consumption were significant at $P \leq 0.05$.

Cultural structure of health and diabetes

Definitions

Theory A set of interrelated concepts and constructs representing a systematic relationship of phenomena to explain or predict the events or situations (186)

Construct An abstract statement composed to merge several interrelated categories and concepts (187)

Category A group of similar concepts used to build constructs (176)

Concept Abstract statements that allow for classification of themes such as attitudes, beliefs or behaviors (187)

Code word An abbreviation used to code or identify a concept in the Ethnograph software (188)

Themes Labels for concepts used in thematic analysis (189)

Overview of transcript analysis Upon receipt of the audiocassettes of the Cultural Structure of Health and Diabetes (Visit 2) and the Weight Valuation Questions (Visit 3) from the interviewers, the tapes were transcribed verbatim into Microsoft Word 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. The weight valuation questions were analyzed by the OSU Department of Sociology and will not be discussed herein.

Grounded theory guided the analysis of the transcripts (176). Open coding constituted the coding strategy for the early data analysis which employed the use of critical analysis of the transcripts to identify and label incidents and text segments with a concept label as described by Miles and Huberman (188). The initial coding scheme was derived through consensus of two researchers reviewing the transcripts; additional code words were added once agreement was achieved on the emerging content. Text segments related to the concepts (tagged by 29 discrete code words in Ethnograph) were evaluated. The transcripts were reviewed throughout the interviewing process; therefore, when new concepts emerged requiring exploration during the interviews, new questions and probes were incorporated into the questioning route.

Next, axial coding was used to refine the related concepts to create categories (176). Also, data were evaluated to identify the relation among the concepts within their respective categories. The final stage of analysis, selective coding, evaluated how the relationships between concepts and categories are used to create constructs, or an umbrella category, drawing together all the related categories.

Thematic analysis The transcripts for the Cultural Structure of Health and Diabetes interview were reviewed by the Nutritional Sciences research team using two methods for improved analytical strength (190). Thematic analysis was used to identify

recurring themes throughout the transcripts (189). Following multiple reviews of the transcripts, key concepts were defined and code words were developed to identify each concept in Ethnograph. A code word list was generated, with descriptive definitions, for consistency of coding throughout the analysis of the transcripts (Appendix Q).

Text segments within the transcripts served as the unit of analysis (188). Text associated with the code words or concepts varied in length from a few words to paragraphs of text; coded segments were derived from direct statements by the participants or from abstract references in the text to a concept in context (188). The transcripts were coded using Ethnograph and the text segments were sorted by code word to aid analysis and generate code word frequency (188;190). Flexibility was provided as the software allowed for multiple and overlapping coded text segments when this segment addressed multiple concepts. For ease of description of the code words, memo narratives were written to explain the content (Appendix R).

Content analysis Additionally, content analysis summarized the themes from the interviews. After reviewing the transcripts and coding of the concepts as previously described, summative quotes were used to personify the themes expressed in the qualitative interviews (189). Content analysis provided verbatim examples of the key concepts from the interviews to reinforce and illustrate the results of thematic analysis.

Inter-rater reliability Two researchers analyzed the transcripts to establish inter-rater reliability. To establish the concurrence of the two coders, a segment of ten central pages was selected for analysis by both coders, separately (188). 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 computed 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% (138).

PHASE III

Participants

Men and women with at least 25% Native blood, between the ages of 18 and 65 years of age by self-report were eligible to participate in the testing of the diabetes assessment tool. Individuals were not excluded if they had diabetes or other chronic diseases. Two hundred participants were recruited for the reliability/validity testing conducted on the *Keeping the Balance: Diabetes and Health Assessment Tool* (assessment tool). Each participant signed an informed consent form prior to completing the assessment tool. Researchers offered to read the questionnaire to volunteers. Otherwise, eligible volunteers completed the self-administered questionnaire. This was followed by a short demographic questionnaire. To increase participation, volunteers who completed the assessment tool and the demographic questionnaire received $10. The Institutional Review Board at Oklahoma State University approved the study protocol (Appendix A).

Methods and Materials

Development of a diabetes prevention assessment tool

Overview of assessment tool development The development of a diabetes assessment tool involved a process of composition and analysis modified from previous research (191) for the specifics of this study. First, a theoretical model was developed that best described the perceptions of health and diabetes from the qualitative interviews that provided the foundation for the tool. Second, the research literature was reviewed to identify previously made questionnaires to aid in question development. Review of several existing tools (92;143;149) provided a guiding framework from which to begin.

The underlying concepts of the constructs were used to develop items for the assessment tool. The theoretical constructs used for the initial version of the diabetes assessment tool were perceptions of health and diabetes, knowledge about diabetes

and the role of the social environment. Each construct was measured through multiple items (>20) written using the terminology of the text segments identified during content analysis. Upon completion, the preliminary assessment tool underwent expert panel review. Feedback provided from the content review was incorporated into the final version of the assessment tool that was administered to NA volunteers.

Once the measures are validated, the questionnaire could potentially serve two purposes. This tool may be used by the health care provider in presenting more individualized and directed preventive care and education for patients at risk for diabetes. Also, health educators may use the tool to provide information to shape community programs targeting diabetes prevention that are culturally appropriate and congruent with the community's attitudes, beliefs and knowledge about diabetes.

Creation of a theory A theoretical framework of health, diabetes and the social environment was composed to address the amalgam of issues and perceptions from the qualitative interviews. Categories and their concepts generated from the qualitative interviews were utilized to generate constructs of the theory and identify the relations among them (176). Items for the assessment tool were written to assess the knowledge and beliefs about health, diabetes, healthy eating and the social environment among NAs and were focused on the preventive aspects of diabetes.

The information obtained from the content analysis of the interview transcripts was used to develop items to capture the concepts of perceptions of health and diabetes that influence lifestyle behaviors related to diabetes prevention. These initial concepts and their overarching constructs shaped the theory that describes the "cultural belief system concerning the manifestation, causes of, prognosis for, possible treatment for and other pertinent knowledge" (192, pg. 881) about diabetes.

Diabetes prevention assessment tool development Specific text segments from the interviews were selected to create items that addressed the specific concepts within

the constructs to be evaluated. Twenty or more items were written to address each of the constructs to be tested; the perceptions of health; perceptions of diabetes; knowledge about diabetes; and the social environment. Text segments addressing the concept being tested were used to compose the items for the assessment tool, using original wording whenever possible. From this list of potential items, the instrument was created using a six-point Likert-type scale for each item (1= Strongly Agree, 2= Agree, 3= Somewhat Agree, 4= Somewhat Disagree, 5= Disagree, 6=Strongly Disagree). Previous personal research experience has demonstrated a cultural propensity to avoid conflict; therefore, a neutral option was withheld to force a choice on the scale.

A total of 98 items were presented to a panel of experts to review for cultural appropriateness, clarity, conciseness and the ability to measure the intended concept.

Expert panel review Experts were recruited for the construct validity phase of the tool development. Health professionals and academicians with demonstrated experience in questionnaire development or NA health, diabetes or research were recruited by personal invitation or through a research or a NA healthcare e-mail list serve. Individuals willing to review the preliminary version of the assessment tool provided a brief description of their background and a copy of their Curriculum Vitae.

The preliminary assessment tool reviewed by the expert panel was comprised 98 items. A web-based survey was developed with Microsoft FrontPage 2002 (Microsoft Corporation, Redmond, WA) to collect expert panel responses. Internet hyperlinks to the web-based survey were provided for the panel to review the developed instrument for cultural appropriateness, clarity, conciseness and the ability to measure the intended concept. Eleven volunteer experts provided online feedback for the items and provided suggestions for rewording of items. Comments from the expert panel were compiled to an online database. Feedback was reviewed by the researchers and used to create the final version of the assessment tool.

Assessment tool administration Key informants at the tribal health clinics aided in finding sites to administer the assessment tool. Upon invitation for each event, a research team traveled to two powwows for data collection. Eighty-one and 116 volunteers provided informed consent (Appendix S) and completed the assessment tool (Appendix T) and demographic form (Appendix U) at the first and second powwows, respectively. Two participants were excluded because they did not meet study criteria despite screening and ten participants were excluded due to patterned responses inconsistent with normal variability for the positively and negatively worded responses. Data analysis was performed on the final useable sample of 185 questionnaires.

Difficulties in the usage of the original recording form (Appendix V) were noted for the first 81 participants at the first powwow. Several participants recorded multiple responses on the same line. The format was revised to spread response recording over two pages and every other line was grayed for ease of reading. This allowed for more space for recording answers (Appendix W). Furthermore, the forms were more thoroughly checked to identify multiple or missing responses. When multiple responses were coded on the same line, the data was entered as missing. No discernable patterns indicated that the assessment tool contained sensitive or offensive content.

Data analysis of the diabetes assessment tool

Overview of assessment tool analysis The responses were entered into SPSS (version 11.0) and validity and reliability analyses were performed. Factor analysis was used to determine the empirical structure of items on each of the categories. This technique evaluates the correlation matrix to identify groups of items that share common correlations with each other. Factor loadings were evaluated to identify whether items loaded on a single or multiple factors.

To assess internal consistency of the items for each of the factors generated from the factor analysis, Cronbach's α was computed on the items loading on each

factor to assess the ability of the items to measure the same conception. Acceptable α levels were set at 0.70 (191).

Assessing validity and reliability

Factorial reliability To identify an empirical structure of the items derived from theoretical content, principle axis factor analysis (PAF) was conducted. This analytic strategy utilizes inter-item correlations to identify unique factors, or linear combinations of items that share common relationships with other items (187;191). Items for each of the constructs (health, diabetes, social environment) were written to identify the underlying concepts surrounding each construct. The theoretical basis for this arrangement indicated a need to factor analyze each construct independently. Each factor analytic examination followed a standardized approach. The items addressing knowledge of diabetes causes, symptoms and prevention methods were not used in a factor analysis.

Items with missing or multiple responses on the same item were coded as missing data. Due to the random nature of the missing data points, missing data were excluded pairwise during the analysis. This means that when a participant had missing data for one item, the correlations for responses of valid items would still be used in the analysis.

First, the 31 items measuring the cultural perceptions of health were included in a PAF. The analysis was conducted initially with no rotation to identify the number of factors to rotate. Three techniques were used to determine the number of factors to rotate. Initially, eigenvalues were examined to identify the factors with values greater than one (Kaiser Rule), which indicates a factor accounts for more variance than is potentially accounted for by a single item (193). Secondly, the Scree Plot, a graphical depiction of the eigenvalues, was evaluated by drawing a line along the descending slope of the first factors and along the bottom of the final factors. Factors are rotated if

they lie above the intersection of the two lines. Thirdly, the proportion of variance accounted for by a given factor was used to determine the amount of additional variance a retained factor would add to the solution by being rotated.

The PAF was repeated rotating the appropriate number of factors with an oblique rotation (Direct Oblimin, delta=0), which allows the factors to correlate. If little correlation was evident ($R<0.3$) between the linear factors, the analysis was repeated using an orthogonal (Varimax) rotation. If a correlation between the factors existed, the underlying themes would have been considered related and the outcomes of this analysis were interpreted. No correlations among the factors were present for any of the constructs tested; therefore, an orthogonal rotation was used in each of the three PAFs performed. An orthogonal rotation places perpendicular factors in the correlation matrix to mathematically maximize the variance accounted for by each factor.

To identify the factorability of the data, the correlation matrix, Kaiser-Meyer-Olkin (KMO) Measures of Sampling Adequacy and the Bartlett's Tests of Sphericity were evaluated (193). KMO values >0.6 indicate there is enough structure within the correlation matrix to provide a factorable solution. Bartlett's Test of Sphericity was used to determine whether the correlation matrix is significantly different ($P<0.05$) from an identity matrix (a correlation matrix where items correlate perfectly with themselves and not at all with other items). If both of these criteria are achieved, the interpretation of the analysis continued.

When evaluating the Factor Matrix, items accounting for at least 16% of the variance on a factor (loadings >| 0.4 |) were considered to load on a factor based on absolute value (193). Factor loadings represent the Pearson Product Moment Correlation of the item with the factor. Items loading on a particular factor were reviewed and used to name the factor. Variables that loaded on more than once factor were examined for ambiguity in wording and would require refinement for future testing to

ensure it is only measuring a single concept.

The same protocol was followed to identify the factor structure of the perceptions of diabetes scale.

Content validity The ability of an instrument to measure the critical foci of a specific problem is supported through measures of content validity (138;187;191). The derivation of concepts and constructs from the qualitative interviews lends increased content validity to the diabetes assessment tool. Additionally, the research committee and an expert panel were involved in determining the effectiveness in the translation of themes from the interviews into appropriately-worded items.

Face validity Unlike content validity, which is established during the development of an assessment tool, face validity is assessed prior to administration (187). To ensure the tool is measuring what it is intended to measure, academicians, practitioners and tribal health clinic staff were asked about the tool's design, layout and whether the instrument measured health and diabetes perceptions and the social environment. Discrepancies between intent and actual content were addressed and reevaluated before the instrument was administered.

CHAPTER IV

MOST COMMONLY CONSUMED FOODS AND PERCEPTIONS OF FOODS IN NATIVE AMERICAN WOMEN

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ABSTRACT

Objective: To identify the most commonly consumed foods by Oklahoma and US Native American (NA) women and to determine the impact of health perception on food consumption.

Design: A descriptive design was used to evaluate food intake data of Oklahoma and US NA women.

Participants: Convenience samples of 74 and 71 Oklahoma women between 25-65 years of age, at least 25% Indian blood quantum completed a non-quantitative 24-hr recall and a 4-d weighed food record, respectively. Twenty-eight NA women, 25 and 65 years, were obtained from the 1994-1996 CSFII database.

Setting: Women were recruited from three tribal health clinics in Oklahoma.

Variables Measured: The most commonly consumed foods were identified from each food intake set. Perceptions of healthy, fat and sugar content were obtained by the food sort method.

Analysis: Frequency analysis was performed to determine the most commonly consumed foods. Relations between food intake behaviors and perception of health value and fat and sugar content were evaluated by Spearman's rank order correlations.

Results: The most commonly consumed foods for each of the three data sources displayed similar results. Few “traditional foods” were noted among the lists and perceptions yielded little differences in consumption patterns.

Conclusions: Understanding the foods consumed by the NA population and the underlying determinants of food intake behavior will aid in appropriate nutrition education planning.

INTRODUCTION

Diabetes has become a major public health concern among the US population. Minority populations, namely Native Americans, disproportionately bear the burden of this multifactorial disease (18), thus determining the role diet plays in the prevention and treatment of diabetes is important (155). Despite the fact that more than half of the Native American population resides in urban, non-reservation areas (8;99), little is known regarding the current dietary practices of the non-reservation living, rural Native American (NA) adults (49).

In less than two generations, NAs have changed their diet and lifestyles so dramatically that they now display one of the highest rates globally for clinical obesity and diabetes (194). They are 2.8 times more likely than non-Hispanic whites to have diagnosed diabetes (195). Genetic predisposition, lack of physical exercise and dietary change from a more subsistence diet to a higher calorie and westernized diet are all factors that contribute to the degenerative health and nutritional problems of Native Americans (24).

Studies investigating the diets of reservation-living NA, such as the Pima and the Diné (Navajo), are more prevalent than research regarding those integrated into western society. NAs are underrepresented in national nutrition monitoring surveys, including the National Health and Nutrition Examination Surveys (NHANES) and the National Food

Consumption Survey (NFCS). Of the over 15,000 participants in the US Department of Agriculture's (USDA) 1994-96 Continuing Survey of Food Intakes by Individuals (CSFII), only 107 were Native American (178).

The gaps in understanding the diets of non-reservation living NA, especially in Oklahoma, limit the ability to provide appropriate community-level nutrition education programs targeting changes in dietary patterns (160-164). The objective of the present study was to identify the most commonly consumed foods of NA women in Northeast Oklahoma to better understand current dietary intake trends. The foods derived from 1-day food lists, a non-quantitative 24-hr recall, and 4-d weighed food records were compared to NAs included in the 1994-96 CSFII data set to ascertain similarities and differences in the current dietary habits of Native American women. The most commonly consumed food from the 1-day food list was then used to assess food perceptions and their impact on food selection behaviors in NA women.

METHODS

Subjects

Three different samples provided data for the analyses. A convenience sample of 74 Oklahoma NA women was used for the collection of the 1-d food lists (food list). Subjects were recruited with the aid of key informants from the tribal health clinics of three Native American tribes in Northeast Oklahoma. Seventy-one Native American women in Oklahoma provided 4-d weighed food records (food record) to be used in the confirmatory analysis. These women also completed the food sort to provide perceptions of foods. Twenty-eight Native American women (CSFII) from the CSFII provided two days of food intake by the multiple-pass, 24-hr recall method.

When recruiting for both Oklahoma samples, women of at least ¼ NA blood quantum between the ages of 25 and 65 were eligible for participation; however, women

were excluded from participation if they were pregnant or lactating. Potential participants were identified through and interviewed at congregate meal sites, tribal health clinics and mobile exam screenings. Advertisement of activities was conducted by the tribes, which included fliers and articles in tribal newsletters and newspapers. Women were screened according to aforementioned criteria prior to participation. The Oklahoma State University Institutional Review Board approved the study protocol for the Oklahoma samples.

Collection and Analysis of Food List Data

The 74 participants completing the food lists were read a verbal script identifying the interviewer and the purpose of the interview and all women that were approached agreed to participate. Three trained researchers completed the interviews. The coordinating dietitian (KSK) was a PhD, RD who trains students to conduct food intake recalls. All interviewers were registered dietitians with one (CT) being trained by the National Institutes of Health (NIH) to conduct food recall interviews with another NA population. Twenty-five women from each of the three clinics were recruited to complete a modified multiple-pass 24-hour recall (43), less the quantification of portion sizes. Twenty-four hour recalls are less reliable for estimating individual nutrient intake but are useful for group analyses (177). Identifying the foods most commonly consumed was the primary goal and nutrient analysis was not an objective; therefore, portion sizes were not collected.

Each woman was asked about all foods and beverages consumed in the past 24-hr period. Probes were used to elicit condiments and additional foods commonly forgotten as per the protocol of the multiple-pass method (178). Upon successful completion of the 1-day food list, participants received $15 subject incentive. Data from one tribal congregate meal site was conducted on a Monday to ascertain foods from a weekend day as well as avoid bias in recording foods received from the same meal

program. The food lists obtained from the other tribal clinics were obtained mid-week. The data from the 1-d food lists were entered into Microsoft Excel 2000 (Microsoft Corporation, Redmond, WA) and imported into SPSS (version 10.0, SPSS Inc., Chicago, IL) for frequency analysis to generate the list of most frequently consumed foods.

To better understand food consumption patterns, foods of similar nutritional content and food type were grouped; however, foods differing in content of fat and sugar were left separate for frequency analysis (179;180). Two of the interviewers (CT, KSK) evaluated the aggregated list of foods from all three tribes, identifying like foods with similar composition in regards to fat and sugar content. Food groups were created after consensus was reached. For example, all artificial sweeteners (i.e. Equal and Sweet 'n Low) were combined into an "artificial sweeteners" category. Additionally, reported chicken intake was divided into a "fried chicken" category (i.e. fried chicken and chicken wings) and a "chicken" category (i.e. baked or boiled chicken). Combination foods (i.e. green salad, sandwiches and stews) were analyzed as whole foods and not as individual components. Butter and margarine were combined to table fats while sour cream and mayonnaise were also grouped together as a mayonnaise and sour cream group. Reported wheat bread was only categorized as "whole wheat bread" if it was specifically stated as such due the fact that many wheat breads available are similar in composition to white bread despite the brown color.

Frequency analysis was completed with the pooled samples of 1-d food list data, displayed in order of descending count using previous research as a guide (180;196;197). The incidence of food consumption was counted for each eating occasion, without regard to quantity. If coffee was consumed with breakfast, lunch and dinner, a frequency of three was achieved. In an attempt to identify the fifty most commonly consumed foods, a threshold frequency of five times resulted in a list of fifty-three most commonly consumed foods. Therefore, foods reported at least five times

from the total sample were considered among the most frequently consumed foods from the 74 days of food intake.

Collection and Analysis of the 4-d Weighed Food Record Data

Seventy-one women completed the 4-d weighed food record, providing a total of 284 days of food intake. The women were trained by female NA interviewers to weigh initial portions and leftovers using an Ohaus CS 2000 or 5000 dietetic scale (Ohaus, Pine Brook, NJ) and record amounts consumed. Additional instructions were provided on recording foods consumed away from home. Data from the food records were entered into Microsoft Excel 2000 and imported into SPSS for frequency analysis to generate the list of most commonly consumed foods. Individual foods were recoded to discrete food groups and frequency analysis was performed using the same protocol as described above for the food list data.

Collection and Analysis of CSFII Data

For a cross-referenced evaluation of the list of commonly consumed foods reported by NA women in Oklahoma, an analysis of the 1994-96 CSFII was conducted using women between 25 and 65 years of age that reported their race as Native American. The CSFII data set contains data for only 108 NAs (43) with only 28 being women within the same age classification as used in the Oklahoma study. Food data was provided using two non-consecutive multiple-pass 24-hour recalls for all but two subjects who provided only one day of food intake, totaling 54 days of food intake from 28 NA women from the CSFII analysis.

Frequency analysis was completed in descending count of the eight digit food codes (food code) assigned by USDA. The researchers concluded that the combination of like foods for similar fat and sugar content in the USDA database into the discrete food groups would provide little additional benefit when compared to the time required to recode foods. For example, different food codes were assigned by USDA to each type

of green beans, reflecting differences in processing and/or preparation. All food codes for green beans were analyzed individually as they were not collapsed into a single category of "green beans"; therefore, frequency analysis provided frequency counts for each of the unique food codes in the CSFII.

Evaluations of Food Perceptions and Food Intake Behaviors

Triangulation of data allows for the use of data from multiple sources to support or refute findings. To determine the relation between perceptions of foods and food intake behaviors, the 4-d weighed food record data was recoded to identify consumption of the 53 most commonly consumed foods as determined from the 1-d food list analysis. Food perceptions were obtained by the trichotomous food sort method. Participants were presented with fifty-three 8" x 8" yellow cards with images of the 53 most commonly consumed foods from the 1-d food list (183). Participants sorted the cards into 3 categories of healthy, not healthy or not sure. The cards were then gathered and resorted as high-fat, low-fat or not sure and again as high-sugar, low-sugar or not sure.

Frequencies of consumption of the 53 most commonly consumed foods across the four days from the weighed food records were tabulated for each participant. Spearman rank order correlations coefficients were computed between frequency of consumption for each of the most commonly consumed foods and the perceptions from the food sort of health value and fat and sugar content. Significance relations were established at 0.05.

RESULTS

No subjects refused participation in either food list generation sample and all responses were used in the data analyses for the Oklahoma NA women. Ninety-two percent of the NA women in the CSFII completed two days of recall. The mean age of the women was 48 ± 12 years (n=74) for the 1-d food list, 44 ± 12 (n=71) years for the 4-

d food record sample and 47 ± 11 (n=28) for the CSFII sample. Twenty-eight percent of food list participants and 36% of the food record participants reported a previous diagnosis of diabetes while 18% of the NA women from the CSFII reported a doctor had told them they had diabetes.

The most commonly consumed foods from the food lists and food records from the Oklahoma NA women are provided in Tables 1 and 2, respectively. The list of 53 foods derived from the Oklahoma 1-day food lists accounted for 73% (854 foods) of all foods reported (1,173 foods, Table 4.1). Some cultural foods, including wild game, corn soup and fry bread, were not reported frequently enough for inclusion. The 53 most commonly consumed foods from the weighed food records accounted for three-quarters of all foods consumed (Table 4.2). Foods derived from the CSFII database from the frequency of raw food codes are presented in Table 4.3, which accounted for 56% (402 foods) of all foods reported (719 foods). Forty-five of the 56 foods from the CSFII most commonly consumed foods were also reported in the Oklahoma 1-day food lists demonstrating high congruency between the two data sets (Table 4.3).

Coffee and tea were the most commonly consumed food in all three samples. Regular and diet soda are in the top 5 foods for both Oklahoma samples and top 15 foods for the CSFII sample. Overall soda consumption (regular and diet soda) exceeded coffee and tea consumption in both Oklahoma samples. When collecting food intake over multiple days in Oklahoma, more convenience foods, like hot dogs and cheeseburgers, as well as the accompanying condiments were recorded than in the 1-d food list data. Otherwise, a high degree of agreement existed between all three sources of food intake data.

When examining the impact of food perception on food consumption patterns, there were 16 out of 159 possible significant relations between the frequency of consumption of the most commonly consumed foods (Table 4.4) and perceptions of

health value and fat and sugar content. A significant relationship between diet soda consumption by the perception it to be healthy; however, no significant differences were found between the participants that perceived regular soda as high sugar (data not shown). Consumption of baked, boiled and mashed potatoes increased significantly with the perception that they were high fat. Consumption of fried potatoes was two-fold higher in the women who considered them high fat, though the intakes and perceptions were not significantly correlated (data not shown). Furthermore, Kool Aid consumption was three-fold higher, though not significantly correlated, among women classifying it as a healthy food (data not shown).

DISCUSSION

The lifestyles of many NA tribes have undergone substantial change over the past century and these changes have had a considerable impact on the dietary practices (8;19;20;25;26;32;51). Traditional and subsistence diets of various tribes were strongly contingent upon hunting and fishing (11;25;27-29), contributing large amounts of protein concurrent with moderate fat and low fiber intakes (18). Reports as early as 1926 indicated that meat or fish, bread, beans, coffee and tea served as dietary staples (198). Few tribes raised corn, squash and melons, making vegetables and fruits small contributors to dietary intake. Milk and eggs were mostly nonexistent. However, a shift toward a more Westernized diet has occurred in response to the changes incurred by the white settlers (18;25;26;40). Recently, various reports have indicated a lack of traditional foods in Native American diets, especially those of the adolescents (19;21;36;40).

Our examination of the most commonly consumed foods indicated a reliance on a Westernized diet and this pattern appears to be mirrored through the data of NA women from a nationally-representative survey. The report of few "cultural" or

"traditional" foods and the increased report of store-bought foods in our survey of Oklahoma NA women are consistent with current studies of NA dietary intake (8;25;26;49). In 1990, Teufel and Dufour (49) indicated that hunting and fishing, gathering, and local farming provided only 10% of total energy consumed in a Hualupi community in Arizona. Convenience shops, cafes, and supplemental food programs, including commodities and WIC, serve as primary food sources for reservation-living NAs in various parts of the US (17;25;26;32;34).

The results of our studies with Oklahoma NA women and the CSFII demonstrated a considerable intake of soda beverages, with approximately two thirds of the reported soda consumption being regular soda in the Oklahoma NA women from the 1-d food list and 4-d food record data. Similarly, 58% of soda consumption by the NA women from the CSFII was from regular soda. These findings are similar to the outcomes of a food frequency administered to non-reservation living NA women in Minnesota (41). The 1999 Minnesota report indicated an increased intake of soda and fruit flavored soft drinks (i.e. Kool Aid) with two-thirds of soda consumed as regular soda. Similarly, Ikeda (38) reported one-third of NA adults and one-quarter of NA children in the Yosemite-Mariposa region in California consumed soda regularly at meals.

Further divergence from traditional food intakes found in our sample mirrored that of NA women in Minnesota concerning the high incidence of consumption of butter/margarine, cheese, eggs and snack chips (including potato, tortilla and corn chips). These trends are becoming more pronounced in NA youth who receive increasing exposure to Western culture. A survey of Cherokee youth in North Carolina indicated a low recognition of traditional foods, such as sweet potato bread, wild game and wild plants (40), with an even smaller proportion of the youths surveyed reported consuming these traditional foods on a regular basis. Movement from traditional practices may prove detrimental to NA cultural identity and overall health status

(28;32;33). In addition to the negative impacts on health status evidenced by high rates of obesity and diabetes, social interaction and cultural heritage has been hindered by the loss of traditional food harvesting and preparation practices (28;34).

A high level of congruency with the 4-d food record data supports the original list of the 53 most commonly consumed foods from the 1-d food lists. Only eight foods from the 4-d food record analysis were absent from the list of most commonly consumed foods from the 1-day food list. Collection of data over four days of intake yielded little additional accuracy or information in identifying food selection in NA women. Despite the collection of 1-d food list data in mid-autumn versus food record collection over the course of a year, the low consumption of vegetables and fruits in both Oklahoma samples minimized the impact of seasonal variability on the actual foods reported. Use of 1-d food lists may provide useful information about food selection behaviors with the caveat that seasonal variation may impact vegetable and fruit estimates.

Critical information is available from the evaluation of food intakes for formative assessment of target populations; however, little is known about the underlying personal and cultural perceptions of food (56). Identifying these issues would shed light on promoters and barriers to healthy food intake behaviors. Analysis of the food sort data paired with food record data indicated little reliance on the label of health value or fat and sugar content for food selection behaviors. Spearman's correlation of perception for each of the 53 most commonly consumed foods with frequency of consumption yielded few significant relationships for health value or fat and sugar content. Consumption of regular soda and coffee and tea were not impacted by the perception that it may be unhealthy. Though not significantly correlated, consumption of fried potatoes and fried chicken were higher for individuals considering these foods to be high in fat. These data indicate a disconnect between foods identified as less-healthy food choices and actual consumption behaviors. Understanding these underpinnings is necessary to develop

culturally appropriate and effective nutrition education interventions to change behaviors in a population at risk for many nutrition-related chronic diseases.

There are several limitations of the current study. First, the women providing food-recall and food record data were derived from a convenience sample and may not be representative of the total NA population in Oklahoma or the US. Additionally, recall bias may compound error in such investigations using 24-hr recalls, as used in the CSFII and our food lists. Furthermore, the process of creating food groups from the data from the Oklahoma NA women may artificially inflate the frequency of consumption of some foods. Finally, the labor-intensive nature of such a task prohibited the merging of the foods in the CSFII database according to the same criterion used for grouping foods from the 1-d food lists. This may limit the ability to detect some foods consumed more often that may have been missed due to the coding strategy used by USDA for foods differing in processing and/or preparation.

IMPLICATIONS FOR RESEARCH AND PRACTICE

The implications of changing dietary habits in response to the changing physical and political environment and Western influence have been manifested in the current state of nutrition and health status of the NA population. Further research is necessary to identify the current use of traditional foods and the barriers impeding the consumption of a healthy diet. Health care professionals should assess the socioeconomic, cultural and environmental factors impacting dietary intake to provide appropriate nutrition education to improve health and decrease risk for chronic disease.

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Table 4.1. Most frequently reported foods of Oklahoma Native American women from the 1-day food lists (n=74)

Description	Frequency[1]	%[2]	Cumulative %
Coffee and tea	102	8.71	8.71
Soda	51	4.36	13.07
Butter/margarine/table fats	47	4.01	17.08
White bread	37	3.16	20.24
Diet soda	35	2.99	23.23
Coffee creamer	30	2.56	25.79
Baked/boiled/mashed potatoes	30	2.56	28.35
Sugar, white	29	2.48	30.83
Sugar substitute	26	2.22	33.05
Meat sandwich	26	2.22	35.27
Crackers	21	1.79	37.06
Bread, whole wheat	19	1.62	38.68
Eggs	19	1.62	40.31
Soup	18	1.54	41.84
Beef (not hamburgers)	18	1.54	43.38
Cereal, ready-to-eat and hot	18	1.54	44.92
Snack chips	18	1.54	46.46
2% milk	17	1.45	47.91
Orange juice	16	1.37	49.27
Bacon and sausage	16	1.37	50.64
Candy	14	1.20	51.84
Cakes, brownies, cookies	14	1.20	53.03
Fried potatoes	13	1.11	54.14
Cheese	12	1.02	55.17
Popcorn and pretzels	11	0.94	56.11
Salad dressing	11	0.94	57.05
Rice	10	0.85	57.90
Mayo and sour cream	10	0.85	58.75
Green salad	10	0.85	59.61
Whole milk	10	0.85	60.46
Broccoli and cauliflower	9	0.77	61.23
Grilled cheese sandwich	9	0.77	62.00
Picante sauce	9	0.77	62.77
Hamburger on a bun/bread	8	0.68	63.45
Banana	8	0.68	64.13
Ice cream	8	0.68	64.82
Chili and stew	8	0.68	65.50
Fried chicken	7	0.60	66.10
Carrots	7	0.60	66.70
Corn and hominy	7	0.60	67.29

Description	Frequency1	%2	Cumulative %
Fruit-flavored drinks and Kool Aid	6	0.51	67.89
Biscuits	6	0.51	67.81
Apple	6	0.51	68.32
Catsup	6	0.51	68.83
Gravy	6	0.51	69.34
Pizza	6	0.51	69.85
Green beans	6	0.51	70.37
Jelly and jam	5	0.43	70.79
Skim milk	5	0.43	71.22
Chicken (not fried)	5	0.43	71.65
Celery	5	0.43	72.08
Orange	5	0.43	72.50
Turkey	5	0.43	72.93

Total foods reported 1171

[1]Frequency values indicate consumption of a food item during a single eating event
[2]% is proportion of frequency to total number of foods reported

Table 4.2. Most frequently reported foods of Oklahoma Native American women from the 4-day food records (n=71)

Description	Frequency[1]	%[2]	Cumulative %
Coffee and tea	263	7.93	7.93
Soda	216	6.51	14.44
White bread	137	4.13	18.57
Butter/margarine/table fats	129	3.89	22.46
Diet soda	120	3.62	26.08
Eggs	84	2.53	28.61
Fried potatoes	75	2.26	30.87
Candies	75	2.26	33.13
Snack chips	68	2.05	35.18
Bacon and sausage	63	1.90	37.08
Fruit-flavored drinks and Kool Aid	58	1.75	38.83
Wheat bread	56	1.69	40.52
Sugar substitute	55	1.66	42.18
Sugar	54	1.63	43.80
Cakes, brownies and cookies	48	1.45	45.25
Cheese	45	1.36	46.61
Baked/boiled/mashed potatoes	45	1.36	47.97
Cereal, ready-to-eat and hot	41	1.24	49.20
Fried chicken	39	1.18	50.38
Beef	36	1.09	51.46
Green salad	35	1.06	52.52
Salad dressing	35	1.06	53.57
Tomatoes	35	1.06	54.63
Orange juice	33	0.99	55.62
Soups and stews	33	0.99	56.62
Hamburger on a bun/bread	32	0.96	57.58
Banana	31	0.93	58.52
Cheeseburger on a bun/bread	29	0.87	59.39
Ice cream	28	0.84	60.24
Crackers	28	0.84	61.08
Gravy	26	0.78	61.86
Coffee creamer	26	0.78	62.65
Onion	26	0.78	63.43
Meat pizza	25	0.75	64.18
Ham	24	0.72	64.91
Mustard	23	0.69	65.60
Rice	23	0.69	66.29
Popcorn and pretzels	23	0.69	66.99
Ground beef	23	0.69	67.68
Green beans	22	0.66	68.34

Description	Frequency1	%2	Cumulative %
Hotdog	22	0.66	69.01
Biscuit	21	0.63	69.64
Fry bread	21	0.63	70.27
Potato salad	20	0.60	70.88
Bologna	19	0.57	71.45
Pickles	19	0.57	72.02
Chicken	18	0.54	72.57
Picante sauce	18	0.54	73.11
Whole milk	18	0.54	73.65
2% milk	17	0.51	74.16
Hotdog bun	16	0.48	74.65
Lettuce	15	0.45	74.10
Bread, whole wheat	15	0.45	75.55

Total foods reported 3317

[1]Frequency values indicate consumption of a food item during a single eating event
[2]% is proportion of frequency to total number of foods reported

Table 4.3 Most frequently reported foods of Native American women in the CSFII (n=28)

Description	Frequency	%	Cumulative %
Coffee, ground	44	6.12	6.12
Lettuce, raw	21	2.92	9.04
White sugar	19	2.64	11.68
Tomatoes, raw	18	2.50	14.19
Sugar substitute (aspartame)	14	2.36	16.55
Cola soft drink	14	1.95	18.50
White bread	12	1.67	20.17
Mustard	12	1.67	21.84
2% milk	11	1.52	23.36
Sugar substitute (sweet-n-low)	11	1.52	24.88
Orange Juice - can/bottle/carton	10	1.39	26.27
Onions - raw	10	1.39	27.66
Diet cola	10	1.39	29.05
100% whole wheat toast	9	1.25	30.30
Tea, unsweetened	9	1.25	31.55
Whole cow's milk	8	1.11	32.66
Cream substitute	8	1.11	33.77
Fried eggs	7	0.97	34.74
White bread toasted	7	0.97	35.71
Roll, white, soft	7	0.97	36.68
Tortillas, flour (wheat)	7	0.97	37.65
Decaf coffee	7	0.97	38.62
Butter	7	0.97	39.59
Margarine	7	0.97	40.56
American cheese	6	0.83	41.39
Apple – raw	6	0.83	42.22
Home fried potatoes	6	0.83	43.05
Fruit flavored drink	6	0.83	43.88
Evaporated whole milk	5	0.70	44.58
Orange, raw	5	0.70	45.28
Carrots, raw	5	0.70	45.98
Ice cream, not chocolate	4	0.56	46.54
American cheese	4	0.56	47.10
Ground beef	4	0.56	47.66
Ground beef, lean, cooked	4	0.56	48.22
Baked potato, peel eaten,	4	0.56	48.78
Cucumber, raw	4	0.56	49.34
Regular mayo	4	0.56	49.90
Fruit drink, w/ added C & sugar	4	0.56	50.46
Cream (half and half)	3	0.42	50.88
Ground beef, regular, cooked	3	0.42	51.30
Pork bacon	3	0.42	51.72
Sliced ham, luncheon meat	3	0.42	52.14
Tuna salad	3	0.42	52.56
Pinto beans	3	0.42	52.98

Description	Frequency	%	Cumulative %
Bread, whole wheat	3	0.42	53.40
Grapefruit juice	3	0.42	53.82
Banana, raw	3	0.42	54.24
Watermelon	3	0.42	54.66
Apple juice w/ added C	3	0.42	55.08
White potato chips	3	0.42	55.50
Catsup	3	0.42	55.92
Herbal tea	3	0.42	56.34
Total foods reported	719		100.00

[1]Frequency values indicate consumption of a food item during a single eating event
[2]% is proportion of frequency to total number of foods reported

Table 4.4 Spearman's correlations between perceptions on fat and sugar content and health value and frequency of consumption of most commonly consumed foods among Native American women (n=71)

	Low Fat	Not Sure	High Fat	Spearman's
Food	**Mean ± SD**	**Mean ± SD**	**Mean ± SD**	**Rho[1]**
coffee and tea	3.00 ± 2.78 n=43	5.23 ± 3.25 n=22	3.00 ± 3.52 n=6	0.237*
coffee creamer	0.10 ± 0.45 n=20	0.00 ± 0.00 n=12	0.62 ± 1.31 n=39	0.303*
baked/boiled/mashed potatoes	0.37 ± 0.49 n=30	1.40 ± 0.89 n=5	1.08 ± 0.91 n=36	0.398**
sugar substitute	1.06 ± 1.65 n=49	0.11 ± 0.46 n=19	0.67 ± 1.15 n=3	-0.309**
sandwich	1.11 ± 1.13 n=38	2.20 ± 2.28 n=5	0.54 ± 0.92 n=28	-0.261*
eggs	1.81 ± 1.56 n=16	1.78 ± 0.67 n=9	0.83 ± 1.02 n=46	-0.381**
cheese	0.20 ± 0.41 n=15	0.00 ± -- n=1	0.84 ± 1.08 n=46	0.267*
jelly and jam	0.10 ± 0.10 n=10	0.00 ± 0.00 n=23	0.32 ± 0.63 n=37	0.269*
	Low Sugar	**Not Sure**	**High Sugar**	**Spearman's**
Food	**Mean ± SD**	**Mean ± SD**	**Mean ± SD**	**Rho[2]**
whole wheat bread	1.33 ± 1.68 n=52	0.00 ± 0.00 n=7	0.36 ± 0.67 n=11	-0.294*
chicken	0.43 ± 0.70 n=51	0.00 ± 0.00 n=11	0.13 ± 0.35 n=8	-0.261*
	Healthy	**Not Sure**	**Not Healthy**	**Spearman's**
Food	**Mean ± SD**	**Mean ± SD**	**Mean ± SD**	**Rho[3]**
diet soda	2.17 ± 3.14 n=23	0.83 ± 2.83 n=18	0.66 ± 1.54 n=29	-0.255*
cheese	0.49 ± 0.86 n=51	1.40 ± 1.34 n=5	1.21 ± 1.19 n=14	0.348**
hamburger	1.44 ± 0.89 n=16	0.70 ± 0.67 n=10	0.70 ± 0.76 n=44	-0.309**
corn and hominy	0.15 ± 0.40 n=66	1.00 ± -- n=1	0.50 ± 0.58 n=4	0.306*
gravy	0.45 ± 0.52 n=11	0.93 ± 0.83 n=14	0.29 ± 0.55 n=45	-0.280*
jelly and jam	0.00 ± 0.00 n=11	0.06 ± 0.24 n=17	0.28 ± 0.59 n=43	0.251*

[1] Spearman's Rho based on low fat=1, not sure=2, high fat=3

[2] Spearman's Rho based on low sugar=1, not sure=2, high sugar=3

[3] Spearman's Rho based on healthy=1, not sure=2, not healthy=3

*P<0.05, **P<0.01

CHAPTER V

IMPACT OF CORE AND SECONDARY FOODS ON NUTRITIONAL COMPOSITION OF DIETS IN NATIVE AMERICAN WOMEN

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ABSTRACT

Objective: To identify the core and secondary foods among Native American women in Oklahoma and to determine their impact on nutrient and Food Guide Pyramid (FGP) serving intakes.

Design: This descriptive study explored food intakes from 4-day weighed food records. Nutrient intakes were estimated using reference data used in national survey data.

Subjects/setting: Seventy-one Native American women receiving services from three tribal health clinics in Northeast Oklahoma.

Statistical analyses performed: A food use frequency score was computed using frequencies of individuals consuming foods across each of 4 days of record. Leading contributors of nutrients and Food Guide Pyramid servings were identified from core and secondary foods.

Results: Thirty foods comprised the list of core foods, lead by soda, coffee and white bread. A majority of total energy, fat, saturated fat, MUFA, PUFA, cholesterol, carbohydrate, calcium, vitamin C, folate, discretionary fat and added sugar were derived cumulatively from the core and secondary foods. Forty percent of fruit FGP servings were accounted for by 2 core foods, bananas and orange juice. More than half of meat and vegetable FGP servings were derived from core and secondary foods.

Applications/conclusions: Food patterning data is helpful to the development of effective nutrition education programs. We identified less nutrient-dense core foods that are contributing to discretionary fat and added sugar intakes. Targeted nutrition education programs for Native Americans should promote the nutrient-dense core and secondary foods, such as wheat bread and fruit, while providing healthier food alternatives to less nutrient-dense foods.

INTRODUCTION

The dietary habits of Native Americans (NA) have undergone major transitions over recent centuries (18;25). Relocation of many Native peoples from their homelands to ecologically dissimilar regions beginning in the mid-19th century triggered dramatic changes in food intake behaviors (25;26). Survival required the adoption of new foods and agronomical practices. For tribes that were removed from their homelands, diets were modified to include a reliance on local small game or the utilization of military rations of white flour, baking powder and lard (25). These rations were used by soldiers to make biscuits but were used by NAs to produce fry bread (25). Other governmental provisions included salt pork bacon, potatoes, beans, sugar, coffee and tea. For those tribes that were allowed to return to a portion of their native lands, return to traditional sustenance activities were challenging because of an altered physical environment as a result of white settlement.

The potential for historically traditional foods to contribute to contemporary dietary intakes is moderated by many factors. Political and economic factors influence the role specific foods may play in current food intake behaviors (17;25;26;32;34). Federal limitations on hunting and gathering practices restrict reliance on fishing and wild game (17;32). Seasonal variation and availability of plant and animals directly impact the food use of some Native groups (35). Furthermore, taste preferences were

significantly correlated to the integration of traditional seafood, berries, wild game and plant roots into contemporary Nuxalk diets (32). Despite these reported preferences, consumption of historically traditional NA foods has decreased to peripheral food status despite the role they could potentially play as more healthy food alternatives (65;66).

In general, investigations of food intake behaviors in NA populations have been focused on nutrient intakes and their comparisons to national survey data or recommended nutrient intakes (22;34;35;42;46;51;199). Few studies have examined foods and the resultant contribution to overall dietary intake (18-20;45). Moreover, food patterning has not been widely studied in NAs even though it is very important to know food patterns to plan effective nutrition education interventions (17;30;46;65). Little is known about the perceptions of Native Americans towards healthy lifestyle behaviors, such as consuming a low fat diet and more vegetables and fruits (56).

Dietary habits are influenced by cultural and social functions and need to be understood prior to development of programs attempting to improve dietary intake (28;57-60). One method of studying overall food habits is the food-patterning method by interviewing the target group and studying the practices of interest. The foods that people commonly eat are typically categorized based on frequency of consumption into core and secondary foods (61-63). When designing a nutrition education intervention, the contribution of core and secondary foods to overall diet should be emphasized and change the focus of the diet based on their contribution (64). The objective of this study was to identify the core and secondary foods and their impact on overall nutrient intakes in NA women in Oklahoma.

METHODS

Subjects

A convenience sample of 81 Oklahoma NA women was used for the collection of

the 4-d weighed food records. Women of at least ¼ NA blood quantum, between the ages of 18 and 65, were eligible for participation. Volunteers were excluded from participation if they were pregnant, lactating or had a chronic disease, such as cancer, that altered food intake. Participants were recruited with the aid of key informants from the tribal health clinics of three NA tribes in Northeast Oklahoma. Women were screened according to aforementioned criteria prior to participation by the NA interviewers prior to beginning the three interview process. The Institutional Review Board at Oklahoma State University and the tribal business council of each tribe approved the study protocol.

Collection and Analysis of the 4-d Weighed Food Record Data

Eighty-one women completed a 4-d weighed food record; however, ten participants were excluded from subsequent analysis because they had incomplete food records or failed to weigh any items across the four days. Seventy-one women provided complete 4-d weighed food record data, yielding a net total of 284 days of food intake. The participants were trained by female NA interviewers to weigh initial portions and leftovers using an Ohaus CS 2000 or 5000 dietetic scale (Ohaus, Pine Brook, NJ) and record amounts consumed. Additional instructions were provided for recording when foods were consumed away from home.

Foods reported in the food records were entered into Microsoft Excel 2000 and were matched to US Department of Agriculture (USDA) survey food codes that are used for calculation of nutrient content for the National Health and Nutrition Examination Survey (NHANES) analyses. Nutrient amounts and Food Guide Pyramid (FGP) servings per 100 g of food from the food codes were used to estimate nutrient content, discretionary fat, added sugars and FGP servings (178) for all foods consumed in the food records. Data were then imported into SPSS (version 10.0, SPSS Inc., Chicago, IL) for frequency analysis to generate the core and secondary foods as well as estimate

nutrient and FGP serving intakes.

Identifying core and secondary foods

The individual foods listed in the 4-d food records were recoded into discrete food groups of similar foods for analysis (179;180). For example, all similar types of American cheese were recoded as American cheese. Foods such as fried chicken nuggets and cheeseburgers from various fast foods establishments were recoded as fast food fried chicken and fast food hamburgers, respectively.

The frequency of consumption of foods during the 4-d weighed food record and the proportion of people consuming these foods were used to identify and verify core and secondary foods using a modification of a method previously developed (62;63). Fanelli et al. (63) assessed three days of intake derived from 24-hour recall data from the Continuing Survey of Food Intakes by Individuals (CSFII); their protocol was modified to accommodate four days of food intake from the weighed food records.

Initially, a raw frequency of the recoded foods was conducted to identify the top 150 foods reported and used in the food use frequency score tabulation (63). A raw frequency of 4 provided a list of 152 foods for core and secondary foods determination. Food record data were originally coded with the subject's ID number and the day of food intake record (1 through 4). Frequency analysis was conducted to ascertain the proportion of subjects consuming each food on each of the four days of recorded food intake.

A food use frequency score (S) was tabulated using the proportions of the population consuming the item on none (R_1), one, two, three and four days (R_5) of record. Also, a scale weighting of one was included for foods not consumed on any of the four days in record (S_1) and a scale weighting of five for foods consumed on all four days (S_5). The food use frequency score was computed using the following formula:

$$\text{Score (S)} = [(R_1S_1 + R_2S_2 + R_3S_3 + R_4S_4 + R_5S_5) / 5]$$

where: R_1 = % of respondents not eating food on any of 4 days

R_2 = % of respondents eating food 1 of 4 days

R_3 = % of respondents eating food 2 of 4 days

R_4 = % of respondents eating food 3 of 4 days

R_5 = % of respondents eating food daily

S_1 = 1 = scale weighting for foods not eaten on any of 4 days

S_2 = 2 = scale weighting for foods eaten 1 of 4 days

S_3 = 3 = scale weighting for foods eaten 2 of 4 days

S_4 = 4 = scale weighting for foods eaten 3 of 4 days

S_5 = 5 = scale weighting for foods eaten 4 of 4 days

The lowest possible score (S) was 20 with only one person consuming a food on one day of recorded food intake and the remainder not consuming the specified food on any day of record. The highest possible score was 100 if a food was consumed by all subjects on all four days of record. A cut off of thirty foods was used to determine the list of core foods. For example, the most frequently reported food was soda. Soda was not consumed by 32.4% of the sample on any days of recorded food intake, while 12.7%, 9.9%, 21.1% and 23.9% consumed soda on one, two, three and four days, respectively. Using the aforementioned formula, the food use frequency score for soda was computed as 58.3.

To determine the contribution of the core and secondary to dietary intake patterns, the proportion of total nutrient and FGP serving intakes derived from core and secondary foods were computed using previous research as a guide (179;180). Leading contributors of FGP groups as well as total energy, carbohydrates, protein, fats, dietary fiber, cholesterol, iron, calcium, sodium, vitamin C and folate were identified among the core and secondary foods.

RESULTS

Of the 71 women completing the 4-d weighed food records, the mean age and degree of Indian blood was 43.8 years and 64%, respectively. Participants from a total of 16 different tribal affiliations were recruited through the three tribal health clinics. A third of the sample had diagnosed diabetes. Based on BMI calculated from self-reported height and weight, approximately one-quarter were overweight and a majority (90%) were classified as obese.

More than 3,300 individual foods were recorded from the food records. Proportions of participants consuming the foods across none, one, two, three and four days and the food use frequency score for each food are reported in Table 1. Core and secondary foods determined by the food use frequency scores were similar to the rankings of foods based on raw frequency. No large differences in food use frequency scores were evident to indicate a clear break between core and secondary foods; therefore the top 30 foods were used to indicate core foods (63). A total of 55 foods comprised the list core and secondary foods among the NA women.

Soda (S=58.2) and coffee (S=49.6) were the foods consumed most often by the NA women. White bread, butter/margarine and tea completed the top 5 core foods with scores of 48.2 and 42.5, respectively. Diet soda, chips, candies, sugar and sugar substitutes completed the list of the ten most commonly consumed core foods. Of all core foods, seven were beverages with only one, orange juice, being a juice. Vegetables and fruits were relatively absent from the list of core foods, with tomatoes, banana, orange juice and onion each being consumed less often than french fried potatoes (homemade and fast food). Of the secondary foods, the most commonly consumed foods were mustard, ice cream, ground beef, rice, green beans and hotdogs. Fry bread, the only cultural (NA) food among the core and secondary foods, was reported less often among the secondary foods.

Cumulative contributions of the core and secondary foods to nutrient and FGP intakes are provided in Table 2. Together, core and secondary foods provided over half of FGP grain and vegetable servings for the NA women. Approximately 40% of total vegetable FGP servings were derived from core foods; vegetables were most commonly in the form of french fries. Secondary foods provided an additional 19% of all vegetable FGP servings consumed. Two foods, orange juice and bananas, provided essentially all of the fruit FGP servings from the core and secondary foods. Nearly one-third of milk FGP servings were derived from secondary foods, including meat pizza and whole milk; secondary foods, such as fried chicken, ground beef and hot dogs, provided one-quarter of total meat FGP servings.

Evaluation of the contribution of core and secondary foods to nutrient intakes indicate a strong impact on overall intakes. A majority of total energy, fat, saturated fat, MUFA, PUFA, cholesterol, carbohydrate, calcium, vitamin C and folate were derived cumulatively from the core and secondary foods. Over 70% of total added teaspoons of sugar and 47% of carbohydrates were derived from core foods, primarily in the form of regular soda. White bread served as the leading contributor of iron, sodium, folate, protein and fiber for the core foods (data not shown). Orange juice and fruit-flavored drinks provided the bulk of the vitamin C amongst core and secondary foods. Discretionary fat was more evenly distributed across various foods, with chips, butter or margarine, meat pizza and french fried potatoes providing the most discretionary fat.

DISCUSSION

Limited data is available in NAs with regard to the role of core and secondary foods to overall food intakes. Previous efforts of food patterning determined core and secondary foods based on frequency of consumption using food frequency (ffq) methodologies (62;65) or from food recall data (44;63). Early work with food patterning

was conducted in Caucasian populations (63;170). Reaburn et al. (62) used a list of foods reported to be commonly consumed food to identify core foods in adults in Toronto, Canada. Results from the analysis of the ffq provided a list of core foods that included 2%, whole and powdered milk, white bread and whole wheat bread. Analysis of the1977-1978 National Food Consumption Survey (NFCS) indicated whole milk, coffee, potatoes and white bread were core foods among older Caucasian Americans (63). Results from the NFCS did not differ greatly based on gender or age. The lists of core foods provided from these two studies are similar to the list generated in this study except for the presence of milk as a core food. Core foods in this study were void of calcium-rich foods, including milk products. Because limited data are available regarding lactose intolerance among Oklahoma NAs, it is not clear if this condition plays a role in the low calcium and milk FGP servings found in the present study.

Of the research addressing food patterning in NAs, Koehler et al. (65) created a food frequency containing foods determined by the researchers to be valid in NA, Mexican American and white children in the southwest US. Their results indicated the following were core foods in Navajo and Jemez Indian children's diets: eggs, whole milk, tortillas, bread, cereal, pancakes, potatoes, bananas, citrus fruit, other fresh fruit, fruit juice, soda, fruit ades and salty snacks. Ballew et al. (44) analyzed 24-hr recall data to report core foods for Navajo adults, which included Navajo tortillas and fry bread, home-fried potatoes, soft drinks, coffee and tea, mutton and mixed dishes containing mutton, and bacon, sausage, lunch and canned meats. These foods provided 41% of total energy intakes among the Navajo, which is similar to the 53% of energy intakes contributed by core and secondary foods in the present study. Further, soft drinks and fried potatoes contributed considerably to carbohydrate and fat intakes, respectively, as well as overall energy intakes in the diets of Navajo adults and our NA women in the current study.

Determining the frequency of consumption and role of historically traditional foods to total nutrient intakes are also important when evaluating food intake behaviors of NAs. For some groups, Native foods have been reduced to use during ceremonies or other special occasions (34). The relative absence of historically traditional foods from the resulting core and secondary foods in our data is of note, as concerns have been expressed about the transition from a historically traditional diet, which is often perceived to be healthier, to a Westernized diet (17;32;33). Between diets described by NAs in three Yukon communities be ideal among and actual intakes, ideal diets contained a two-fold greater number of historically traditional foods as compared to actual measured food intakes (17). Therefore, if historically traditional foods have the potential to improve the health and quality of food intakes, future research is needed to identify the NA perceptions of these foods and the potential benefits and barriers to incorporation into contemporary diets.

Several challenges have been identified in food patterning in NAs. The use of the ffq may provide little flexibility in identifying historically traditional native foods and their contribution to overall nutrient intakes (200). In addition to the source of data, seasonal variation and regional and cultural differences can provide further limitations in estimating core and secondary foods (63). Food intake data for the present study was collected over a 14 month period, which helps account for seasonal variability in food intakes. Another limitation is the use of convenience sampling in Oklahoma NA women; the results may not be reflective of all NA women. Further research is necessary to better understand food patterning and the role of core and secondary foods to nutrient intake.

APPLICATIONS/CONCLUSIONS

Core and secondary foods have the capability to greatly influence overall energy, nutrient and FGP serving intakes. Our results indicate that these foods contribute to one-half or more of the total nutrient and FGP intakes across four days of food records. Identification of the core and secondary foods provides valuable information for nutrition education programming. The more nutrient-dense core and secondary foods should be encouraged while also teaching moderation and the substitution of more-healthy alternatives for less nutrient-dense foods. Efforts should focus on limiting less healthy core foods, including regular soda, chips, candies and fried foods, to improve total energy, fat and added sugar intakes and increasing healthier core foods, such as wheat bread, bananas and tossed salad with mixed greens and vegetables. Also, nutrition education programs should promote nutrient-dense secondary foods, such as rice and 2% milk that could contribute to more healthy nutrient intakes. Further, programs should continue to encourage consumption of a variety of vegetables and fruits, especially whole fruits and non-fried vegetables.

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Table 5.1. Frequency of consumption and food use frequency score tabulation for determination of core and secondary foods.

	Food[1]	Raw Freq	Rank	% Consuming on n days					Score
				0	1	2	3	4	
Core Foods	soda	216	1	32.4	12.7	9.9	21.1	23.9	58.3
	coffee	128	2	45.1	16.9	4.2	12.7	21.1	49.6
	white bread	125	3	31.0	22.5	26.8	14.1	5.6	48.2
	butter/margarine	114	5	38.0	29.6	16.9	12.7	2.8	42.5
	tea	104	6	52.1	11.3	19.7	12.7	4.2	41.1
	diet soda	119	4	63.4	9.9	4.2	8.5	14.1	40.1
	chips	66	8	42.3	36.6	16.9	4.2	0.0	36.6
	candies	75	7	52.1	28.2	9.9	7.0	2.8	36.0
	sugar substitute	56	t9	67.6	14.1	9.9	4.2	4.2	32.7
	sugar	54	11	67.6	14.1	9.9	4.2	4.2	32.7
	wheat bread	56	t9	67.6	12.7	9.9	9.9	0.0	32.5
	french fries	40	12	60.6	28.2	7.0	4.2	0.0	31.0
	fried eggs	37	13	70.4	16.9	7.0	4.2	1.4	29.8
	salad dressing	35	t14	69.0	18.3	9.9	2.8	0.0	29.3
	tomatoes	35	t14	66.2	25.4	4.2	4.2	0.0	29.3
	orange juice	33	t16	70.4	19.7	2.8	7.0	0.0	29.2
	bacon	33	t16	69.0	21.1	5.6	2.8	1.4	29.2
	American cheese	32	t19	69.0	21.1	8.5	1.4	0.0	28.5
	banana	31	t21	70.4	21.1	5.6	2.8	0.0	28.1
	tossed salad	32	t19	73.2	15.5	9.9	1.4	0.0	27.9
	crackers	28	t24	73.2	18.3	5.6	2.8	0.0	27.6
	scrambled eggs	27	26	69.0	23.9	7.0	0.0	0.0	27.6
	kool aid	33	t16	76.1	16.9	2.8	4.2	0.0	27.0
	sweetened tea	31	t21	80.3	9.9	4.2	5.6	0.0	27.0
	sausage	30	23	71.8	21.1	7.0	0.0	0.0	27.0
	cookies	28	t24	71.8	23.9	2.8	0.0	1.4	27.0
	ff french fries	26	t27	71.8	23.9	1.4	2.8	0.0	27.0
	coffee creamer	26	t27	83.1	8.5	2.8	4.2	1.4	26.5
	onion	26	t27	71.8	23.9	4.2	0.0	0.0	26.4
	ham	24	31	73.2	22.5	2.8	1.4	0.0	26.4
Secondary Foods	mustard	23	t32	77.5	14.1	8.5	0.0	0.0	26.2
	ice cream	23	t32	78.9	14.1	5.6	0.0	1.4	26.2
	ground beef	23	t32	73.2	23.9	1.4	1.4	0.0	26.2
	rice	23	t32	73.2	22.5	4.2	0.0	0.0	26.2
	green beans	22	36	76.1	19.7	2.8	1.4	0.0	25.9
	hotdog	21	t37	76.1	19.7	2.8	1.4	0.0	25.9
	meat pizza	25	30	74.6	22.5	2.8	0.0	0.0	25.6
	brown gravy	21	t37	76.1	22.5	0.0	1.4	0.0	25.3
	bologna	19	t42	77.5	18.3	4.2	0.0	0.0	25.3
	fry bread	21	t37	85.9	4.2	8.5	1.4	0.0	25.1
	potato salad	20	t40	81.7	12.7	4.2	1.4	0.0	25.1
	fried chicken	20	t40	76.1	22.5	1.4	0.0	0.0	25.1
	salsa	18	t44	81.7	11.3	7.0	0.0	0.0	25.1
	ff cheeseburger	18	t44	78.9	18.3	1.4	1.4	0.0	25.1
	mashed potatoes	18	t44	77.5	19.7	2.8	0.0	0.0	25.1
	ff fried chicken	19	t42	81.7	14.1	2.8	1.4	0.0	24.8
	biscuit	17	t49	78.9	18.3	2.8	0.0	0.0	24.8
	pickles	17	t49	80.3	15.5	4.2	0.0	0.0	24.8
	boiled eggs	18	t44	84.5	12.7	0.0	1.4	1.4	24.5
	whole milk	18	t44	81.7	14.1	4.2	0.0	0.0	24.5
	2% milk	17	t49	83.1	11.3	5.6	0.0	0.0	24.5
	hamburger	17	t49	78.9	19.7	1.4	0.0	0.0	24.5
	popcorn	16	t54	78.9	19.7	1.4	0.0	0.0	24.5

[1]**ff indicates fast food**

Table 5.2. Contribution of core and secondary foods to total nutrient intakes and Food Guide Pyramid intakes from the 4-d weighed food records.

	Mean ± SD	Core Foods	Secondary Foods	Cumulative %
FGP Servings		**% of total FGP serving intakes**		
Grain	6.4 ± 2.7	29.3%	20.8%	50.1%
Vegetable	3.4 ± 1.6	42.1%	19.4%	61.6%
Fruit	0.9 ± 1.0	40.9%	0.0%	40.9%
Milk	0.7 ± 0.6	12.9%	36.3%	49.3%
Meat	2.1 ± 0.7	16.1%	28.1%	44.3%
Nutrient		**% of total nutrient intakes**		
Energy (kcals)	1884 ± 595	36.3%	19.3%	55.6%
Pro (g)	68± 22	18.6%	25.3%	43.8%
Total Fat (g)	76 ± 27	30.3%	24.2%	54.5%
Sat Fat (g)	25 ± 9	29.6%	25.1%	54.7%
MUFA (g)	30 ± 11	31.1%	24.1%	55.2%
PUFA (g)	15 ± 8	31.4%	22.9%	54.3%
Cholesterol	292 ± 135	33.4%	26.4%	59.8%
CHO (g)	231 ± 86	47.1%	13.7%	60.8%
Dietary Fiber (g)	13 ± 5	28.1%	15.5%	43.6%
Iron (mg)	12.5 ± 4.4	26.2%	18.0%	44.2%
Calcium (mg)	522 ± 256	24.3%	28.8%	53.1%
Sodium (mg)	2646 ± 945	26.3%	21.3%	47.6%
Vitamin C (mg)	66 ± 42	42.7%	9.4%	52.1%
Folate (mcg)	297 ± 122	35.1%	15.6%	50.7%
Discretionary Fat (g)	58 ± 23	32.4%	24.2%	56.6%
Added Sugar (tsp)	22 ± 15	70.4%	6.0%	76.4%

CHAPTER VI

SOCIAL AND CULTURAL BARRIERS TO DIABETES PREVENTION IN OKLAHOMA AMERICAN INDIAN WOMEN

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ABSTRACT

Introduction: The prevalence of diabetes is disproportionately higher among minority populations, especially American Indians. Prevention or delay of diabetes in this population would improve quality of life and reduce health care costs. Identifying cultural definitions of health and diabetes is critically important to developing effective diabetes prevention programs.

Methods: In-home qualitative interviews were conducted with 79 American Indian women from 3 tribal clinics in northeast Oklahoma to identify a cultural definition of health and diabetes. Grounded theory was used to analyze verbatim transcripts.

Results: The women interviewed defined health in terms of physical functionality and absence of disease, with family members and friends serving as treatment promoters. Conversely, the women considered their overall health to be a personal issue to be addressed individually without burdening others. The women presented a fatalistic view of diabetes, regarding the disease as an inevitable event that destroys health and ultimately results in death.

Conclusions: Further understanding of the perceptions of health in at-risk populations will aid in developing diabetes prevention programs.

INTRODUCTION

The American Indian people and culture have sustained serious hardships throughout the last 2 centuries; their greatest struggle, however, may now be impending. The rate of diabetes is disproportionately higher in minority populations, especially the American Indian population (30;81;201;202). Indian Health Service (IHS) national outpatient data indicate that the age-adjusted prevalence rate of diabetes among American Indians is an estimated 88.7 per 1000 for individuals more than 15 years of age (2). In the Oklahoma City area, the largest of IHS areas, the age-adjusted prevalence rate of diabetes is 60 per 1000 individuals (81), indicating that American Indians are 2.43 times more likely to have diabetes than the general population at 39 per 1000 individuals (81;82). Furthermore, national data indicates age-adjusted prevalence rates are greater for American Indian women (12.0%) compared to American Indian men (9.7%) (81). Lee et al. (70) observed that 38% of American Indian men had diabetes compared with 42% of American Indian women in an Oklahoma sample.

Diabetes is a multifaceted disease that is reaching epidemic proportions in the American Indian community (201). If diabetes could be prevented or delayed in this population, the benefits in quality of life and health care cost savings would be considerable. Rhoades et al. (100) estimated 882 years of productive life lost due to diabetes mellitus itself over a 3 year period among American Indians receiving healthcare services from IHS. Diabetes results in compromises to longevity and quality of life as well in economic disadvantages. Health care costs for treatment of non-American Indian patients with diabetes in 1994 were 2.4 times greater than non-American Indian controls, with long-term complications accounting for 38% of the costs (102). Through a Monte Carlo study based on American patients with diabetes, intensive blood sugar control was estimated to produce reductions in health care costs of 3% over 30 years (102). Additionally, Oklahoma Behavioral Risk Factor Surveillance Survey data

demonstrated a significantly greater number of days of disability and poor physical health for patients with diabetes compared to control subjects without diabetes (103). These data have obvious ramifications for workplace productivity. Success at delaying or preventing the onset of diabetes will reduce the costs of diabetes treatment and prolong an individual's potential to be a contributing member of the economy.

A greater understanding of American Indian perceptions of health and diabetes is paramount to the success of diabetes prevention programs among these populations (160-163). Perceptions of the inevitability of diabetes within the reservation environment have been reported (72;76;91). Perceptions of health among American Indian elders in an urban setting have also been presented (75). Data is lacking on the relationship of diabetes to health and the social environment as well as the perception of the feasibility of diabetes prevention. This study used in-depth qualitative interviews to ascertain a cultural definition of health and diabetes from American Indian women residing outside a reservation setting. The information learned will be used to plan culturally appropriate nutrition education and health promotion programs aimed at preventing or delaying the onset of diabetes among American Indians in Oklahoma.

METHODS

The data contained herein is a portion of a larger study, which involved a series of 3 sessions with each study participant. The first session included demonstration of informed consent, completion of a demographic questionnaire and a rank-order assessment of life concerns, and training for a 4-day weighed-food record collection. During the second interview, the participants responded verbally to questions from the *Cultural Structure of Health and Diabetes* questioning guide (Table 6.1) and completed a free food sort of previously determined most-commonly consumed foods which allows the participants to classify foods into groups based on their own classifications. The final

session included a weight valuation interview to identify the cultural perceptions of body image and a trichotomous food sort of the most commonly consumed foods used for the previous food sort where the participant sorts foods based on their perception of healthy value and fat and sugar content. The research protocol was reviewed and approved by the Institutional Review Board at Oklahoma State University and the executive counsels for the Iowa, Kanza and Pawnee tribes.

Interviewer Training Five female American Indian interviewers were hired to conduct the in-depth interviews. Each interviewer 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 $125 for each participant that completed all three interviews.

Participants Women of at least one quarter American Indian blood, between the ages of 18 and 65 years of age, who were not pregnant or lactating, were eligible for the study. A diagnosis of chronic disease, including diabetes, did not prevent inclusion; however, women diagnosed with chronic diseases that have an impact on appetite (including women receiving cancer treatment), were excluded from the study. Women were recruited proportionately from Iowa, Kanza and Pawnee tribal health clinics in northeast Oklahoma using a non-probability sampling design. To increase participation rates, women who successfully completed the interview process received $125.

Key informants and the American Indian interviewers at each of the clinics recruited potential subjects for the research study. Articles were published in tribal newsletters and newspapers to promote the study. Women interested in participating were referred to one of the interviewers to receive more information, determine eligibility,

and schedule interviews. Additional subjects were recruited from tribal diabetes education programs and the 3 tribal general health clinics.

Data Collection and Analysis This study reports results of the interviews during the second session, in which participants responded orally to questions from the *Cultural Structure of Health and Diabetes* questioning guide (Table 6.1). Questions from previous research (183) were modified to identify cultural perceptions of health and the diabetes. 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 reviewed the questions for cultural sensitivity prior to their administration. Results based on each interviewer's session with the first participant served as a pilot; responses were analyzed as the data became available, and appropriate changes were made to the questioning guide.

Two researchers (KSK, CT) analyzed the verbatim transcripts from the audiotapes during data collection. Grounded theory guided analysis of the transcripts (176). An initial list of code words was derived from recurring themes in the transcripts (Table 6.3). Then, key concepts or recurring themes derived from the qualitative interviews were integrated into the questioning guide using the method of constant comparisons. The transcripts were reviewed throughout the interviewing process. Code word definitions were drafted to encompass the meaning of text segments. When new themes recurred in the transcripts, they were either assigned a new code word or a subcategory of an existing code word. Furthermore, the questioning guide was modified to capture more detail about the emerging themes. Text segments were coded with the corresponding code words using Ethnograph (version 5.04, Qualis Research Associates, Denver, CO). Following open coding, axial coding was used to identify subcategories with code words (176). The final step, selective coding, provides the means to assess

the relationship among constructs and to assess how concepts are related to their constructs to establish an overall phenomenon.

RESULTS

Eighty-one American Indian women completed the qualitative interviews. Two transcripts were not available because of technical failure of the recording devices, resulting in 79 usable interviews. Demographic characteristics of the sample are provided in Table 6.2. The mean age of the women was 43 $\pm$ 11 years while mean degree of American Indian blood was 65%. Though the sample was collected from 3 tribal health clinics, 16 different tribal affiliations were reported, making analysis by tribe impractical. Of the 79 women, 26 (33%) reported a previous clinical diagnosis of diabetes. Approximately 70% reported education beyond a high school; however, 72% indicated an annual household income of less than $25,000.

Twenty-nine 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 code words. The results of the analysis for code words associated with health and diabetes are presented below.

Cultural definition of health The American Indian women who took part in this study defined health predominantly in terms of lifestyle behaviors. Individuals performing positive behaviors — such as consuming a “healthy” diet, exercising, and not smoking — were considered healthier than those who did not. Being overweight was also considered to reflect negatively on health status.

Health was also defined in terms of the presence or absence of disease. For example, when individuals were asked to define their current health, they sometimes mentioned the presence or absence of several chronic conditions, including arthritis, diabetes, heart disease, and cancer. In the absence of a chronic disease, individuals

considered themselves to be healthy. Even if clinically diagnosed with disease, individuals did not perceive diminished health until there was a physical feeling of illness. Until an individual perceived a feeling of illness, they considered their health to be satisfactory. One woman said, “I haven't been throwing-up sick in years, but a little cold here and there.” This was especially true of diabetes, as the women interviewed did not consider the disease to be severe until it was manifested through long-term complications.

Another indicator of health status was defined through physical functionality. The women considered poor health to be an impairment to one’s ability to perform daily tasks: “Oh, my current health. I feel like I'm pretty healthy. I can still lift up things and get around.” The women viewed being healthy as having the capacity and energy to perform daily tasks and other activities. However, there were certain accommodations made for age. Furthermore, the women expected health to decline with age; many defined their health status according to expectations for their current age. One woman described feeling “not too good about my health and myself. It seems like I've been more tired. But I guess that's just this age.”

Cultural definition of diabetes Diabetes was defined most commonly in terms of long-term complications, which were often tied to fear and concern. The most frequently noted complication was amputation, expressed by one woman as “becoming a member of the stub club.” Some confusion existed about diabetes and its symptomology and long-term complications. Many women were unclear about long-term complications; some women said that dialysis and blindness were symptoms of diabetes. Confusion about hyperglycemia and hypoglycemia — and which one indicated diabetes — also existed. The women expressed the belief that hypoglycemia is an early symptom of diabetes that later converts to hyperglycemia.

Similarly, others expressed a fear of diabetes, calling it a “scary disease.” Diabetes was portrayed as devastating. As one participant said, “It ruins your health, and ultimately it will kill you.” Furthermore, diabetes was considered a malicious disease. One woman stated: “Diabetes is scary. It's a scary process. It's demeaning. I think it is a very, very cruel breakdown of your system.” The perception existed that a body being “out of balance” causes diabetes, and an error in the inner workings of the body results in a blood sugar imbalance.

“Fatalism” (91) toward diabetes and its complications was a strong theme among the women. One woman said, “I knew it was going to happen, but when it did happen, it was a surprise to me. And I felt like I was doomed.” The women interviewed expressed that being of American Indian descent leads to a belief in increased susceptibility to diabetes as well as a belief in the inevitability of getting diabetes.. Furthermore, the women feared having diabetes for an extended period of time without being diagnosed. The American Indian social network also fostered apprehension about diabetes, as most of interview participants knew someone with the disease.

Another prominent concern among the American Indian women was the possibility of their own or a family member’s diagnosis of diabetes. Interestingly, the women were more concerned about their children being diagnosed with diabetes than about their own possible diagnosis. Their statements about children being at risk reflected an overall concern for children developing diabetes. The women were also concerned about other members of their family, including siblings, spouses, and parents.

The women expressed the idea that after an individual is diagnosed with diabetes, his or her lifestyle behaviors must change. Diabetes was perceived to require thorough, demanding care. Appropriate care involved eating right, taking medicine, and doing “what the doctor tells you to do.” The women regarded diabetes care and behavior change as solely the responsibility of the individual.

Diabetes prevention When asked if it were possible to prevent diabetes, many of the women responded in terms of personal behaviors that may prevent or help delay the onset of diabetes. These responses centered on changing behaviors that cause diabetes, such as eating a poor diet and not exercising. To explore those responses, we asked further questions about when these potential preventative behaviors should begin, and a portion of the respondents indicated the need to reach children at young ages. Other participants with a more fatalistic view of diabetes suggested that diabetes was inevitable in individuals with a strong family history of the disease.

Barriers to diabetes prevention and treatment Some interview participants indicated that frequent visits to their health care professionals represented an appropriate method of diabetes prevention. Furthermore, the women perceived diabetes screening as a method of diabetes prevention in the absence of changing lifestyle factors. Issues of denial and avoidance of diagnosis were also strong, providing an additional challenge to diabetes prevention and treatment. Despite efforts to increase public awareness and opportunities for diabetes screening, women still avoided screening. Because an individual was considered to be in good health in the absence of physically feeling ill or the clinical diagnosis of a chronic disease, avoiding a visit to a health care professional (thus avoiding a screening) freed the individual from diagnosis and evaded the need for self-care — despite a personal suspicion of having the disease. One woman mentioned “[t]here might be a tendency for people to suspect it but not want to have it confirmed maybe....” In such situations, care for diabetes is delayed and the increased likelihood of long-term complications rises.

Furthermore, individuals did not express personal concern about diabetes until they were themselves facing diagnosis. If a positive diagnosis was made, those women expressed a strong sense of denial. One participant mentioned a family member who was “in denial, and won't go to the doctor, and then it gets worse, and then they'll go

after it starts getting too bad." Individuals often postponed care until they perceived a physical ailment — likely indicative of long-term complications.

Supporting social structure The women mentioned many sources of social support and information. They cited health care professionals as only one of many sources of information about health and diabetes. Community and family members served as both a considerable source of information and misinformation. Misconceptions ranged from the idea that diabetic individuals are forced into strict dietary modifications with a complete absence of sugar to the idea that diabetes can be "gotten rid of, if you take care [of yourself]." The women obtained much information about diabetes prevention, symptoms, and treatment from discussions with — or observation of the treatments received by — immediate or extended family and friends. Shared knowledge within these circles does not reflect the current state of diabetes care, but defer to an older pedagogy of diabetes care.

In addition to serving as sources of information, families were portrayed as mediators of health self-care. Many self-care concerns are rooted in the women's family caregiver roles, especially as gatekeepers of healthy meals. Their roles are challenged by having to make personal lifestyle behavior changes. For example, American Indian women are responsible for providing meals that satisfy the entire family. If their health requires dietary changes, they find it unacceptable to put their needs above the wants or needs of the family unit, greatly reducing the likelihood of behavior modification.

When asked how the family could aid in diabetes prevention efforts, familial and parental support was most commonly reported. Family discussions about health and diabetes as well as family attendance of educational sessions were indicated as methods of family involvement in diabetes prevention. However, one woman indicated that when she suspected she might have diabetes, her family discouraged screening because they thought it unlikely she would be diagnosed with the condition. This

demonstrates both the positive and negative social environment affecting diabetes prevention and treatment.

DISCUSSION

The qualitative method used in our study demonstrates an attempt to obtain a cultural definition of health and diabetes from American Indian women. The pervasiveness of diabetes was readily apparent: most participants had at least one family member or friend that had diabetes. Although one third of the participants had diabetes, the responses received from those without diabetes mirrored the responses of those with diabetes. An analysis of responses stratified by diagnosis of diabetes would provide little additional information.

Many factors — historical, political, sociocultural, and geographical — impact health perceptions among American Indians (75). Challenges abound in trying to define health as American Indians perceive it, especially through the lens of Western medicine. A gap exists between the discernment of a biologically defined chronic disease and the more culturally relevant presence of physical symptoms; this gap presents a strong barrier to accurate assessment of personal health status (67;72;77). In one study of Diné (Navajo) families with asthmatic children, asthma is perceived by the families as a series of individual episodic reactions requiring attention instead of an underlying physiological chronic inflammatory condition (23); the findings of the Diné study agree with our findings. Hatton (77) reported that elderly American Indians define their health in terms of the absence or presence of various chronic diseases. These results also concur with perceptions found in our sample. Also in the Hatton report, the capacity of individuals to perform activities of daily living and take care of themselves was regarded as an important aspect of personal health assessment (75); this capacity was deemed important by our study participants as well.

Of particular interest was the mutual dependency of the cultural definitions of health and diabetes. The women in our study held the belief that being unhealthy was discernable by physically feeling ill. Interviews with older American Indians residing in urban areas considered themselves to be healthy in the absence of any outward, perceivable sign of illness (75). The disjointed impression among our respondents that long-term complications are *symptoms* of disease (instead of the *consequences* of poor diabetes control) may be explained by the perception that one is not unhealthy unless a perceptible feeling of illness is present. When our study participants faced a clinical diagnosis of diabetes, they delayed self-care until long-term complications — accompanied by a decrease in physical function — became evident. To these women, long-term complications serve as the only tangible evidence of illness. It is this strong reliance on physical symptomology that provides a great obstacle to diabetes prevention, screening, and care.

A strong sense of inevitability pervaded the many ideas surrounding the pursuit of health and prevention of diabetes among our American Indian sample. Many — but not all — participants believed that diabetes is inevitable and ultimately leads to death, especially for individuals who have strong family histories of the disease. Previous research with the Gila River Indian Community describes these feelings of inevitability as “fatalistic” attitudes that moderate the perception of diabetes prevention and may serve as additional barriers to adopting prevention behaviors (91). Kozak (91) reported an overall sense of surrender to diabetes, which was viewed as an inevitable, uncontrollable disease that resulted in death. Additionally, Judkins (76, pg 1322) reported “highly fatalistic attitudes and verbalizations” about diabetes among the Seneca, accompanied by a feeling of powerlessness against the disease. It has been theorized that fatalism has developed as a social coping mechanism to deal with the severity of the diabetes epidemic and the resulting compromised quality of life (91).

Compensatory mechanisms built into cultural personality to deal with environmental and personal stress may precipitate denial or avoidance behaviors (76). A sense of inevitability may ultimately result in a decreased propensity to take necessary steps for disease prevention, which is often misconstrued by the administrators of Western medicine as non-compliance (72;91).

Additional barriers were evident in the prevention and treatment of diabetes in these American Indian women. Family dynamics play a critical role in health care in American Indians (67). With a shift from traditional economic strategies to mainstream business practices, traditional American Indian families are shifting toward more Western nuclear families, which has an impact on family dynamics (67). Additionally, family resistance to alterations in dietary habits serves as an additional barrier to diabetes prevention and care in American Indian women. To achieve successful behavior change, nutrition education and diabetes prevention programming must involve the family unit. To what extent will family obligations or positive social support structures within Native American communities allow self-care behaviors? How receptive are American Indian individuals to external support, and what is their capacity to overcome barriers for health promotion? These questions — as yet unanswered — require more research.

In addition to conflicts between healthy lifestyle behaviors and family obligations, avoidance of diabetes screening serves as an additional barrier to diabetes treatment. The women expressed an inclination to avoid screening even if they harbored suspicions of having the disease. Many diagnoses were reported while women were seeking medical treatment for unrelated reasons. If a clinical diagnosis is made, denial is likely, especially when no physical symptoms are apparent. Similarly, Huttlinger et al. (72) reported a case of a Diné woman who was taken to the doctor for a routine check-up against her will and subsequently diagnosed with diabetes. Though vehemently claiming

she felt fine, she had to undergo amputation because of the serious progression of her uncontrolled diabetes. This case demonstrates the family's role in encouraging women to seek care and how the lack of the physical signs of disease can hinder treatment.

There are several limitations of the current study, one of which is that American Indian women were hired from local American Indian communities to conduct the interviews, regardless of previous experience in qualitative interviewing techniques. Despite training in such techniques, they varied in the amount they probed on topics important to the research team. To address this concern, transcript reviewers analyzed interview tapes soon after retrieval and provided feedback to interviewers as additional training and guidance. Two, because transcript reviewers functioned as the research instrument, the lens through which reviewers read the transcripts provided bias. To address this concern, transcripts were read by the two researchers independently and then discussed until consensus was reached on coding. We achieved an inter-rater reliability of more than 90%. Furthermore, the lack of responses related to traditional healing practices and the role of spirituality may have been due to the recruitment of participants through tribal health clinics and is likely not representative of all American Indian cultures. Though snowball sampling aided in recruitment, participants recruited from the health clinics may have been more likely to seek medical treatment through the health clinics than traditional healing practices. Finally, the sample was derived through non-probability methods. Though these methods may decrease the generalizability of the findings, they are often needed to identify individuals from an at-risk population (75).

Despite these limitations, the congruency of the data to other reports of perceptions of diabetes among other American Indian groups provides support for our findings (75). Though results similar to ours have been reported, they were derived from reservation-living American Indian groups; we have identified perceptions of health and diabetes among a sample population outside the reservation setting. Our findings

indicate a more comprehensive approach to the underlying issues in health promotion and diabetes prevention than previous reports. Previous reports did not address the interrelationships of perceptions of health nor did they discuss issues of diabetes prevention. We have attempted to address some of these issues; however, each new issue presents new unanswered questions, indicating a need for further investigation of the cultural definitions of health and diabetes.

Efforts to identify disparities in health perceptions and worldviews are essential for developing nutrition education interventions that precipitate behavior change (157-159). Previous research and multi-site programs, including *Awakening the Spirit: Pathways to Diabetes Prevention & Control* (American Diabetes Association) and the National Diabetes Prevention Program (National Institute of Diabetes Digestive and Kidney Diseases), have demonstrated improved diabetes prevention and treatment by targeting specific lifestyle behaviors within the context of American Indian communities (173;203;204). American Indian communities vary widely in tribal affiliation and location; future researchers must identify the characteristics of each American Indian population studied to ensure that they meet the community's specific needs (96). The importance of solid formative data on a population is paramount, especially considering that a large portion of research is conducted on reservations. Furthermore, the extent to which the perceptions held by American Indian women in Northeast Oklahoma are congruent with other American Indians within and outside of Oklahoma needs to be examined to assist in designing effective education programs.

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Table 6.1. Cultural Structure of Health and Diabetes: Questioning guide for interviewing Oklahoma American Indian women about cultural perceptions of health and diabetes

1. Describe your current health to me.
2. Describe how you feel about your health.
3. What, if any, health concerns do you have?
4. What are the major health concerns of other Indian women you know?
5. What do you think is the leading cause of death for Indian women in the United States?
6. What comes to mind when I mention diabetes?
7. 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?
8. What do you think happens to a woman once she develops diabetes?
9. Can you think of anyone who is at risk for developing diabetes? (Is he or she Indian?)
10. How can a person tell if he or she has diabetes? How do they feel?
11. Tell me about anything that you know of that might keep a woman 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?
12. What may prevent a woman from doing the things that may prevent diabetes?
13. What treatments are there for diabetes that you know about?
    If diet, describe the diet.
14. Who are you concerned about developing diabetes?
    What are the reasons that you are concerned about this person(s)?
15. What can parents or family do to help prevent this person/child from developing diabetes?
16. What can the tribe or community do to help prevent this person/child from developing diabetes?
17. How do you feel about diabetes?
18. What is your greatest fear about diabetes?
19. What control do you think a person has over diabetes?
20. Can you prevent diabetes?
    When can a person begin to do these things to prevent diabetes?
21. 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 6.2 Demographic characteristics of Oklahoma American Indian women interviewed about cultural perceptions of health and diabetes

Characteristic[a]		
Age (years)	43.4 ± 11.4	
Degree of Indian blood (%)	64.6 ± 0.3	
Body mass index[b] (kg/m^2)	32.1 ± 6.9	
	N	**%**
Marital status[c]		
Married	30	38.5
Not married	48	61.5
Education		
High school or less	24	30.3
Some college	44	55.7
College degree	11	13.9
Employment		
Employed	52	65.8
Not employed	27	34.2
Annual household income[c]		
< $15,000	36	46.2
$15,000-$24,000	20	25.6
>$25,000	22	27.2
BMI categories (kg/m^2)[b, c]		
Healthy (18.5-24.9)	9	12.2
Overweight (25.0-29.9)	21	28.4
Obese (>30)	44	59.5
Diagnosed Diabetes[c]		
Yes	26	32.9
No	50	63.3

[a]Presented as mean ± SD.
[b]Based on self-reported height and weight.
[c]Does not sum to n=79 due to missing data

Table 6.3. Parent code words used in initial coding of verbatim transcripts of interviews of Oklahoma American Indian women 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
AWARENESS	Lack of or increased awareness of diabetes
BAR DM	Barriers in controlling diabetes
BAR EXER	Perceived barriers preventing exercise
BAR FOOD	Perceived barrier to eating a healthy diet
CONTROL	Methods used to control diabetes
DEF DIET	Cultural definition of a healthy diet
DEF DM	Cultural definition of diabetes
DEF EXER	Cultural definition of exercise
DEF HEALTH	Cultural definition of health
DENIAL	Denial experienced post-diagnosis of diabetes
DM CAUSES	Perceived causes of diabetes
DM CONCERN	Concerns and fear about diabetes
DM DIET	Perceived diabetic diet and dietary changes required by diabetes diagnosis
DM LT COMP	Perceived long-term complications of diabetes
DM PREVENT	Methods to prevent or delay onset of diabetes
DM SYMPTOM	Perceived symptoms of diabetes onset
DM TREAT	Perceived treatments for diabetes
FAMILY	Role of family in diabetes prevention and treatment
HEALTHCARE	Issues in quality and continuity of health care
MEN HEALTH	Perceptions of men and health
NA DEATH	Perceived leading causes of death for American Indian women
NA WOMEN	Perceived health issues of other American Indian women
PERSONAL	Personal health concerns
SOCIAL	Social aspects of diabetes care and prevention
SOURCE	Sources of health and nutrition knowledge
TRAD DIET	Cultural definition of a “traditional diet”
TRIBE	Role of tribe/community in diabetes prevention and treatment

CHAPTER VII

KEEPING THE BALANCE DIABETES ASSESSMENT TOOL: DEVELOPMENT AND TESTING OF AN ASSESSMENT TOOL FOR DIABETES PREVENTION IN NATIVE AMERICANS.

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ABSTRACT

Objective: Native Americans are at a disproportionately higher risk for type 2 diabetes. Few data are available about the perceptions of diabetes and there are no culturally appropriate tools available for assessment of perceptions related to health, diabetes prevention and healthy eating.

Research Design and Methods: A diabetes prevention assessment tool was developed to measure perceptions of health, diabetes and healthy eating. Predominant themes from qualitative interviews provided the content for instrument. An expert panel reviewed the instrument for cultural appropriateness, clarity and content. Reliability testing was performed using 182 Oklahoma Native American volunteers. Principal axis factor analysis was conducted to identify the underlying empirical structure.

Results: Five underlying factors resulted from the perceptions of health, including 1) lifestyles, 2) barriers to health, 3) personal responsibility, 4) self-care behaviors and 5) culturally-defined well-being. Two factors described perceptions of diabetes. First, a cognitive factor reflected knowledge derived from life experiences and the surrounding environment. The affective factor contained emotional responses to diabetes.

Conclusions: Our diabetes assessment tool identified factors that should be considered when working with this high-risk population. Understanding the cultural underpinnings that impede behaviors related to health promotion and diabetes prevention is important to developing effective nutrition education programs. A valid assessment tool for the NA population could provide valuable formative data in developing successful interventions aimed at diabetes prevention.

INTRODUCTION

Diabetes has become one of the most prevalent chronic diseases in the US, with 16 million cases reported by 1996 (205). Minority populations experience a disproportionately higher rate of diabetes, especially among Native Americans (NA) (30;81;201;202). Indian Health Service (IHS) data for the Oklahoma City Area, the largest area of IHS, estimate an age-adjusted rate for diabetes at 60/1000 (81), which indicated that NA were 2.43 times more likely to have diabetes than the general population (82). Reports from the Strong Heart Study demonstrated that nearly 40% of Oklahoma NA adults had diabetes, with women bearing the greater burden of disease.

Despite the impact of culture on health beliefs and lifestyle behaviors (67;72;77;206), limited data are available that explores the cultural perceptions of health or diabetes in the NA population. Various authors have examined the definitions of health and diabetes in the NA culture through the lens of Western medicine (67;72;75;77;207). These reports indicated that NA cultural views of health and diabetes differ considerably from the central dogma of Western medicine, which classifies health in terms of altered physiological variables and their resulting manifestations (75;77;207). Conversely, our previous work using qualitative interviews in NA men and women in Oklahoma indicated NA men and women defined health by the presence or absence of physical symptoms of disease (207). In the absence of discomfort or limitations in

physical functionality, one was considered to be healthy (207).

Furthermore, some researchers have reported a sense of hopelessness in reservation-living populations towards developing diabetes (39;72;76;91). Interviews with Pima (91) and Seminole Indians (76) indicated a strong sense of inevitability towards developing diabetes, which served as a barrier to diabetes prevention behaviors. Thus, this feeling of inevitability serves as a barrier to health promotion and diabetes prevention, especially when the physical cues to action, often in the form of symptomology, are absent (67;207). Therefore, when the separation between cultural health perceptions and Western ideology were not addressed, efforts in health promotion and diabetes prevention with NA people have produced less than desirable results (72;77;91). A large proportion of the research investigating perceptions of health and diabetes was conducted in the reservation setting; a greater understanding of non-reservation living NA perceptions of health and diabetes is paramount to the success of health promotion and diabetes prevention programs nationwide (160-163;206).

Numerous studies have examined the benefits in healthcare costs and improvements in quality of life from diabetes prevention and control (100-103). Targeted nutrition education efforts promoting healthy lifestyles to prevent diabetes may combat the rising rates of diabetes in NA populations and the resultant rise in health care costs (100-103;201); however, for these benefits to be realized, effective healthcare systems must bridge the gap between Western medicine and diverse cultures (72).

The existence of a culturally appropriate instrument that measures perceptions of health and diabetes would provide valuable formative data necessary to gauge the relationship between perceptions and behavior. Understanding these interactions is critical for the development of targeted health promotion and diabetes prevention programs (208). If the onset of diabetes could be prevented or delayed, the improvements in quality of life and healthcare costs would be considerable (100-103).

RESEARCH DESIGN AND METHODS

Assessment Tool Development

As part of a previous study, qualitative interviews were conducted with 79 Native American women (207) and 20 Native American men to identify cultural perceptions of health and diabetes. The use of qualitative data in the generation of items aids in bolstering the content validity of the instrument, as it presents issues more germane to the audience than using those derived from the research literature (138). Dominant themes and text segments from the interviews were used to create items for the four categories in the development of the *Keeping the Balance Diabetes Assessment Tool*, a questionnaire measuring diabetes knowledge and perceptions of health, diabetes and the social environment with a focus on diabetes prevention. Results from the analysis of the verbatim transcript from the original qualitative interviews are reported elsewhere (207).

An initial list of items was written to address four major categories, including perceptions of health, perceptions of diabetes, knowledge about the etiology of diabetes and the role of the social environment. Approximately 20 items were written to measure each of the predominant themes. Whenever possible, the original wording of the respondents was used to create the items to enhance content validity. Each item was written as a statement about health, diabetes or the social environment. A 6-point Likert-type scale was used to denote the level of agreement for each statement about health, diabetes and the social environment, including strongly agree, agree, somewhat agree, somewhat disagree, disagree and strongly disagree.

Ninety-eight items were presented to a panel of experts to review for cultural appropriateness, clarity, conciseness and the ability to measure the intended concept. Experts with experience in questionnaire development or in Native American health research or practice were recruited through personal invitation and through a research

and a Native American healthcare e-mail list serve. Eleven volunteers provided online feedback for the items and suggestions for rewording items to accurately measure a single concept. Comments and suggested revisions from the expert panel were used to create the final version of the instrument.

Study population

Men and women of at least 25% Native blood, between the ages of 18 and 65 years of age by self-report were eligible to participate. Individuals were not excluded if they had diabetes or other chronic diseases. Key informants at two tribal health clinics aided in identifying public events to administer the assessment tool. Upon invitation for each event, a research team traveled to two powwows for data collection.

Eighty-one and 116 volunteers completed the assessment tool at the first and second powwows, respectively for a total of one-hundred ninety seven volunteers. Two participants were excluded because they did not meet study criteria despite screening and ten participants were excluded due to patterned responses inconsistent with normal variability for the positively and negatively worded items or incomplete responses. Data analysis was performed on the final useable sample of 185 (94%) of the 197 total questionnaires completed.

Assessment tool distribution

Each participant provided signed informed consent prior to completing the assessment tool. The self-administered questionnaire was presented to eligible volunteers and was followed by a brief demographic questionnaire. To increase participation, volunteers who completed both questionnaires received $10. Due to several cases of multiple responses recorded for the same item on the response recording form used at the first powwow, modifications were made to the form to allow more space for recording responses. The Institutional Review Board at Oklahoma State University approved the study protocol.

Factor analysis

Principal axis factor analysis was performed using the items from the four categories to identify the underlying empirical structures. The factors derived from the health and diabetes scales will be discussed herein. This analytic strategy utilizes inter-item correlations to identify a factor structure of items that share common relationships with similar items (193). Due to the random nature of the missing data points, data were excluded pairwise during the analysis for items with missing or multiple responses.

The factor analysis for each scale (health, diabetes) followed a standardized approach; the health scale was analyzed independently of the diabetes scale. First, the 31 items measuring the perceptions of health were included in a principal axis factor analysis. The correlation matrix, Kaiser-Meyer-Olkin (KMO) Measures of Sampling Adequacy and the Bartlett's Tests of Sphericity were evaluated for the factorability of the correlation matrix (193). KMO values greater than 0.6 indicated enough structure within the correlation matrix to provide a factorable solution. Bartlett's Test of Sphericity determines whether the correlation matrix is significantly different from an identity matrix, a correlation matrix where items correlate perfectly with themselves and not at all with other items.

Examination of the eigenvalues greater than one in conjunction with the Scree Plot and the proportion of variance accounted for by a given factor were used to determine the number of factors to rotate (193). The analysis was repeated with an oblique rotation (Direct Oblimin, delta=0), which allows the factors to correlate, rotating the appropriate number of factors. The correlations between the linear factors were evaluated and if little correlation was evident between the factors, the analysis was repeated using a more rigid, orthogonal (Varimax) rotation. Items accounting for at least 16% of the variance on a factor (factor loadings >| 0.4 |) were considered to load on a factor (193). Items loading on a factor were then used to name the factor based on the

contextual information for all of the items loading on each factor. The same protocol was used for analysis of the items measuring the perceptions of diabetes.

Internal Consistency

Cronbach's α reliability was computed for all items loading on each factor with values above 0.7 considered desirable measures of internal consistency (191).

RESULTS

Of the 185 volunteers completing the Keeping the Balance Diabetes Assessment Tool, about two-thirds were female. The mean age and degree of Native blood was 37 years of age and 69%, respectively. Twenty-six percent of the sample self-reported a diagnosis of type 2 diabetes.

Perceptions of health factor analysis

Evaluation of the correlation matrix indicated relations among the items. The KMO (0.71) and Bartlett's Test of Sphericity ($P<0.0001$) indicated a factorable correlation matrix. Initial factor extraction from the 31 items measuring the perceptions of health indicated a potential for a three, four or five factor solution based on the Scree plot (Figure 1) and the eigenvalues (Table 1). The five-factor solution provided the best conceptual explanation of the perceptions of health, which accounted for 33.1% of the total variance. When an oblique rotation was conducted, little correlation ($R<0.2$) was found among the factors; therefore, a Varimax rotation was performed and interpreted.

Items with factor loadings greater than or equal to an absolute value of 0.4 added substantively to defining the factor. The factor loadings for each of the five factors are presented in Table 2. The five items loading on the first factor indicated lifestyle behaviors related to health maintenance while the second factor had five items considered barriers to health. Culturally derived personal responsibilities for health and wellness comprised the third factor. The fourth factor focused on the need to take care

of oneself to be healthy while the fifth factor indicated the link between wellness and mental and physical well-being.

Perceptions of diabetes factor analysis

Analysis of the correlation matrix, KMO (0.79) and Bartlett's Test of Sphericity ($P<0.0001$) for the 21 items related to the perceptions toward diabetes suggested a factorable correlation matrix. Examination of the initial eigenvalues (Table 1) and the Scree plot (Figure 1) suggested a two factor solution. A Varimax rotation was conducted because the oblique solution presented weak correlations ($R<0.3$) between the two factors. Thirty-two percent of the variance was explained by the rotation of the two factor solution.

Factor loadings for both factors are provided in Table 2. Nine items that measured the cognitive aspects of diabetes through knowledge and personal experiences loaded on the first factor (cognitive). Strong threads of fatalism and avoidance of diabetes screening were manifested in this factor. The second factor (affective) was comprised of eight affective items, hinging on concern and fear of diabetes and its complications. One item, the perception of diabetes as a death sentence, loaded on the cognitive (0.45) and affective (0.44) factors. As it fits both the experience-driven nature of the cognitive factor while also manifesting an affective, emotional response, the item was allowed to load on both factors.

Internal Consistency

Internal consistency coefficients (Table 1) were modest to desirable for the five factors and two factors for the perceptions of health and diabetes, respectively.

CONCLUSIONS

Understanding the underlying cultural factors related to health is critical to health promotion and diabetes prevention efforts in minority populations (67;72;73;96). The

paucity of data regarding health perceptions of non-reservation living NAs prompted our use of qualitative interviews to identify a cultural definition of health and diabetes (207). Responses from the verbatim transcripts provided the contextual variables used in the development of the diabetes assessment tool for prevention as has been used in previous research with African Americans (14;94;137;205;209). This validation of the measures of these constructs focusing on diabetes prevention indicated pertinent factors related to the perception of health and diabetes, which could provide valuable formative data for health promotion and diabetes prevention programming and interventions.

Of the empirical factors from the perceptions of health items, we discovered two factors (*lifestyle behaviors* and *self-care*) that focused on the impact of individual's behavior on their own health status, which is consistent with the research literature (73;76). Good health was strongly related to the performance of healthy lifestyle behaviors from our qualitative interviews (207); responses on these lifestyle behavior items accounted for the greatest amount of variance (9.5%) from the items related to the perceptions of health in the assessment tool. In addition, our *self-care* factor was comprised of items that measured the importance of taking an active role in health maintenance. Hatton (75) reported similar results for self-care behaviors in urban NA where taking care of one's health was important in maintaining an individual's health. Additionally, several items from our instrument loaded onto a factor that identified *barriers to health maintenance* that were tied to resistance or reluctance to changing one's own lifestyle behaviors and to the perceived financial and time investment required for health maintenance.

Reliance on physical symptoms for determination of personal health status was a dominant theme from our qualitative interviews (207). Participants believed that lifestyle behaviors did not need to change in the absence of physical symptoms of illness. The *personal responsibility* and *self-care* factors contained similar items measuring the cues

to action and variables used in defining personal health status. Items measuring the role of perceivable symptoms in triggering the need to take care of one's health and to see a doctor (from the *personal responsibility* factor) demonstrate the reliance on perceivable signs in taking care of one' health. Further, the perception that one is healthy if one does not have a disease (from the *cultural wellness* factor) may further mediate changing lifestyle behaviors important for health promotion and diabetes prevention. These findings are similar to those of Van Sickle et al. (77) who interviewed Diné families with asthmatic children. This chronic, inflammatory condition was defined as a series of individual bouts of severe reactions requiring emergency medical attention. Bouts of acute asthma were often endured without medicinal treatment to train the body to deal with the condition.

Internal consistency coefficients for the final three factors (Cronbach's α=0.50-0.55) of the perceptions of health were lower than desired and may be attributable to the partialing of variance - and the factoring of residualized variance - inherent in the factor analytic method or the smaller sample size. Methodologically, a challenge arose concerning the number of factors to rotate for the perceptions of health. Despite the lower Cronbach's α values, the five-factor solution provided a more sound theoretical explanation of health perceptions. Further testing of the assessment tool in larger samples is needed to determine the saliency of the items and the stability of the factor structure.

Cultural minorities have become an underserved population in the US healthcare system (67;210). Gaps in health status between NAs and the general US populations are becoming increasingly wider as rates of various chronic diseases, including diabetes, are reaching epidemic levels in NA (68). The pervasiveness of diabetes has reached levels as high as 50% of adults over the age of 35 in some Southwest tribes

(100). It is the high rate of diabetes and its resultant long-term complications (125;131-133) that likely mediates the two factors, *cognitive* and *affective*, obtained from the items measuring the perceptions of diabetes.

Strong feelings of hopelessness and fear of the morbidity associated with diabetes, as described in the *affective* factor of our assessment tool, were also evident in our qualitative interviews (207) and in research with other minority groups (39;76;90;91). Items measuring the susceptibility of NA to developing diabetes and the fear of diabetes and its long-term complications loaded to form the *affective* factor of the perceptions of diabetes. The feelings of inevitability toward disease and the inability to control their health status have been shown to alter the behaviors and perceptions of health among minority groups (93). Kozak (91) reported feelings of inevitability toward getting diabetes Arizona Pima, which resulted in a cultural defense mechanism he defined as “surrender” that resulted in a perceived futility toward diabetes prevention. These feelings may provide a barrier to performing lifestyle behaviors that may aid in diabetes prevention; however, another report in Pima Indians without diabetes indicated that an internal locus of control was positively related to performance of regular physical activity, which has been shown to aid in diabetes prevention (211). Further study should identify the barriers to changes in lifestyle behaviors that may influence the effectiveness of diabetes prevention efforts.

Research with Mexican Americans reported that women judged the severity of diabetes by extent of physiological damage it caused (90). Diabetes then became a “scary” disease “because of all the damage.” While measuring the cultural relevance of several diabetes education materials, concerns about diabetes among African American adults were strongly linked to emotional factors including fears about diabetes, denial, insulin therapy and required lifestyle changes, as also found in this study (93). Similar experiences were reported in our qualitative interviews (207) and in the present study,

which suggests a fear of diabetes and the damage it ultimately causes.

Perceptions of health were similar to perceptions of diabetes as the absence of physical symptomology indicated health. Therefore, participants believed that lifestyle behaviors did not have to change until diabetes was manifested through perceivable signs and symptoms. In African American women, diabetes manifested itself as physical fatigue (94). Native American women viewed diabetes in terms of kidney failure, blindness and other long-term complications (207). In 1981, Hopper (95) reported that African American women felt that diabetes was not a serious disease and that medication alone would "cure" the disease. Most of the African American women believed that the lack of symptoms of diabetes indicated they no longer had diabetes. These perceptions were repeated in the present study and supported the perception that diabetes care was confined to medication unless physical symptoms were present.

Lang (89) described the role of the social experiences of Dakota Sioux in the development of cultural perceptions of illness; the experiences of individuals within the tribe were used to collectively describe the experiences of the community and ultimately the cultural perceptions of health. Experiences and personal history have also been linked to beliefs about health and illness in Mexican Americans (90); these experiences were ultimately manifested through social functioning and physical and mental health. Personal and social experiences of individuals with diabetes similarly shaped the perceptions of diabetes prevention, treatment and etiology from our interviews with NA in Oklahoma (207). Therefore, the items that loaded on the *cognitive* factor in this study likely reflected perceptions of diabetes related to knowledge of diabetes obtained from previous personal experience. Of great concern, however, is that these items generally reflected misinformation about the development and treatment of diabetes.

There are several limitations of the current study. The sample derived through non-probability methods may decrease the generalizability of the findings but is often

needed to identify individuals from an at-risk population (75). Further, the sample size may not have been adequate to account for the variance associated with the perceptions of health and diabetes. This could account for the less desirable internal consistencies for the latter health factors and the loading of the perceived "death sentence" inherent with diabetes on both the *cognitive* and *affective* factors of diabetes. In future versions, the item may need to revisiting because, as it reads now, it reflects both the experientially driven knowledge about diabetes and the emotional fear resulting from these experiences.

Previous research has identified several consistent behaviors and traits considered to transcend tribal affiliation, which include the perception that health is the responsibility of the individual, that health and disease follow the natural progression of life and spirituality plays an mediating role in these perceptions (73). However, identifying variances in tribal characteristics and the extent to which an individual prescribes to his or her tribe's cultural beliefs are important pieces of information when developing health promotion activities (67;73;78;96). Culturally appropriate health education programming should be targeted toward the specific group and built around the variables or mediators that influence behavior (157-159;206). Our results indicate many similarities to the research literature while demonstrating the interconnectedness of the mediating factors related to health and diabetes. Future efforts must explore the important determinants in the perceptions of health and diabetes for successful health promotion and diabetes prevention programs; therefore, further refinement of an assessment tool targeting diabetes prevention would provide invaluable formative data for program development.

Table 1: Initial eigenvalues, proportions of variance and internal consistencies for the perceptions of health and diabetes factors

Category	Factor	Eigenvalue	Cumulative % of Variance	Cronbach's α
Health	Lifestyles	4.67	9.5	0.794
	Barriers	3.20	18.0	0.756
	Personal Responsibility	2.29	23.4	0.500
	Self-care	1.63	28.6	0.549
	Cultural wellness	1.58	33.1	0.527
Diabetes	Cognitive	4.54	17.9	0.831
	Affective	3.12	32.0	0.773

Figure 1. Scree plots of perceptions of health and diabetes factor analyses

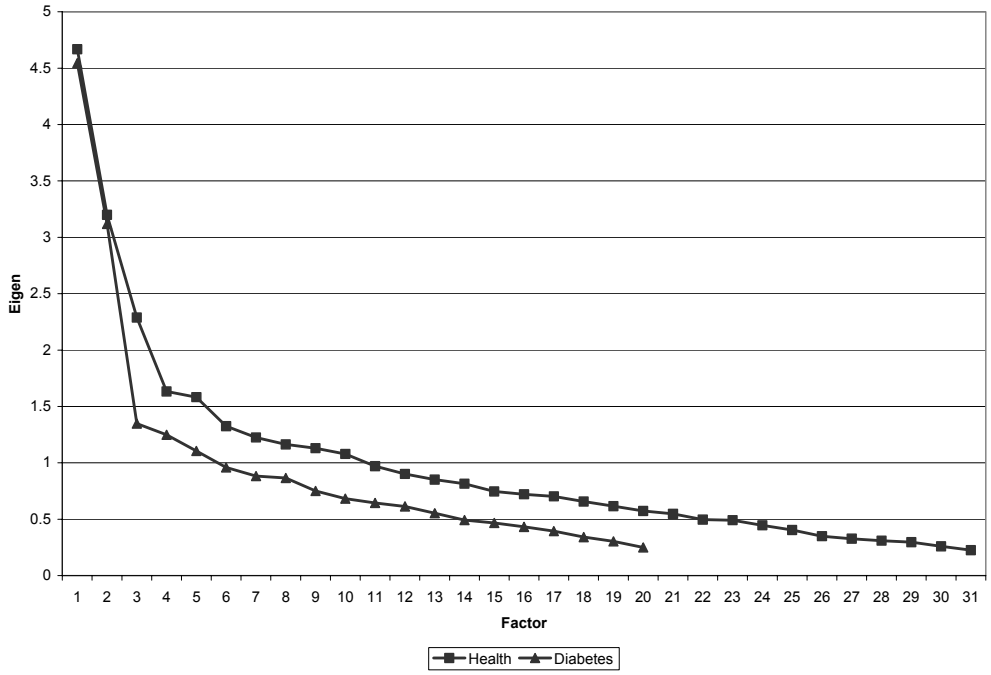


Table 2: Factor Loadings on the perceptions of health and diabetes factors

Category	Factor	Description	Loading	Mean ± SD
Health	Lifestyles	Start early to take care of health	0.787	1.8 ± 1.0
		Start early to eat healthy	0.744	2.0 ± 1.1
		Start early to be physically active	0.736	1.9 ± 1.0
		Starchy foods are bad	0.532	2.6 ± 1.3
		A lot of fat is bad	0.489	2.1 ± 1.2
	Barriers	Hard to change diet	0.740	3.3 ± 1.5
		Hard to be more active	0.669	3.5 ± 1.4
		Hard to eat healthy	0.579	3.5 ± 1.4
		Good health takes money	0.539	3.4 ± 1.6
		Good health takes time	0.497	3.1 ± 1.5
	Personal Responsibility	Go to the doctor when feel sick	0.532	3.5 ± 1.6
		Heath shouldn't burden others	0.498	2.2 ± 1.1
		Only I can take care of my health	0.471	2.0 ± 1.3
		Take care of health when feel sick	0.459	2.9 ± 1.6
	Self-care	Prevent problems when care for health	0.660	1.6 ± 0.9
		Healthy if take care of self	0.631	1.6 ± 0.8
		Stay healthy if visit the doctor regularly	0.405	2.3 ± 1.3
	Cultural wellness	Unhealthy people are irritable	0.554	3.1 ± 1.5
		Unhealthy people are depressed	0.547	3.0 ± 1.4
		Healthy if I do not have a disease	0.413	2.4 ± 1.4
Diabetes	Cognitive	Control DM by medicine without changing diet	0.712	3.7 ± 1.6
		Control DM by medicine without changing physical activity levels	0.673	3.7 ± 1.5
		Activities don't need to change until get DM	0.656	4.1 ± 1.4
		Avoid screening to not have to care for DM	0.630	4.5 ± 1.4
		DM is taking insulin shots	0.593	3.5 ± 1.5
		DM is inevitable for NA	0.583	4.6 ± 1.4
		Can tell someone has DM by looking at them	0.540	4.7 ± 1.4
		Won't think about it until it happens to me	0.400	4.2 ± 1.5
		DM is a death sentence	0.450	3.6 ± 1.6
	Affective	DM is scary	0.679	2.2 ± 1.3
		DM ruins health	0.602	3.0 ± 1.4
		Fear of DM	0.583	2.7 ± 1.5
		DM requires a lot of changes	0.529	2.6 ± 1.4
		DM attacks your organs	0.491	2.5 ± 1.3
		People with DM need to eat different foods	0.511	2.7 ± 1.4
		NA are at higher risk	0.467	1.9 ± 1.2
		DM is a death sentence	0.439	3.6 ± 1.6

CHAPTER VIII

CONCLUSIONS AND IMPLICATIONS

Various challenges exist in attempting to define health in cultures with values and norms that differ from that of Western society. This study was an attempt to fill the void of information on dietary intakes and perceptions of health and diabetes among Native Americans (NA) living outside of the reservation system. Additional research is needed to verify the findings presented herein within Oklahoma and also among other NA non-reservation communities.

Analysis of 1-d food lists, food records and food sort data indicated a similarity between the diets of NAs in Oklahoma and reports of nutrient intake from tribes in other regions. What has not been explored extensively in NAs is how the perceptions of food in terms of fat and sugar content and health value impact food selection behaviors. The food sort data and consumption data from this study indicated that perceptions of foods as healthy or low in fat or sugar had little influence on frequency of consumption of the foods. Future endeavors need to identify what variables impact food selection behaviors.

Previous research and the present study demonstrated a shift in intakes from historically traditional foods to a more Western diet. We demonstrated that these traditional foods do not contribute considerably to overall intakes due to the infrequency of consumption. Participants indicated that traditional foods were often consumed at tribal gatherings, such as powwows, funerals and celebrations. The frequency of such events may dictate the extent to which these foods contribute to overall intakes and should, therefore, be addressed. Additional research is needed to further describe the dietary habits of NAs as well as the variables linked to food selection behaviors.

Several barriers were identified that impeded the ability of NA women to consume a healthy diet. Some of these barriers included the perceived higher cost of "healthy" foods, culinary skills and time needed for preparation of healthy meals as well as the acceptability of family members to changing meal patterns and composition. Our data also indicate low intakes of milk and fruit servings. Educators should evaluate dietary intakes to determine the likelihood of their participant reaching minimum recommendations and identify additional barriers to food selection behaviors and food tolerance issues. Anecdotally, NA 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 efforts.

In addition to exploring food intake behaviors, we identified the cultural perceptions of health and diabetes in this at-risk population. The resultant theoretical model of the cultural perceptions of health and diabetes is provided in Figure 8.1. Through the use of qualitative methodology, we identified various factors involved in the cultural definition of health including the presence of physical symptoms of illness, physical functionality, the role of lifestyle behaviors and personal responsibility in determining one's health status. We also described many differences between NAs and Western medicine in definitions of health and diabetes. Of considerable note was NAs reliance on physical symptoms as a determinant of health status. Many of these factors also filter through into the perceptions of diabetes, hence the overlapping of the rings. Physical limitations, the destruction of organs (namely the need for amputation and dialysis) and the body being out of "balance" were important in the NA's perception of diabetes and its consequences.

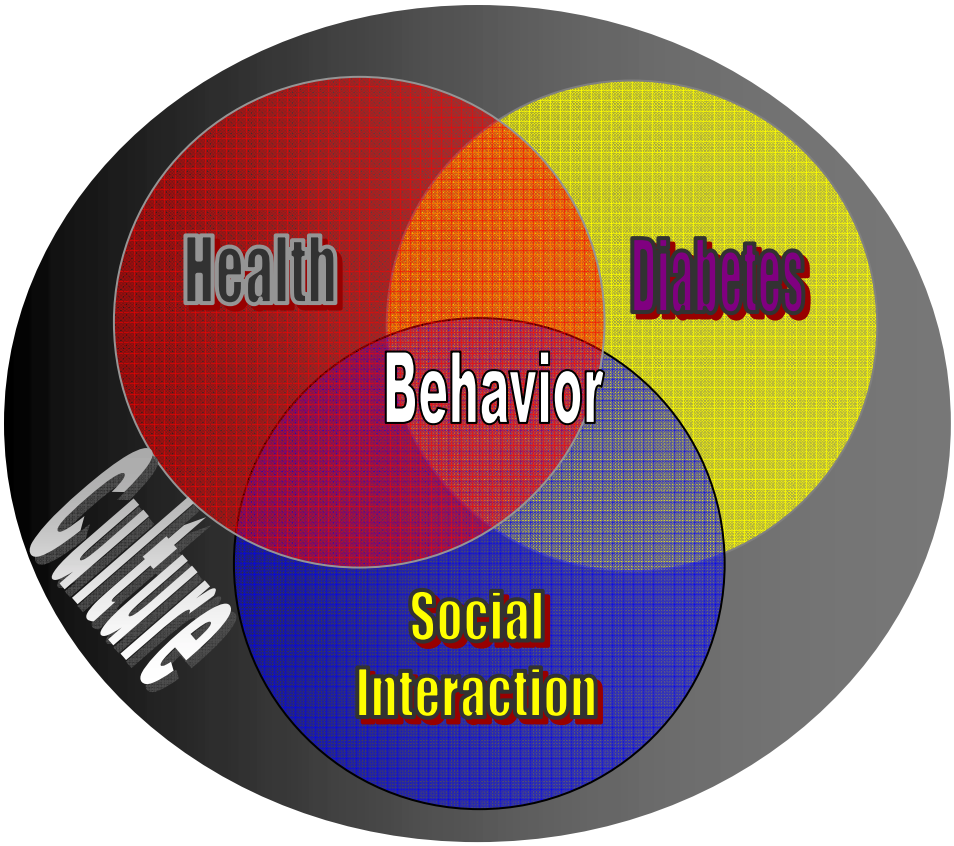


Figure 8.1 Theoretical Structure of Native American Health

Social interaction also played a mediating role in NA's perceptions of health and diabetes, as close family and friends were considerable sources of information and misinformation. These interactions further shape and mold the perceptions of health and diabetes. Finally, culture underscores and moderates these perceptions, noted by the shaded circle behind the health, diabetes and social factors in Figure 8.1. The transition from light to dark signifies the discernable blending of the NA culture and the influence of Western society. All of these domains and factors impact an individual and their synergistic effects shape the resultant individual lifestyle behaviors.

Conversations with the staff at the tribal health clinics and the business counsel of the Pawnee tribe presented many unanswered questions from the qualitative data. Health was considered to be a personal problem that should not be imposed upon

others. Furthermore, one should not put his or her own needs above the needs and desires of the family. In this regard, it is unlikely that one-on-one nutrition counseling would produce lasting behavior modification if needed dietary changes for health promotion and disease prevention for an individual conflicted with the will of the family. Moreover, considering the belief in personal responsibility for one's health status, it is not known how receptive NA individuals may be to assistance from family and friends. These issues require further investigation.

Also of note is the relative absence of spirituality and the links between mind, body and spirit that are often associated with the NA culture. It is possible the interview structure and specific questions were not conducive to extracting such information. Other potential explanations are the personal nature of health and the discussions surrounding health or apprehension to share spiritual feelings with interviewers (who are serving as research instruments). Future research should develop culturally sensitive methods of identifying the role of spirituality in health perceptions.

The absence of tools measuring perceptions of health or diabetes prevention among NAs provided the impetus to develop an assessment tool from the content of the qualitative interviews. Items were written using the original wording of the participants when possible to measure the three major domains surrounding health: perceptions of health, diabetes and the social environment. The factors forming the empirical (factor analytic) model are provided in Figure 8.2.

Factors derived from the two domains (health and diabetes) resembled many of the relationships among the key themes from the qualitative data. The role of healthy behaviors in health determination, factors interfering with the adoption of these behaviors and the personal responsibility for health shaped NA's perceptions of health (Figure 8.2a).

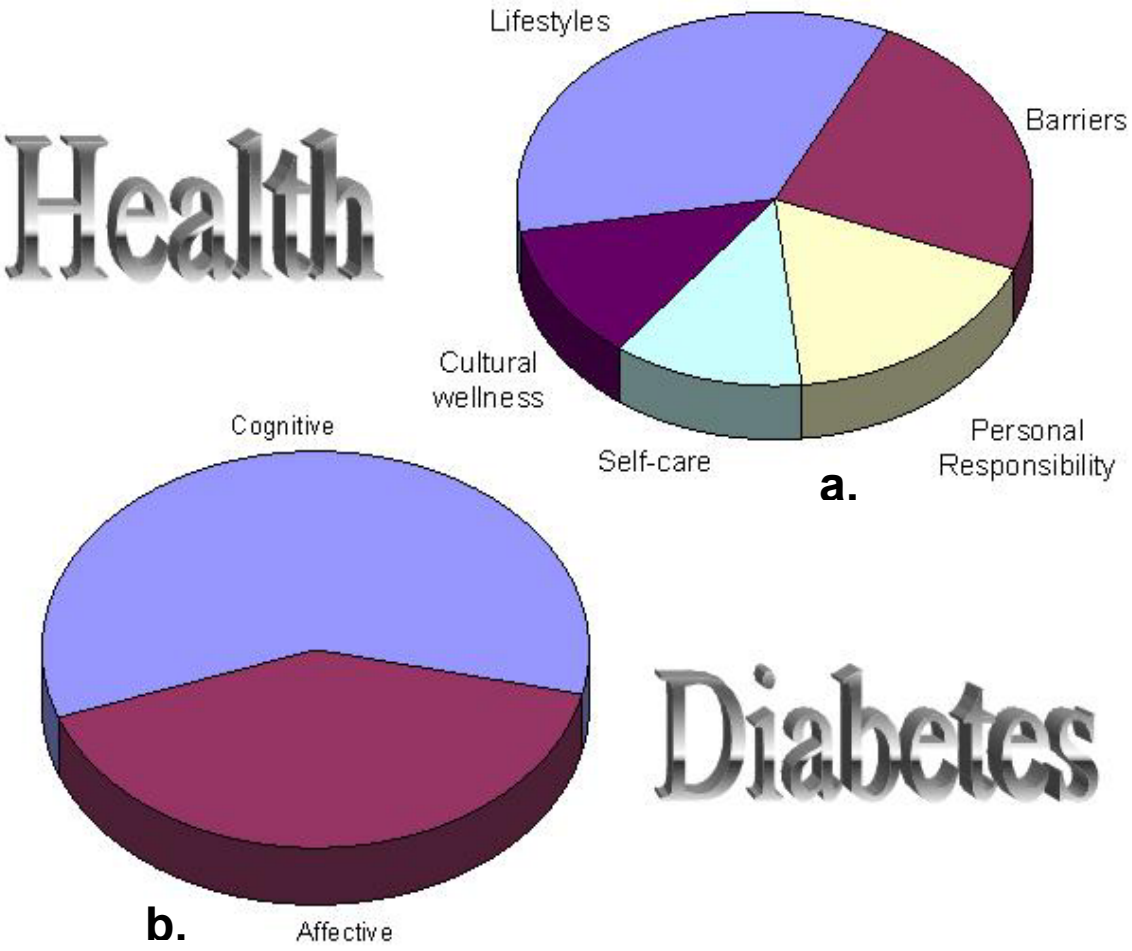


Figure 8. Empirical structure of Native American health and diabetes from Factor Analysis of the assessment tool.

Also of note is the division of items from the perceptions of diabetes across the cognitive and affective factors (Figure 8.2b). Knowledge about diabetes obtained from previous experiences accounted for a greater proportion of variance; however, a great deal of this knowledge was in the form of misinformation.

Future testing of the tool should address some methodological issues experienced. Retesting efforts should attempt to collect a larger, representative sample of the desired NA groups to ensure a spread in sociodemographic characteristics. The sample for preliminary testing was a convenience, self-selecting sample of NAs

attending powwows that could bias results. Concerns about the sample size of the exploratory factor analysis and the undesirable internal consistency coefficients for the latter health factors; future research is needed to determine the resiliency of the factor structure.

In light of the NA's reliance on the physical cues of disease, health promotion and disease prevention efforts need to focus on promoting healthy lifestyle behaviors by reducing the barriers to performing these activities, while also considering cultural values and norms. Furthermore, health promotion efforts need to be more pervasive in disseminating knowledge about lifestyle behaviors to overcome the bountiful sources of misinformation.

The current study has provided a considerable amount of interesting yet perplexing phenomena, such as the personal responsibility for health and the reliance on physical symptomology as a cue for health maintenance behaviors. For each theme that was discovered from the qualitative interviews and the assessment tool, many more questions arose about the underlying reasons for the phenomenon. Future research is needed to uncover the many underlying themes related to health promotion and disease prevention behaviors. Specific questions to address the promoters and barriers to healthy lifestyle behaviors, acceptance of diabetes prevention efforts and the role of the family in the nutrition care process would aid the development of targeted health promotion and disease prevention efforts. Additionally, we found that food selection behaviors were not impacted by perceptions of foods as healthy. Future endeavors should address determinants of food selection, the role of historically traditional foods and the nutritional adequacy of food intake patterns for optimal health and disease prevention.

REFERENCES

1. Howard BV, Lee ET, Fabsitz RR et al. Diabetes and coronary heart disease in American Indians: The Strong Heart Study. Diabetes 1996;45 Suppl 3:S6-13.
2. Prevalence of diagnosed diabetes among American Indians/Alaskan Natives- - United States, 1996. Morb Mortal Wkly Rep. 1998;47:901-4.
3. Roubideaux YD, Moore K, Avery C, Muneta B, Knight M, Buchwald D. Diabetes education materials: recommendations of tribal leaders, Indian health professionals, and American Indian community members. Diabetes Educ. 2000;26:290-4.
4. Rhoades ER, Deer Smith MH. Health care of Oklahoma Indians. J Okla State Med Assoc. 1996;89:165-72.
5. Goldsmith MF. First Americans face their latest challenge: Indian health care meets state medicaid reform. JAMA 1996;275:1786-8.
6. Acton KJ, Shields R, Rith-Najarian S et al. Applying the diabetes quality improvement project indicators in the Indian Health Service primary care setting. Diabetes Care 2001;24:22-6.
7. McFall SL, Solomon TG, Smith DW, Kelley M. Preventive services and satisfaction of Cherokee Nation patients. J Public Health Manag Pract. 2001;7:76-83.
8. Nolan LJ, Freeman WL, D'Angelo AJ. Local research: Needed guidance for the Indian Health Service's urban mission. Pub Health Rep. 1996;111:320.
9. Boufford JI, Lee PR. Federal programs and Indian country: A time for reinvention. Pub Health Rep. 1998;113:34-5.
10. Wright MH. A Guide to the Indian Tribes of Oklahoma. Norman: University of Oklahoma Press, 1986.
11. Lowie RH. Indians of the Plains. Lincoln: University of Nebraska Press, 1982.
12. Marks PM. In a Barren Land American Indian Dispossession and Survival. New York: William Morrow, 1998.

13. Gibson AM. The American Indian Prehistory to the Present. Lexington, Mass: D.C. Heath, 1980.
14. Elasy TA, Samuel-Hodge CD, DeVellis RF, Skelly AH, Ammerman AS, Keyserling TC. Development of a health status measure for older African-American women with type 2 diabetes. Diabetes Care 2000;23:325-9.
15. Davis SM, Reid R. Practicing participatory research in American Indian communities. Am J Clin Nutr. 1999;69:755S-9S.
16. Byers T, Hubbard J. The Navajo Health and Nutrition Survey: research that can make a difference. J Nutr. 1997;127:2075S-7S.
17. Wein EE. Foods and nutrients in reported diets versus percreived ideal diets of Yukon indian people. J Nutr Ed 1996;28:202-8.
18. Gittelsohn J, Wolever TM, Harris SB, Harris-Giraldo R, Hanley AJ, Zinman B. Specific patterns of food consumption and preparation are associated with diabetes and obesity in a Native Canadian community. J Nutr. 1998;128:541-7.
19. Wolever TMS, Hamad S, Gittelsohn J et al. Nutrient intake and food use in an Ojibwa-Cree community in northern Ontario assessed by 24h dietary recall. Nutr Res. 1997;17:603-18.
20. Kuhnlein HV, Soueida R, Receveur O. Dietary nutrient profiles of Canadian Baffin Island Inuit differ by food source, season, and age. J Am Diet Assoc. 1996;96:155-62.
21. Murphy NJ, Schraer CD, Thiele MC et al. Dietary change and obesity associated with glucose intolerance in Alaska Natives. J Am Diet Assoc. 1995;95:676-82.
22. Nobmann ED, Lanier AP. Dietary intake among Alaska native women resident of Anchorage, Alaska. Int J Circumpolar Health 2001;60:123-37.

23. Dillinger TL, Jett SC, Macri MJ, Grivetti LE. Feast or famine? Supplemental food programs and their impacts on two American Indian communities in California. Int J Food Sci Nutr. 1999;50:173-87.
24. Welty TK. Health implications of obesity in American Indians and Alaska Natives. Am J Clin Nutr. 1991;53:1616S-20S.
25. Teufel NI. Nutrient-health associations in the historic and contemporary diets of Southwest Native Americans. J Nutr Environ Med. 1996;6:179-90.
26. Teufel NI. Nutrient characteristics of Southwest Native American pre-contact diets. J Nutr Environ Med. 1996;6:273-86.
27. Edwards KA, Pryor S, Campbell J, Jacobsen S, Booton-Hiser D. Calorie use and obesity among diabetic and non-diabetic Mvskoke Indians. J Cult Divers. 2000;7:36-40.
28. Turner NJ, Kuhnlein HV. Two important "root" foods of the Northwest Coast Indians: Springbank Clover (Trifolium wormskioldii) and Pacific Silverweed (Potentilla anserina ssp. pacifica). Economic Botany 1982;36:411-32.
29. Zawadiuk ER. Historical look at foods eaten by Native people in Northeasern Alberta in the early 1900s. Can Home Econ J 1990;40:64-5.
30. Jackson MY. Nutrition in American Indian health: past, present, and future. J Am Diet Assoc. 1986;86:1561-5.
31. Christensen NK, Sorenson AW, Hendricks DG, Munger R. Juniper ash as a source of calcium in the Navajo diet. J Am Diet Assoc. 1998;98:333-4.
32. Kuhnlein HV. Factors influencing use of traditional foods among the Nuxalk people. J Can Diet Assoc 1989;50:102-6.
33. Wein EE, Hawrysh ZJ, Gee MI. Food preferences and food health beliefs of native school children and mothers in Northern Alberta. Ecol Food Nutr. 1993;29:259-73.

34. de Gonzague B, Receveur O, Wedll D, Kuhnlein HV. Dietary intake and body mass index of adults in 2 Ojibwe communities. J Am Diet Assoc. 1999;99:710-6.
35. Nobmann ED, Byers T, Lanier AP, Hankin JH, Jackson MY. The diet of Alaska Native adults: 1987-1988. Am J Clin Nutr. 1992;55:1024-32.
36. Terry RD, Bass MA. Food practices of families in an Eastern Cherokee township. Ecol Food Nutr. 1984;14:63-70.
37. Bell P. Economic barriers to optimum nutrition in Native communities in British Columbia. Arctic Med Res. 1991;Suppl:756-7.
38. Ikeda JP, Dugan S, Feldman N, Mitchell R. Native American in California surveyed on diets, nutrition needs. Calif Agric 1993;47:8-10.
39. Shanklin DS, Usher CL, Wildfire JB. Nutrition education needs and services among American Indians participating in a federal food assistance program. J Nutr Ed 1992;24:298-304.
40. Story M, Bass MA, Wakefield LM. Use of traditional Indian foods by Cherokee youths in Cherokee, North Carolina. J Am Diet Assoc. 1985;85:975-7.
41. Harnack L, Sherwood N, Story M. Diet and physical activity patterns of urban American Indian women. Am J Health Promot. 1999;13:233-6, iii.
42. Ikeda JP, Murphy S, Mitchell RA et al. Dietary quality of Native American women in rural California. J Am Diet Assoc. 1998;98:812-4.
43. Basiotis PP, Lino M, Anand R. The diet quality of American Indians: evidence from the Continuing Survey of Food Intakes by Individuals. Fam Econ Nutr Rev. 1999;12:44-6.
44. Ballew C, White LL, Strauss KF, Benson LJ, Mendlein JM, Mokdad AH. Intake of nutrients and food sources of nutrients among the Navajo: findings from the Navajo Health and Nutrition Survey. J Nutr. 1997;127:2085S-93S.

45. Vaughan LA, Benyshek DC, Martin JF. Food acquisition habits, nutrient intakes, and anthropometric data of Havasupai adults. J Am Diet Assoc. 1997;97:1275-82.
46. Bell RA, Shaw HA, Dignan MB. Dietary intake of Lumbee Indian women in Robeson County, North Carolina. J Am Diet Assoc. 1995;95:1426-8.
47. Williams DE, Knowler WC, Smith CJ et al. The effect of Indian or Anglo dietary preference on the incidence of diabetes in Pima Indians. Diabetes Care 2001;24:811-6.
48. Wolfe WS, Sanjur D. Contemporary diet and body weight of Navajo women receiving food assistance: an ethnographic and nutritional investigation. J Am Diet Assoc. 1988;88:822-7.
49. Teufel NI, Dufour DL. Patterns of food use and nutrient intake of obese and non-obese Hualapai Indian women of Arizona. J Am Diet Assoc. 1990;90:1229-35.
50. Teufel NI. Alcohol consumption and its effect on the dietary patterns of Hualapai Indian women. Med Anthropol. 1994;16:79-97.
51. Zephier EM, Ballew C, Mokdad A et al. Intake of nutrients related to cardiovascular disease risk among three groups of American Indians: the Strong Heart Dietary Study. Prev Med. 1997;26:508-15.
52. Bernard MA, Lampley-Dallas V, Smith L. Common health problems among minority elders. J Am Diet Assoc. 1997;97:771-6.
53. Lebrun JB, Moffatt ME, Mundy RJ et al. Vitamin D deficiency in a Manitoba community. Can J Pub Health 1993;84:394-6.
54. Narayan KM, Hanson RL, Smith CJ et al. Dietary calcium and blood pressure in a Native American population. J Am Coll Nutr. 1998;17:59-64.
55. Costacou T, Levin S, Mayer-Davis EJ. Dietary patterns among members of the Catawba Indian nation. J Am Diet Assoc. 2000;100:833-5.

56. Wierenga ME, Hewitt JB. Facilitating diabetes self-management. Diabetes Educ. 1994;20:138-42.
57. Axelson ML. The impact of culture on food-related behavior. Ann Rev Nutr. 1986;6:345-63.
58. Fitzgerald JT, Anderson RM, Funnell MM et al. Differences in the impact of dietary restrictions on African Americans and Caucasians with NIDDM. Diab Educ 1997;23:41-7.
59. Dignan M, Sharp P, Blinson K et al. Development of a cervical cancer education program for native American women in North Carolina. J Cancer Educ. 1995;9:235-42.
60. Friedman MM. Transcultrual family nursing: Application to Latino and Black families. J Ped Nurs. 1990;5:214-22.
61. Jerome NW. Diet and Acculturation: The Case of Black-American Immigrants. In: Nutritional Anthropology. Pleasantville, Redgrave Publishing 1980:275-325.
62. Reaburn JA, Krondl M, Lau D. Social determinants in food selection. J Am Diet Assoc. 1979;74:637-41.
63. Fanelli MT, Stevenhagen KJ. Characterizing consumption patterns by food frequency methods: core foods and variety of foods in diets of older Americans. J Am Diet Assoc. 1985;85:1570-6.
64. Kristal AR, Abrams BF, Thornquist MD et al. Development and validity of a food use checklist for evaluation of community nutrition interventions. Am J Pub Health. 1990;80:1318-22.
65. Koehler KM, Harris MB, Davis SM. Core, secondary, and peripheral foods in the diets of Hispanic, Navajo, and Jemez Indian children. J Am Diet Assoc. 1989;89:538-40.

66. Jackson MY, Mead P. Nutrition education for Indian elders. J Nutr Ed 1990;22:311-3.
67. Sobralske MC. Perceptions of health: Navajo indians. Top.Clin.Nurs. 1985;7:32-9.
68. Roubideaux Y. Perspectives on American Indian health. Am J Public Health. 2002;92:1401-3.
69. Shapiro J. Non-insulin-dependent diabetes mellitus among American Indians: A problem in human ecology. Am Ind Cult Res J. 1997;21:197-227.
70. Lee ET, Howard BV, Savage PJ et al. Diabetes and impaired glucose tolerance in three American Indian populations aged 45-74 years. The Strong Heart Study. Diabetes Care. 1995;18:599-610.
71. Will JC, Strauss KF, Mendlein JM, Ballew C, White LL, Peter DG. Diabetes mellitus among Navajo Indians: findings from the Navajo Health and Nutrition Survey. J Nutr. 1997;127:2106S-13S.
72. Huttlinger K, Krefting L, Drevdahl D, Tree P, Baca E, Benally A. "Doing battle": a metaphorical analysis of diabetes mellitus among Navajo people. Am J Occup Ther. 1992;46:706-12.
73. Pichette EF. Cultural identification of American Indians and it's impact on rehabilitition services. J Rehab. 1999;65:3-10.
74. Plawecki HM, Sanchez TR, Plawecki JA. Cultural aspects of caring for Navajo Indian clients. J Holist Nurs. 1994;12:291-306.
75. Hatton DC. Health perceptions among older urban American Indians. West J Nurs Res 1994;16:392-403.
76. Judkins RA. American Indian Medicine and contemporary health problems. IV. Diabetes and perception of diabetes among Seneca Indians. NY State J Med. 1978;78:1320-3.

77. Van Sickle D, Wright AL. Navajo perceptions of asthma and asthma medications: clinical implications. Pediatrics 2001;108:E11-18.
78. Parks CA, Hesselbrock MN, Hesselbrock VM, Segal B. Gender and reported health problems in treated alcohol dependent Alaska natives. J Stud Alcohol. 2001;62:286-93.
79. Sugarman J, Percy C. Prevalence of diabetes in a Navajo Indian community. Am J Public Health 1989;79:511-3.
80. Gohdes D, Rith-Najarian S, Acton K, Shields R. Improving diabetes care in the primary health setting. The Indian Health Service experience. Ann Intern Med. 1996;124:149-52.
81. Shalala DE, Trujillo MH, Hartz GJ, Paisano EL. Trends in Indian Health, 1998-1999. Rockville, MD: U.S. Department of Health and Human Services, 2000.
82. Valway S, Freeman W, Kaufman S, Welty T, Helgerson SD, Gohdes D. Prevalence of diagnosed diabetes among American Indians and Alaska Natives, 1987. Estimates from a national outpatient data base. Diabetes Care 1993;16:271-6.
83. Mendlein JM, Freedman DS, Peter DG et al. Risk factors for coronary heart disease among Navajo Indians: findings from the Navajo Health and Nutrition Survey. J Nutr. 1997;127:2099S-105S.
84. Burrows NR, Geiss LS, Engelgau MM, Acton KJ. Prevalence of diabetes among Native Americans and Alaska Natives, 1990- 1997: an increasing burden. Diabetes Care 2000;23:1786-90.
85. Long TP. The prevalence of clinically treated diabetes among Zuni reservation residents. Am J Public Health 1978;68:901-3.
86. Carter J, Horowitz R, Wilson R, Sava S, Sinnock P, Gohdes D. Tribal differences in diabetes: prevalence among American Indians in New Mexico. Pub Health Rep. 1989;104:665-9.

87. Bennett PH. Type 2 diabetes among the Pima Indians of Arizona: an epidemic attributable to environmental change? Nutr Rev. 1999;57:S51-S54.
88. Baschetti R. Diabetes epidemic in newly westernized populations: is it due to thrifty genes or to genetically unknown foods? J R Soc Med. 1998;91:622-5.
89. Lang GC. "Making sense" about diabetes: Dakota narratives of illness. Med Anthropol. 1989;11:305-27.
90. Alcozer F. Secondary analysis of perceptions and meanings of type 2 diabetes among Mexican American women. Diabetes Educ. 2000;26:785-95.
91. Kozak D. Surrendering to diabetes: An embodied response to perceptions of diabetes and death in the Gila River Indian community. Omega 1997;35:347-59.
92. Womak RB. Measuring the Attitudes and Beliefs of American Indian Patients With Diabetes. Diab Educ. 1993;19:205-9.
93. Anderson RM, Funnell MM, Arnold MS, Barr PA, Edwards GJ, Fitzgerald JT. Assessing the cultural relevance of an education program for urban African Americans with diabetes. Diab Educ. 2000;26:280-9.
94. Samuel-Hodge CD, Headen SW, Skelly AH et al. Influences on day-to-day self-management of type 2 diabetes among African-American women: spirituality, the multi-caregiver role, and other social context factors. Diabetes Care 2000;23:928-33.
95. Hopper S. Diabetes as a stigmatized condition: the case of low-income clinic patients in the United States. Soc Sci Med.[Med.Anthropol.] 1981;15B:11-9.
96. Pichette EF, Berven NL, Menz FE, La Fromboise TD. Effects of cultural identification and disability status on perceived community rehabilitation needs of American Indians. J Rehab. 1997;63:38-45.
97. Garrett M, Pichette EF. Red as an apple: Native American acculturation and counseling with or without reservation. J Couns Devel. 2000;78:3-13.

98. Wellever A, Hill G, Casey M. Commentary: Medicaid reform issues affecting the Indian health care system. Am J Public Health. 1998;88:193-5.

99. Noren J, Kindig D, Sprenger A. Challenges to Native American health care. Pub Health Rep. 1998;113:22-33.

100. Rhoades ER, Hammond J, Welty TK, Handler AO, Amler RW. The Indian burden of illness and future health interventions. Pub Health Rep. 1987;102:361-8.

101. Caro JJ, Ward AJ, O'Brien JA. Lifetime costs of complications resulting from type 2 diabetes in the U.S. Diabetes Care 2002;25:476-81.

102. Clark CM, Fradkin JE, Hiss RG, Lorenz RA, Vinicor F, Warren-Boulton E. Promoting early diagnosis and treatment of type 2 diabetes: the National Diabetes Education Program. JAMA 2000;284:363-5.

103. Valdmanis V, Smith DW, Page MR. Productivity and economic burden associated with diabetes. Am J Public Health 2001;91:129-30.

104. American Diabetes Association, National Institute of Diabetes, Digestive and Kidney Diseases. The prevention or delay of type 2 diabetes. Diabetes Care 2002;25:742-9.

105. Diabetes Prevention Program Research Group. The Diabetes Prevention Program. Design and methods for a clinical trial in the prevention of type 2 diabetes. Diabetes Care 1999;22:623-34.

106. Diabetes Prevention Program Research Group. The Diabetes Prevention Program: baseline characteristics of the randomized cohort. Diabetes Care 2000;23:1619-29.

107. Diabetes Prevention Program Research Group. The Diabetes Prevention Program (DPP): description of lifestyle intervention. Diabetes Care 2002;25:2165-71.

108. Tuomilehto J, Lindstrom J, Eriksson JG et al. Prevention of type 2 diabetes mellitus by changes in lifestyle among subjects with impaired glucose tolerance. N Engl J Med. 2001;344:1343-50.

109. Buchanan TA, Xiang AH, Peters RK et al. Preservation of pancreatic beta-cell function and prevention of type 2 diabetes by pharmacological treatment of insulin resistance in high-risk hispanic women. Diabetes 2002;51:2796-803.

110. Chiasson JL, Josse RG, Gomis R, Hanefeld M, Karasik A, Laakso M. Acarbose for prevention of type 2 diabetes mellitus: the STOP-NIDDM randomised trial. Lancet 2002;359:2072-7.

111. Chiasson JL, Gomis R, Hanefeld M, Josse RG, Karasik A, Laakso M. The STOP-NIDDM Trial: an international study on the efficacy of an alpha-glucosidase inhibitor to prevent type 2 diabetes in a population with impaired glucose tolerance: rationale, design, and preliminary screening data. Study to Prevent Non-Insulin-Dependent Diabetes Mellitus. Diabetes Care 1998;21:1720-5.

112. Franz MJ, Bantle JP, Beebe CA et al. Evidence-based nutrition principles and recommendations for the treatment and prevention of diabetes and related complications. Diabetes Care 2003;26 Suppl 1:S51-S61.

113. Haffner SM. Epidemiology of type 2 diabetes: risk factors. Diabetes Care 1998;21 Suppl 3:C3-C6.

114. American Diabetes Association. Evidence-based nutrition principles and recommendations for the treatment and prevention of diabetes and related complications. Diabetes Care 2002;25:202-12.

115. Martin JF, Johnston CS, Han CT, Benyshek DC. Nutritional origins of insulin resistance: a rat model for diabetes- prone human populations. J Nutr. 2000;130:741-4.

116. Dabelea D, Pettitt DJ, Hanson RL, Imperatore G, Bennett PH, Knowler WC. Birth weight, type 2 diabetes, and insulin resistance in Pima Indian children and young adults. Diabetes Care 1999;22:944-50.

117. Neel JV. Diabetes Mellitus: A "Thrifty" Genotype Rendered Detrimental by "Progress" ? Am J Hum Genet. 1962;14:353-62.

118. Kriska AM, Hanley AJ, Harris SB, Zinman B. Physical activity, physical fitness, and insulin and glucose concentrations in an isolated Native Canadian population experiencing rapid lifestyle change. Diabetes Care 2001;24:1787-92.

119. Lee ET, Anderson PS, Bryan J, Bahr C, Coniglione T, Cleves M. Diabetes, parental diabetes and obesity in Oklahoma Indians. Diabetes Care 1985;8:107-13.

120. Muneta B, Newman J, Wetterall S, Stevenson J. Diabetes and associated risk factors among Native Americans. Diabetes Care 1993;16:1619-20.

121. Byers T. The epidemic of obesity in American Indians. Am J Dis Child 1992;146:285-6.

122. McIntyre L, Shah CP. Prevalence of hypertension, obesity and smoking in three Indian communities in northwestern Ontario. CMAJ. 1986;134:345-9.

123. Kimball EH, Goldberg HI, Oberle MW. The prevalence of selected risk factors for chronic disease among American Indians in Washington State. Pub Health Rep. 1996;111:264-71.

124. Wolever TM, Hamad S, Gittelsohn J et al. Low dietary fiber and high protein intakes associated with newly diagnosed diabetes in a remote aboriginal community. Am J Clin Nutr. 1997;66:1470-4.

125. Carter JS, Gilliland SS, Perez GE, Skipper B, Gilliland FD. Public health and clinical implications of high hemoglobin A1c levels and weight in younger adult Native American people with diabetes. Arch Intern Med. 2000;160:3471-6.

126. Bouchard C. Current understanding if the etiology of obesity: genetic and nongenetic factors. Am J Clin.Nutr. 1991;53:1561s-5s.

127. Valencia ME, Bennett PH, Ravussin E, Esparza J, Fox C, Schulz LO. The Pima Indians in Sonora, Mexico. Nutr Rev. 1999;57:S55-S57.

128. Neumark-Sztainer D, Story M, Resnick MD, Blum RW. Psychosocial concerns and weight control behaviors among overweight and nonoverweight Native American adolescents. J Am Diet Assoc. 1997;97:598-604.

129. Ritenbaugh C, Goodby CS. Beyond the thrifty gene: metabolic implications of prehistoric migration into the New World. Med Anthropol. 1989;11:227-36.

130. McCance DR, Pettitt DJ, Hanson RL, Jacobsson LT, Knowler WC, Bennett PH. Birth weight and non-insulin dependent diabetes: thrifty genotype, thrifty phenotype, or surviving small baby genotype? BMJ 1994;308:942-5.

131. Freeman WL, Hosey GM. Diabetic complications among American Indians of Washington, Oregon, and Idaho. Diabetes Care. 1993;16:357-360.

132. Newman JM, DeStefano F, Valway SE, German RR, Muneta B. Diabetes-associated mortality in Native Americans. Diabetes Care 1993;16:297-9.

133. Shalala DE, Trujillo MH, Hartz GJ, D'Angelo AJ. Regional Differences in Indian Health, 1998-1999. Rockville, MD: U.S. Department of Health and Human Services, 2000.

134. Lee ET, Lee VS, Kingsley RM et al. Diabetic retinopathy in Oklahoma Indians with NIDDM. Incidence and risk factors. Diabetes Care 1992;15:1620-7.

135. Valway SE, Linkins RW, Gohdes DM. Epidemiology of lower-extremity amputations in the Indian Health Service, 1982-1987. Diabetes Care 1993;16:349-53.

136. Macaulay AC, Montour LT, Adelson N. Prevalence of diabetic and atherosclerotic complications among Mohawk Indians of Kahnawake, PQ. CMAJ. 1988;139:221-4.

137. Skelly AH, Samuel-Hodge C, Elasy T, Ammerman AS, Headen SW, Keyserling TC. Development and testing of culturally sensitive instruments for African American women with type 2 diabetes. Diabetes Educ. 2000;26:769-7.

138. Stewart B, Olson D, Goody C et al. Converting Focus Group Data on Food Choices into a Quantitative Instrument. J Nutr Ed 1994;26:34-6.

139. Fitzgerald JT, Davis WK, Connell CM, Hess GE, Funnell MM, Hiss RG. Development and validation of the Diabetes Care Profile. Eval Health Prof. 1996;19:208-230.

140. Welch G, Smith RB, Walkey FH. Styles of psychological adjustment in diabetes: a focus on key psychometric issues and the ATT39. J Clin Psychol. 1992;48:648-58.

141. Dunn SM, Smartt HH, Beeney LJ, Turtle JR. Measurement of emotional adjustment in diabetic patients: validity and reliability of ATT39. Diabetes Care 1986;9:480-9.

142. Bradley C, Speight J. Patient perceptions of diabetes and diabetes therapy: assessing quality of life. Diabetes Metab Res Rev. 2002;18 Suppl 3:S64-S69.

143. Garcia AA, Villagomez ET, Brown SA, Kouzekanani K, Hanis CL. The Starr County Diabetes Education Study: development of the Spanish- language diabetes knowledge questionnaire. Diabetes Care 2001;24:16-21.

144. Pouwer F, Snoek FJ. Patients' Evaluation of the Quality of Diabetes Care (PEQD): development and validation of a new instrument. Qual Saf Health Care 2002;11:131-6.

145. Shultz JA, Sprague MA, Branen LJ, Lambeth S. A comparison of views of individuals with type 2 diabetes mellitus and diabetes educators about barriers to diet and exercise. J Health Commun. 2001;6:99-115.

146. Peyrot M, Rubin RR. Structure and correlates of diabetes-specific locus of control. Diabetes Care 1994;17:994-1001.

147. Van Der Ven NC, Weinger K, Yi J et al. The confidence in diabetes self-care scale: psychometric properties of a new measure of diabetes-specific self-efficacy in Dutch and US patients with type 1 diabetes. Diabetes Care 2003;26:713-8.

148. Hernandez CA. The development and pilot testing of The Diabetes Activities Questionnaire (TDAQ): an instrument to measure adherence to the diabetes regimen. Appl Nurs Res. 1997;10:202-11.

149. Bernal H, Woolley S, Schensul JJ, Dickinson JK. Correlates of self-efficacy in diabetes self-care among Hispanic adults with diabetes. Diabetes Educ. 2000;26:673-80.

150. Schlenk EA, Hart LK. Relationship between health locus of control, health value, and social support and compliance of persons with diabetes mellitus. Diabetes Care 1984;7:566-74.

151. Hartley L. Functional Health Status of Persons With Diabetes in a Nurse-Managed Clinic. Diab Educ. 2002;28:106-14.

152. Sprague MA, Shultz JA, Branen LJ, Lambeth S, Hillers VN. Diabetes educators' perspectives on barriers for patients and educators in diabetes education. Diab Educ. 1999;25:907-16.

153. Dunn SM, Beeney LJ, Hoskins PL, Turtle JR. Knowledge and attitude change as predictors of metabolic improvement in diabetes education. Soc Sci Med. 1990;31:1135-41.

154. Nobmann ED, Mamleeva FY, Klachkova EV. A comparison of the diets of Siberian Chukotka and Alaska Native adults and recommendations for improved nutrition, a survey of selected previous studies. Arctic Med Res. 1994;53:123-9.

155. Osborn KL, Davis SM, Slattery M et al. Four Corners Research Consortium for Native Americans and cancer research. Cancer. 1996;78:1629-32.

156. Gittelsohn J, Toporoff E, Story M et al. Food Perceptions and Dietary Behavior of American-Indian Children, Their Caregivers, and Educators: Formative Assessment Findings from Pathways. J Nutr Ed. 1999;31:2-13.

157. Contento IR, Michela JL, Goldberg CJ. Food choice among adolescents: population segmentation by motivations. J Nutr Ed. 1988;20:289-98.

158. Murphy A. Doing the best evaluation possible. In: Doner L, ed. Charting the Course for Evaluation: How Do we Measure the Success of Nutrition Education and

Promotion in Food Assistance Programs? U.S. Department of Agriculture 1997:28-30.

159. Devine CM, Wolfe WS, Bisogni CA, Frongillo EA. Life-course events and experiences: associations with fruit and vegetable consumption in 3 ethnic groups. J Am Diet Assoc. 1999;99:303-14.

160. Stegmayer P, Lovrien FC, Smith M, Keller T, Gohdes DM. Designing a diabetes nutrition education program for a Native American community. Diab Educ. 1988;14:64-6.

161. Pelican S, Proulx JM, Wilde J, Del Vecchio A. Dietary guidance workshop helps tribal program cooks make changes. J Am Diet Assoc. 1995;95:591-2.

162. Lawn J, Lawn P. Nutrition education for Native treatment centres. Arctic Med Res. 1991;Suppl:758-60.

163. Algert SJ. Teaching elementary school children about healthy Native American foods. J Nutr Educ Behav. 2003;35:105-6.

164. Johnston JL, Schneider LS. Effects of a one-month nutrition and exercise program in Blackfoot women elders. J Can Diet Assoc. 1988;49:249-53.

165. Narayan KM, Hoskin M, Kozak D et al. Randomized clinical trial of lifestyle interventions in Pima Indians: a pilot study. Diabet Med. 1998;15:66-72.

166. Hudson P, Taylor-Henley S. Beyond the rhetoric: Implementing a culturally appropriate research project in First Nations communities. Am Ind Cult Res J. 2002;25:93-105.

167. Olson B. Applying medical anthropology: Developing diabetes education and prevention programs in American Indian cultures. Am Ind Cult Res J.1999;23:185-203.

168. Griffin JA, Gilliland SS, Perez G, Upson D, Carter JS. Challenges to participating in a lifestyle intervention program: the Native American Diabetes Project. Diabetes Educ. 2000;26:681-9.

169. Macaulay AC, Cross EJ, Delormier T, Potvin L, Paradis G, McComber A. Developing a Code of Research Ethics for research with a Native community in Canada: a report from the Kahnawake Schools Diabetes Prevention Project. Int J Circumpolar Health. 1998;57 Suppl 1:38-40.

170. McComber AM, Macaulay AC, Kirby R, Desrosiers S, Cross EJ, Saad-Haddad C. The Kahnawake Schools Diabetes Prevention Project: community participation in a diabetes primary prevention research project. Int J Circumpolar Health. 1998;57 Suppl 1:370-4.

171. Macaulay AC, Delormier T, McComber AM et al. Participatory research with native community of Kahnawake creates innovative Code of Research Ethics. Can.J Public Health. 1998;89:105-8.

172. Hood VL, Kelly B, Martinez C, Shuman S, Secker-Walker R. A Native American community initiative to prevent diabetes. Ethn Health. 1997;2:277-85.

173. Gilliland SS, Azen SP, Perez GE, Carter JS. Strong in body and spirit: lifestyle intervention for Native American adults with diabetes in New Mexico. Diabetes Care. 2002;25:78-83.

174. Carter JS, Perez GE, Gilliland SS. Communicating through stories: experience of the Native American Diabetes Project. Diabetes Educ. 1999;25:179-88.

175. Teufel NI, Ritenbaugh CK. Development of a primary prevention program: insight gained in the Zuni Diabetes Prevention Program. Clin Pediatr. 1998;37:131-41.

176. Corbin J, Strauss A. Grounded theory research: Procedures, canons, and evaluative criteria. Qual Soc. 1990;13:3-21.

177. Woteki CE. Measuring dietary patterns in surveys. Vital Health Stat.4 1992;101-8.

178. Agricultural Research Service. Design and Operation: the Continuing Survey of Food Intakes by Individuals and Health Knowledge Survey, 1994-1996. NFS Report No. 96-1. 1997. Washington, DC., US Department of Agriculture.

179. Hampl JS, Taylor CA, Johnston CS. Intakes of vitamin C, vegetables and fruits: which schoolchildren are at risk? J Am Coll Nutr. 1999;18:582-90.

180. Taylor CA, Hampl JS, Johnston CS. Low intakes of vegetables and fruits, especially citrus fruits, lead to inadequate vitamin C intakes among adults. Eur J Clin Nutr. 2000;54:573-8.

181. Lieberman LS, Probart CK, Schoenberg NE. Classification of food by African American women with diabetes. [abstract] Diabetes 39 Suppl;52:52A.

182. Lieberman LS, Probart CK, Schoenberg NE. Dietary habits and nutrient composition of diets of low income, rural African American women with diabetes. [unpublished work] 1991.

183. Parker,SP. Understanding Health Risk in Limited-Income Women. Dissertation. Oklahoma State University. 2002.

184. Kumanyika SK, Tell GS, Shemanski L, Martel J, Chinchilli VM. Dietary assessment using a picture-sort approach. Am J Clin Nutr. 1997;65:1123S-9S.

185. Tehard B, van Liere MJ, Com NC, Clavel-Chapelon F. Anthropometric measurements and body silhouette of women: validity and perception. J Am Diet Assoc. 2002;102:1779-84.

186. Glanz K, Linkins, RW, Risica, PM. Health Behavior and Health Education. San Francisco, CA: Jossey-Bass, 1997.

187. Portney LG, Watkins MP. Foundations of Clinical Research: Applications to Practice. 2nd. 2000. New Jersey, Prentice Hall.

188. Miles MB, Huberman AM. Qualitative Data Analysis: an expanded sourcebook. 2nd Edition. 1994. Thousand Oaks, CA, Sage. Publications

189. Morse JM Field PA. Qualitative Research Methods for Health Professionals. 2nd Edition, 139-141. 1995. Thousand Oaks, Sage Publications.

190. Morgan DL. Focus Groups as Qualitative Research. (16), 1988. Newbury Park, CA, Sage Publications. 64-69.

191. Windsor R, Baranowski T, Clark N, Cutter G. Evaluation of Health Promotion, Health Education, and Disease Prevention Programs. 1994. Mountain View, CA, Mayfield Publishing Company. 234-239.

192. Christian P, Bentley ME, Pradhan R, West KP. An ethnographic study of night blindness "ratauni" among women in the Terai of Nepal. Soc Sci Med. 1998;46:879-89.

193. Stevens JP. Applied Multivariate Statistics for the Social Sciences. Mahwah, N.J: Lawrence Erlbaum Associates, 2002.

194. Broussard BA, Johnson A, Himes JH et al. Prevalence of obesity in American Indians and Alaska Natives. Am J Clin Nutr. 1991;53:1535S-42S.

195. Centers for Disease Control and Prevention. Diabetes Statistics in the United States. Publication No. 99-3892. 1999. Washington, DC, NIH.

196. Hampl JS, Taylor CA, Booth CL. Differences in dietary patterns of nonsmoking adults married to smokers vs. nonsmokers. Am J Health Promot. 2001;16:1-6.

197. Hampl JS, Heaton CL, Taylor CA. Snacking patterns influence energy and nutrient intakes but not body mass index. J Hum Nutr Diet. 2003;16:3-11.

198. Merian L. The Problem of Indian Administration. 1928. Washington DC, Institute for Government Research.

199. Parkinson AJ, Cruz AL, Heyward WL et al. Elevated concentrations of plasma omega-3 polyunsaturated fatty acids among Alaskan Eskimos. Am J Clin Nutr. 1994;59:384-8.

200. Blum RE, Wei EK, Rockett HR et al. Validation of a food frequency questionnaire in Native American and Caucasian children 1 to 5 years of age. Matern Child Health J. 1999;3:167-72.

201. Gohdes D, Kaufman S, Valway S. Diabetes in American Indians. An overview. Diabetes Care. 1993;16:239-43.

202. Smith CJ, Nelson RG, Hardy SA, Manahan EM, Bennett PH, Knowler WC. Survey of the diet of Pima Indians using quantitative food frequency assessment and 24-hour recall. Diabetic Renal Disease Study. J Am Diet Assoc. 1996;96:778-84.

203. Gittelsohn J, Evans M, Story M et al. Multisite formative assessment for the Pathways study to prevent obesity in American Indian schoolchildren. Am J Clin Nutr. 1999;69:767S-72S.

204. Caballero B, Davis S, Davis CE et al. Pathways: A school-based program for the primary prevention of obesity in American Indian children. J Nutr Biochem. 1998;9:535-43.

205. Stover JC, Skelly AH, Holditch-Davis D, Dunn PF. Perceptions of health and their relationship to symptoms in African American women with type 2 diabetes. Appl Nurs Res. 2001;14:72-80.

206. Carter JS, Gilliland SS, Perez GE et al. Native American Diabetes Project: designing culturally relevant education materials. Diabetes Educ. 1997;23:133-139.

207. Taylor CA, Keim KS, Sparrer AC, Van Delinder JL, Parker SP. The cultural definition of health and diabetes of Native American women. PCD 2003 (in press).

208. Chandola T, Jenkinson C. Validating self-rated health in different ethnic groups. Ethn Health 2000;5:151-9.

209. Keyserling TC, Ammerman AS, Samuel-Hodge CD et al. A diabetes management program for African American women with type 2 diabetes. Diab Educ. 2000;26:796-805.

210. Carter JS, Pugh JA, Monterrosa A. Non-insulin-dependent diabetes mellitus in minorities in the United States. Ann Intern Med. 1996;125:221-32.

211. Gregg EW, Kriska AM, Narayan KM, Knowler WC. Relationship of locus of control to physical activity among people with and without diabetes. Diabetes Care. 1996;19:1118-21.

Appendix A
Oklahoma State University Institutional Review Board Approval

Oklahoma State University
Institutional Review Board

Protocol Expires: 2/5/2004

Date: Thursday, February 06, 2003 IRB Application No HE0347

Proposal Title: DEVELOPMENT OF A NATIVE AMERICANS DIABETES PREVENTION TOOL

Principal Investigator(s):

Kathryn Keim
421 HES
Stillwater, OK 74078

Chris Taylor
425 HES
Stillwater, OK 74078

Reviewed and Processed as: Expedited

Approval Status Recommended by Reviewer(s): Approved

Dear PI :

Your IRB application referenced above has been approved for one calendar year. Please make note of the expiration date indicated above. It is the judgment of the reviewers that the rights and welfare of individuals who may be asked to participate in this study will be respected, and that the research will be conducted in a manner consistent with the IRB requirements as outlined in section 45 CFR 46.

As Principal Investigator, it is your responsibility to do the following:

1. Conduct this study exactly as it has been approved. Any modifications to the research protocol must be submitted with the appropriate signatures for IRB approval.
2. Submit a request for continuation if the study extends beyond the approval period of one calendar year. This continuation must receive IRB review and approval before the research can continue.
3. Report any adverse events to the IRB Chair promptly. Adverse events are those which are unanticipated and impact the subjects during the course of this research; and
4. Notify the IRB office in writing when your research project is complete.

Please note that approved projects are subject to monitoring by the IRB. If you have questions about the IRB procedures or need any assistance from the Board, please contact Sharon Bacher, the Executive Secretary to the IRB, in 415 Whitehurst (phone: 405-744-5700, sbacher@okstate.edu).

Sincerely,

Carol Olson

Carol Olson, Chair
Institutional Review Board

OKLAHOMA STATE UNIVERSITY
INSTITUTIONAL REVIEW BOARD

Date:	January 21, 2000	IRB #:	HE-00-143
Proposal Title:	"DIABETES RISK FACTORS IN NATIVE AMERICAN OKLAHOMA WOMEN"		
Principal Investigator(s):	Kathryn Keim		
Reviewed and Processed as:	Exempt		

Approval Status Recommended by Reviewer(s): Approved

Signature:

Carol Olson

Carol Olson, Director of University Research Compliance

January 21, 2000
Date

Approvals are valid for one calendar year, after which time a request for continuation must be submitted. Any modification to the research project approved by the IRB must be submitted for approval with the advisor's signature. The IRB office MUST be notified in writing when a project is complete. Approved projects are subject to monitoring by the IRB. Expedited and exempt projects may be reviewed by the full Institutional Review Board.

Appendix B
Letters of Cooperation from Tribes

Pawnee Nation of Oklahoma

Executive Office
P.O. Box 470
Pawnee, Oklahoma 74058
PHONE: 918/762-3621
FAX: 918/762-6446
Email: Pawneenation.org

November 29, 2000

Kathryn S. Keim, Ph.D., R.D., L.D.
Nutritional Sciences Department
425 Human Environmental Sciences
Stillwater, Oklahoma 74078-6141

Dear Dr. Keim:

The Pawnee Nation of Oklahoma would like to take this opportunity to express our support and commitment to the proposed project to study Native American women's awareness of type 2 diabetes mellitus and diet quality. Diabetes has had a devastating effect on our tribal members.

The Nutritional Sciences Department of Oklahoma State University will develop the proposed project. It will provide the data and information needed to develop effective nutrition education interventions regarding diet on the prevention and treatment of diabetes mellitus for Native American women.

The Pawnee Nation of Oklahoma works with Native American women with type 2 diabetes mellitus and those without type 2 diabetes mellitus. The Pawnee Nation of Oklahoma has a Diabetes Program in place that is educational and preventional in nature. There are approximately 130 members on the diabetes register. Our Diabetes Educator, Juanita Kerns will be assisting your project with information that we can provide.

We would request favorable consideration to this much-needed project.

Sincerely,

Robert L. Chapman, President
Pawnee Business Council

Iowa Tribe of Oklahoma

R.R. 1, Box 721
Perkins, Oklahoma 74059
(405) 547-2402
Fax: (405) 547-5294

January 11, 2000

Dear Dr. Keim,

The Iowa Tribe, Diabetes Prevention, would like to take this opportunity to express our support and commitment to the proposed project to study Native American Women's Awareness of type 2 diabetes and diet quality.

The proposed project will be developed by the Nutritional Sciences Department, Oklahoma State University. It will provide the data and information needed to develop effective nutrition education interventions regarding diet in the prevention and treatment of diabetes mellitus for Native American women.

The Iowa Tribe, Diabetes Prevention, works with Native American women with type 2 diabetes mellitus and those without type 2 diabetes mellitus. These programs include initial intake with referrals to needed medical care for physicians, diet, and supportive medical therapies, transportation when needed, distribution of meters and strips, diabetic foot wear, exercise consultation and use of on site fitness equipment, bi-weekly aerobics classes, diabetes support group, home visits as needed, and telephone reassurance. There are approximately 35 members in the diabetes register. The personnel at these facilities will work with the research team to enhance this effort and increase effective services to tribal members.

We would request favorable consideration to this much needed project.

Sincerely,

Elyse Montgomery

Elyse Montgomery
Diabetes Coordinator

KANZA HEALTH CENTER

P.O. Box 474 • 3151 East River Road • Newkirk, OK 74647-0474
Phone (580) 362-1039 • Bus. Office Fax (580) 362-2988
Doctor/Nurse Fax (580) 362-1405

December 28, 1999

Dear Dr. Keim:

The Kanza Health Center would like to take this opportunity to express our support and commitment to the proposed project to study the develop instruments to measure stages of change and methods of nutrition education to work with Kaw Nation members with type 2 diabetes mellitus.

The proposed project will be developed by the Nutritional Sciences Department, Oklahoma State University. It will provide the data and information needed to develop effective nutritional education interventions regarding diet in the prevention and treatment of diabetes mellitus for Native American women.

The Kanza Health Center works with Native American women with type 2 diabetes mellitus and those without type 2 diabetes mellitus. There are 98 known diabetics on the register. The personnel at the Kanza Health Center will work with the research team to enhance this effort and increase effective services to the Kaw Nation members.

We would request favorable consideration to this much needed project.

Sincerely,

Wanda Stone, CEO
Chairperson
Kaw Tribe

Appendix C
Advertisement Used in Participant Recruitment

RESEARCH PARTICIPANTS NEEDED

The Departments of Nutritional Sciences and Sociology at Oklahoma State University are conducting a research project concerning Oklahoma Indian women and diabetes. Eligible participants in the study will be women between the ages of 25 – 65 years of age with at least ¼ degree Indian blood. Women may not be pregnant or breastfeeding. Participation in the study may affect your ability to receive food stamps. Participants will be required to complete three (3) interviews. The interview will be audio recorded and may take place in the home or other convenient location.

The first interview will gather background demographic information and provide training in how to use a scale to weigh foods eaten for a period of four (4) days. During the second interview participants will be asked opinions about certain foods and questions about health and diabetes. The final interview will ask questions about body image and more questions about food. When all three (3) interviews are completed, participants will receive $125.00 in compensation. Also a trained nutritionist will discuss the overall diet information.

For more information or if you are interested in becoming a participant please contact

Appendix D

1-Day Food List Recording Form

Date_____
Site_____
successful
Interviewer_____
(initial here)

☐ I understand participation is voluntary and I will receive $15.00 for completion._____

Age_____

Have Diabetes Y N

I am _____ from Oklahoma State University and I would like to ask you about what you ate over the past 24 hours. Participation is completely voluntary and you are free to decline. Upon completion of the 1-day food list, you will receive $15 dollars cash. Your responses will be kept completely confidential and your name will not be used.

Time and place	Eating Occasion	Food	Condiments, Toppings	Description

Appendix E

Interviewer Job Description

Qualitative Interviewer

Job Summary:
Individual responsible for conducting 3 qualitative interviews of Indian women according to protocols established by the research team.

Essential Functions:
- Will complete training on interview structure, data collection, collecting 4-day weighed food records and response recording.
- Will recruit subjects for qualitative interviews and 4-day weighed food records.
- Will conduct audio-taped interviews with Indian women concerning sensitive areas including perceptions of food, health, body weight, and diabetes.

Qualifications:
- No previous interviewing experience required
- Indian women preferred
- Dependable transportation

Compensation:
- $100 will be paid after successful completion of training
- $125 for each completed participant (3 interviews per participant)
- Mileage will be paid ($0.22 per mile) for travel to and from interviews

Application Procedure:
- Send letter of application and two business references to Elyse Montgomery at:

Elyse Montgomery
Iowa Tribe of Oklahoma
RR 1 Box 721
Perkins, OK 74059
Phone: (405) 547-2402
Fax: (405) 574-5294

Appendix F
Interviewer Application Form

DIABETES AND OKLAHOMA INDIAN WOMEN
INTERVIEWER APPLICATION FORM

Please Print or Type.

Name _____ Tribal Affiliation _____

Address _____ **Percent Indian Blood** _____

_____ **Gender M F**

Age _____

Telephone ( )_____ Home

( )_____ Office or other _____

Do you have a valid driver's license? Y N

Do you have reliable transportation? Y N

1. Please record your education background below:

School Name and Location	Years Attended AND Grade Classification	Major or Course Specialization	Degree (if completed)

2. Please record your employment history below:

Name of Employer:	Address:
Name of Immediate Supervisor: **Phone Number:**	**Please describe your job duties and responsibilities:**
Type of Business or Institution:	
Dates of Employment:	
Full or Part-time work:	
Reason for Leaving:	

Employment History (continued)

Name of Employer:	**Address:**
Name of Immediate Supervisor: **Phone Number:**	**Please describe your job duties and responsibilities:**
Type of Business or Institution:	
Dates of Employment:	
Full or Part-time work:	
Reason for Leaving:	

3. Professional References

Name	Title	Address	Telephone
			( )
			( )

4. What skills and abilities do you have that would make you a good interviewer?

5. Is there anything else you would like us to know about you?

Please return this application form no later than Friday, February 9th, 2001 to:

Cordelia Clapp
Kanza Health Clinic (Kaw)
P.O. Box 474
Newkirk, Ok 74647
Phone: (580) 362-1039 ext 20

Appendix G
Interviewer Contract

Oklahoma State University, Nutritional Sciences Department
Project: OCAST GRANT # HR00-069 ("Diabetes-Oklahoma Indian Women)

INTERVIEWER AGREEMENT

This Agreement is between Oklahoma State University, Nutritional Sciences Department, 425 HES, Stillwater, Oklahoma 74078-6141(hereinafter "Department") and (name of interviewer)_____(hereinafter "Interviewer").

SECTION I - Scope of Services

1.01 The Department hires Interviewer on a contract basis to interview Indian women in Oklahoma for the above noted Project. The Project involves conducting oral interviews related to the cultural definition of diabetes, diet quality, and body image.

1.02 The Department will provide administrative supervision of the Project. Equipment and supplies for the Project, transportation excluded, will be provided by the Department. The Department graduate students and faculty will review the materials collected by the Interviewer on a weekly, or more frequent basis, as determined by the Department.

1.03 The Department will own all materials collected by the Interviewer during or for the Project, including but not limited to oral interview tapes, field notes, documentation, data, etc.

1.04 The Interviewer will provide the following services:

A. Attend a day long training on interviewing skills and study procedures.
B. Work with the Department graduate students and faculty to identify possible participants.
C. Complete three (3) interviews per participant.
D. The collection of 3 interviews and weighed food records, with the progress in this area monitored by the Department graduate students and faculty at weekly intervals.
E. Obtain a signed consent form from all participants.
F. Keep accurate and useable notes during the interviews.
G. Provide assistance to the transcriber in deciphering portions of tapes, as necessary.
H. Label all materials in accordance with the Department's study policies.
I. Adhere to the work schedule developed jointly by the Interviewer and the Department's graduate students and faculty and provide all necessary logs and invoices in a timely fashion.
J. Adhere to the Oklahoma State University code of ethics.
K. Provide such other services for the Project as determined necessary by the Department.

SECTION II - Compensation and Expenses

2.01 Department agrees to pay Interviewer the following:

A. $100 upon completion of interviewer training.
B. $125 upon completion of 3 interviews per participant.

2.02 Payment for the interview portion is contingent on satisfactory completion of the interviews and return of all materials (food records, audio tapes) and all applicable forms, in proper order, to the Department's graduate students or faculty.

2.03 The Department will reimburse Interviewer for related Project mileage. Reimbursement of expenses can only be made with proper receipts. Mileage will be paid at $0.22 per mile and will be paid after the mileage log invoice has been submitted. Payment of mileage expenses will be made in a timely manner upon receipt and approval of the reimbursement request.

2.04 Interviewer is solely responsible for the payment of income, social security, and other employment taxes due to the proper taxing authorities on any payment received under this Agreement.

2.05 All payments hereunder will be paid in a timely manner upon of receipt of required invoices and adequate receipts and documentation as requested by the Department to support reimbursement of mileage expenses and subject completion.

2.06 Each interviewer will be compensated for interviewing no more than 9 Indian women before August 31, 2001 unless prior written approval is obtained from the Department. Each interviewer will be compensated for interviewing no more than 9 Indian women from September 1, 2001 to end of this contract (August 31, 2002) unless prior written approval is obtained from the Department.

2.07 This Project is funded by the Oklahoma Center for the Advancement of Science and any payment hereunder is contingent upon receipt by the Department of monies for said Project by the funding agency.

SECTION III - Confidentiality

3.01 Interviewer agrees to keep Confidential and not disclose to third parties any information provided by the Department or obtained by the Interviewer in the performance of services under this Agreement. This provision shall survive the termination of this Agreement.

SECTION IV - Term

4.01 This Agreement shall be considered in effect from (start date) _____ until completion of the Project, but in no event later than August 31, 2002.

4.02.1 Department may terminate this Agreement for any reason upon ten (10) days written notice to Interviewer. In the event of termination by the Department under this provision, the amount of compensation, if any, to be paid Interviewer shall be determined by the Department based upon the work completed and the terms of the Project grant.

SECTION V - Interviewer's Capacity and Responsibilities

5.01 It is expressly understood that in performing the services under this Agreement, Interviewer is acting as an independent contractor and not an employee, agent, or partner of the Department or Oklahoma State University and the Interviewer is not entitled to tax withholding, Workers' Compensation, unemployment compensation, employee benefits, insurance coverage, statutory or otherwise, of Oklahoma State University.

5.02 Interviewer does not have the authority to enter into any contract or agreement or otherwise bind Oklahoma State University and Interviewer shall not represent to anyone that Interviewer has such authority.

5.03 It is the Interviewer's responsibility to obtain and/or maintain the necessary insurance to cover Interviewer's services rendered under this Agreement. Any personal injury to Interviewer or third parties or any property damage incurred in the course of performance of services under this Agreement are the responsibility of the Interviewer.

SECTION VI - Miscellaneous Provisions

6.01 This Agreement constitutes the entire understanding between the parties with respect to the subject matter of this Agreement and may not be amended except in writing signed by the Interviewer and an authorized representative of the Department.

6.02 This Agreement shall be governed by and construed under the laws of the State of Oklahoma.

6.03 This Agreement is not assignable by the parties.

_____

Interviewer

Date

Oklahoma State University, Department of Nutritional Sciences
By:

_____

Thomas C. Collins
Date
Vice President for Research

_____

Kathryn S. Keim, PhD, RD, LD Date
Assistant Professor, Nutritional Sciences
Project Principal Investigator

Appendix H
Consent Form for Qualitative Interviews

Oklahoma State University

Individual's Consent to Voluntary Participation in a Research Project

I, _____, voluntarily consent to participate in the study entitled: Diabetes risk factors in Native American Oklahoma women, sponsored by Oklahoma Center for the Advancement of Science and Technology and the College of Human Environmental Sciences at Oklahoma State University.

PURPOSE: The purpose of this study is to learn about nutrition and health influences that affect the development of diabetes mellitus.

PROCEDURE(S) AND DURATION: I will meet with the interviewer at least three times. Each of these meetings will be audio taped for analysis by the research team. If I agree, all of the meetings will be in my home or in a clinic. I will always be aware of the times that the interviewer will visit my home. The interviewer will not drop by unannounced on any occasion.

During the first visit, I will be asked to answer background demographic questions. After that, I will be asked to weigh and record foods that I eat for four days. I will be given measuring cups, spoons, and beanbags that estimate food portions to assist me when measuring food intake. During those four days a researcher will call me to make sure that I am not having any problems with the scales. Finally, I will be asked about my priorities in life.

During the second visit with the interviewer, I will be asked questions about my health. She will then show me pictures of foods and I will give her my opinions about those foods. This interview will take about 2 ½ hours. After this interview, the interviewer may call me to ask additional questions about the answers that I have given if anything is unclear to her.

During the third visit, I will be asked to sort pictures of women of different body shapes according to my beliefs and preferences. I will also be asked about my food habits. The interviewer will show me pictures of foods again and I will be asked to give my opinions and sort the foods based on the questions that she asks me. This will take about 2 ½ hours. After this interview, the interviewer may call me to ask additional questions about the answers that I have given if anything is unclear to her.

BENEFITS: I will receive $125.00 for completing all interview and 4 days of food records. Receiving this money as compensation may conflict with my ability to receive food stamps and it is my responsibility to report this income to my caseworker. I understand that I will not receive any of the money until I have completed all parts of the study. I will receive information about my dietary intake at the end of the study if I would like this information. A trained nutritionist will explain the information from the nutrient analysis to me. This research is beneficial in that it provides information about health risks experienced by women. The information gained from this study may be useful in helping women choose nutritionally adequate diets that are beneficial in decreasing chronic disease risk

ALTERNATE TO PARTICIPATION: I have the right to withdraw from this study at any time by contacting the researchers. I may stop participating in the study at any time without penalty or loss of benefits that I am otherwise entitled to receive.

I understand that by signing this consent form I have not waived any of my legal rights or released this institution for liability or negligence.

I understand that records from this study will be held confidential and that I will not be identified by name in any report or publication resulting from this study. My food records will be reviewed and analyzed by the project director or her authorized representatives. Food records will be filed in the project director's office until completion of the study when they will be destroyed by shredding them.

I understand that if I have questions about this study, or need to report adverse effects, I may contact Dr. Kathy Keim at (405) 744-8293 or Dr. Jean VanDelinder at (405) 744-4613. If I have any question about my rights as a research subject, I may contact Sharon Bacher at the Office of University Research Services, 305 Whitehurst, Oklahoma State University, Stillwater, OK 74078 at (405) 744-5700.

SIGNATURES: I have read this consent form and understand its contents. I freely consent to participate in this study as described herein. I will receive a copy of this consent form.

Date _____ Time_____

Subject's Name (Please Print)_____

Subject's Signature_____

Permanent Address_____

City _____State_____Zip Code _____

I certify that I have personally explained all parts of this form to the subject before requesting the subject to sign it.

Signature _____(Project Director or Authorized Representative)

Printed Name_____(Project Director or Authorized Representative)

Appendix I

Demographic Form for Qualitative Interviews

DIABETES AND INDIAN WOMEN

1. What is your current marital status? (Please circle one)
    a. Married / Not married but living with a partner
    b. Widowed
    c. Divorced / Separated, or
    d. Never married
2. What is your degree of Indian blood?

    _____
    _____
3. What which tribe are you an enrolled member?

    _____
4. Total number of persons in your household including yourself.
    _____Number of adults
    _____Number of children (under age 18)
5. What is the highest level of education you have completed? (Please circle one)
    a. Some high school or less
    b. High school graduation / GED
    c. Some college / Some technical school
    d. A 4-year college degree
    e. A postgraduate degree
6. Which category best represents your total earned household income (gross) or retirement over the past year? (Please circle one)
    a. Less than $10,000
    b. $10,000 - $14,999
    c. $15,000 - $19,999
    d. $20,000 - $24,999
    e. $25,000 - $29,999
    f. $30,000 - $35,000
    g. $35,000 - $40,000
    h. $40,000 and over
7. Please select the places where you buy or get food. (Circle all that apply).
    a. Grocery store
    b. Convenience store
    c. Home gardens
    d. Hunting / Fishing
    e. Fast Food / Restaurants
    f. Other _____
8. Which of the following describes you current work status? (Circle one)
    a. Employed full time
    b. Employed part time
    c. Homemaker
    d. Unemployed (not working)
    e. Retired
9. Has a doctor ever told you that you have (Circle all that apply):
    a. Diabetes
    b. High Blood Pressure/Hypertension
    c. Heart Disease
    d. Osteoporosis
    e. High blood cholesterol
    f. Stroke

10. During this past month, did you participate in any physical activities or exercises such as running, calisthenics, gardening, or walking for exercise vigorously enough to work up a sweat? (Please circle one)
    a. Yes
    b. No
    c. Don't know/ Not sure
11. How often do you participate in physical activity vigorously enough to work up a sweat? (Please circle one)
    a. Daily
    b. 5-6 Times per week
    c. 2-4 times per week
    d. Once a week
    e. 1-3 times per month
    f. Rarely or never
12. Is anyone in this household receiving benefits from the following programs? (Please circle all that apply)
    a. Women Infant and Children Supplemental Program (WIC / CSFP)
    b. Food Stamps
    c. Social Security Income (SSI)
    d. FDPIR (Food Distribution Program on Indian Reservations/Commodities)
    e. TANF (Temporary Assistance to Needy Families)
    f. Elderly Meals
13. Do you consider yourself (Please circle one):
    a. Underweight
    b. Appropriate weight
    c. Overweight
    d. Not sure
14. Are you currently trying to lose weight? (Please circle one)
    a. Yes
    b. No
15. Are you on any special diet? (Please circle one) **IF NO, SKIP TO Q17**
    a. Yes
    b. No
16. If yes, what type of diet are you currently on? (Please circle all that apply)
    a. Weight Loss or Low Calorie Diet
    b. Low Fat or Cholesterol Diet
    c. Low Salt or Sodium Diet
    d. Low Fiber Diet
    e. High Fiber Diet
    f. Diabetic Diet
    g. Other _____
17. I'm going to review a list of appliances. Please respond to the ones that you have and are working. (Check all that apply)

Yes	No	
☐	☐	a. Refrigerator
☐	☐	b. Microwave
☐	☐	c. Stove-top
☐	☐	d. Oven
☐	☐	e. Freezer
☐	☐	f. Toaster Oven
☐	☐	g. Hot plate

18. What is your date of birth? _____
19. What is your current height? _____
20. What is your current weight? _____
21. How did you learn about the study? _____

Appendix J

Directions to Rank Order Life Concerns

Participants will be asked to name their concerns in life. Their concerns will be written on note cards. They will be asked to sort their concerns from most important to least important in a ladder like fashion. After this, the participant will be given a card with body weight on it. They will be asked to insert the card according to importance on the scale. The cards will be turned over and numbers will be placed on them (1=least important, bottom of the ladder).

Food Diary

My Diary of What I Eat And What I Drink

ID #_____

Date_____

We would like to know what kinds of foods you eat and what you drink. For the next 4 days, please write down everything that you eat and drink. Be sure to tell us the amount that you eat and drink. Use the scales to measure what you eat and drink and follow the directions that are in this booklet.

Remember to be very specific when recording. We really appreciate your cooperation.

If you ever have trouble with the scales be sure to call us at work. You may need to leave a message and your call will be returned.

Thanks,

Dr. Kathryn Keim
Work#: (405) 744-8293
Alicia Sparrer
Work#: (405) 744-5073
Chris Taylor
Work #: (405) 744-5073

Directions for keeping your food diary

We would like you to weigh all of the foods and drinks that you eat. If you eat out, you do not have to weigh your foods unless it is convenient for you. You will write down those foods and estimate portions using the directions in this booklet.

Everything you put in your mouth and swallow is important to record. This includes all meals, snacks, nibbling, candy, drinks (including alcohol), everything. Record in your diary immediately after eating a meal, snack, or drink.

Also be very specific when you record what you eat and drink. Describe every item and how it was prepared.

- **Record one item per line**
- **Be specific about how it was prepared**
  - write fried, baked, broiled...- not just chicken
- **Be very specific when describing the item**
  - Write whole milk, skim milk, 2%...- not just milk
  - Write wheat, white, etc...-not just bread
  - Record the name brand when you know it (i.e. snickers candy bar)

Directions for how to use the scales

1. Turn the scale on.
2. Put your plate on the scale.
3. Press the "On/Off button", the scale should read 0.
4. Put the first food on the scale.
5. Record the amount in the "How much served?" column on the food record.
6. Push the button again. The scale should read 0.
7. Put the next food on the plate. Record the amount in the "How much served?" column.
8. Continue in this way until you have recorded all foods you plan to eat.
9. It is important for you to weigh leftovers, follow the instructions for leftovers if you do not eat everything on your plate.

Recording leftovers

1. Put a paper plate on the scale and press the "on/off button".
2. Scrape the first food not eaten onto the empty plate.
3. Record the amount in the "How much left?" column.
4. Press the "on/off button".
5. Scrape the next food not eaten onto the plate.
6. Record the amount in the "How much left?" column.

7. Continue this way until you have recorded all left overs.

Recording foods eaten away from home

1. If you eat out, you should use the food serving size bag.
2. The 3 oz portion should be used for estimating meats, fish, chicken, and cheese. It is the size of a 3-ounce serving.
3. Use the measuring spoons for estimating jelly, syrup, butter, gravy, salad dressing, ketchup, mustard, and other toppings.
4. Use the measuring cups and bean bags to estimate amounts for vegetables, rice, noodles, cereal, soup, stew, casseroles, ice cream, Jell-O, and canned fruits.
   - ❖ The green bean bag is 1 cup
   - ❖ The red bean bag is ½ cup
   - ❖ The black bean bag is ¼ cup.

Recording Fast Foods

If you eat out at McDonald's, Burger King, Long John Silvers, Whataburger, etc. tell us what size you ate in the column 2 marked "How much served?" See the example.

EXAMPLE Date 1/05/00 Day of week wed.

I ate and drank this:	**How much served?**	**How much left?**
Orange juice from concentrate	278 g	50 g
Eggs scrambled in margarine	92 g	
White bread toasted with margarine	142 g	
Fried pork sausage	256 g	16 g
McDonald's Big Mac	1	
Coke	1 biggie	
French Fries	1 biggie	¼ order
Snickers candy bar	120 g	
Orange soda	20 fl. oz	
2 Fried chicken thighs	172 g	
Green beans	250 g	
Mashed potatoes with milk and margarine	452 g	
Sweetened tea	300 g	10 g
Sour cream and onion potato chips	56 g	
Sweetened tea	300 g	

Food Diary

Day 1 Date_____ Day of week _____

I ate and drank this:	How much served?	How much left?

Day 1 Date_____ Day of week _____

I ate and drank this:	How much served?	How much left?

Day 2 Date_____ Day of week _____

I ate and drank this:	How much served?	How much left?

Continue on the next page if needed.

Day 2 Date_____ Day of week _____

I ate and drank this:	How much served?	How much left?

Day 3 Date_____ Day of week _____

I ate and drank this:	How much served?	How much left?

Continue on the next page if needed.

Day 3 Date_____ Day of week _____

I ate and drank this:	How much served?	How much left?

Day 4 Date_____ Day of week _____

I ate and drank this:	How much served?	How much left?

Continue on the next page if needed.

Day 4 Date_____ Day of week _____

I ate and drank this:	How much served?	How much left?

Thank You

Oklahoma State University
Nutritional Sciences Department
Stillwater, OK 74078

Appendix L
Cultural Structure of Health and Diabetes Questions

Interviewer name:_____ ***Subject #_____***
Date:_____

Questions of Cultural Structure of Health and Diabetes

1. Describe your current health to me.
2. Describe how you feel about your health.
3. What, if any, health concerns do you have?

   What are the major health concerns of other Indian women you know?
4. What do you think is the leading cause of death for Indian women 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?

   What are the reasons that you think <u>these things (mentioned above)</u> causes diabetes?

   How did you find the information that you just told me?

   If read, where? Books, magazines (which ones)

   If heard, where? From who?
7. Can you think of anyone who is at risk for developing diabetes? (Are they Indian?)
8. What do you think happens to a woman once she develops diabetes?
9. How can a person tell if they have diabetes?

   How do they feel?
10. Tell me about anything that you know of that might keep a woman from developing diabetes.

    What are the reasons that you think <u>these things (mentioned above)</u> prevents diabetes?

    Where did you find out this information?

    If read, where? Books, magazines (which ones)

    If heard, where? From who?

    What may prevent a woman from doing these things that may prevent diabetes?
11. What treatments are there for diabetes that you know about?

    If diet, describe the diet.

12. Who are you concerned about developing diabetes?

    What are the reasons that you are concerned about this person(s)?

    (Are any of them your children? Nieces, nephews?)

    What can parents/family do to help this person/child not develop diabetes?

    What can the tribe/community do to help this person/child not develop diabetes?

13. How do you feel about diabetes?

    What is your greatest fear about diabetes?

    What control do you think a person has over diabetes?

    Can you prevent diabetes?

    When can a person begin to do these things to prevent diabetes?

14. Is there anything else would you like to tell me about diabetes?

Appendix M
Food Sort 1 Recording Form

Interviewer name:_____ Subject #:_____

Date:_____

Food Sort 1
Directions:
1. Take the set of 50 food cards and randomly sort these cards face up on the table.
2. Ask the participant to sort the cards as she chooses and then have her give a name to each grouping.
3. Enter the name of each group provided by the participant in the heading boxes.
- Write down the numbers of the foods (numbers are on the backs of the cards) in each food group.
- For example, if the participant named a group as fruit, record all those numbers under the heading fruit.
- Do this for all food groups the participant creates. *See example below:

Example:

fruit		
1, 18, 32, 23, 46, 7		

Appendix N
Questions for Weight Valuation

Interviewer name:_____ **Subject #_____**

Date:_____

Questions for Weight Valuation

I. Weight and height will be self-reported. (On demographic questionnaire.)

II. Drawings will be used to get classifications of body size.

a. Respondents will be handed one drawing at a time and will be asked to describe the body. The purpose of this is to learn perceptions of body size.

b. Responses will be audio taped and recorded on response form.

Show participant each card individually and record responses.

Card Number	Participants description of body weight
1	
2	
3	
4	
5	
6	
7	
8	
9	

III. Body shapes will be placed in random order. The following questions will be asked.

1. [Have participant rank from most healthy to least healthy.]

Record the number that is on the back of the card in the order that the subject rates the drawings

	Most								Least
1. Healthy									

a. Which person looks healthy? Why?

2. [Have participant put them in order from most attractive to least attractive.]

	Most								Least
2. Attractiveness									

a. What body size is the **MOST** attractive for a woman Why? What body size is the **LEAST** attractive? Why?

b. In general, what makes a woman attractive? (Age, hair length, clothes, body size?)

3. Which do you consider to be the **best** size for a woman of your age? (*Point to body size chart*.)

Put an (X) in the column that corresponds with the number on the back of the card.

Question	1	2	3	4	5	6	7	8	9
3. Best size									

a. What made you choose that one over the others? Why do you think this is the best size?

4. Which do you consider to be too large?

Put an (X) in the column that corresponds with the number on the back of the card.

Question	1	2	3	4	5	6	7	8	9
4. Too large									

a. Why do you think some women are too large?

5. Which one do you consider to be an average size female?

Put an (X) in the column that corresponds with the number on the back of the card.

Question	1	2	3	4	5	6	7	8	9
5. Average size female									

6. What looks most like you?

Put an (X) in the column that corresponds with the number on the back of the card.

Question	1	2	3	4	5	6	7	8	9
6. Looks like you									

a. How do you feel about your body size?

7. If you wanted to lose weight, what body size do you want to be?

IF NOT WANTING TO LOSE WEIGHT, SKIP TO Q7A

Put an (X) in the column that corresponds with the number on the back of the card.

Question	1	2	3	4	5	6	7	8	9
7. What body size do you want to be?									
Which could you achieve?									

Which one do you think you could achieve?

What would other people think of you if you changed your body size?

a. Why do you think women want to lose weight?

b. Have you tried to lose weight before?

c. What are reasons that you (have) or (have not) tried to lose weight?

d. Have you ever tried to lose weight and quit?

What do you think are the reasons you were not able to lose weight? (Family? Friends?)

8. Which size would you like to be?

Put an (X) in the column that corresponds with the number on the back of the card.

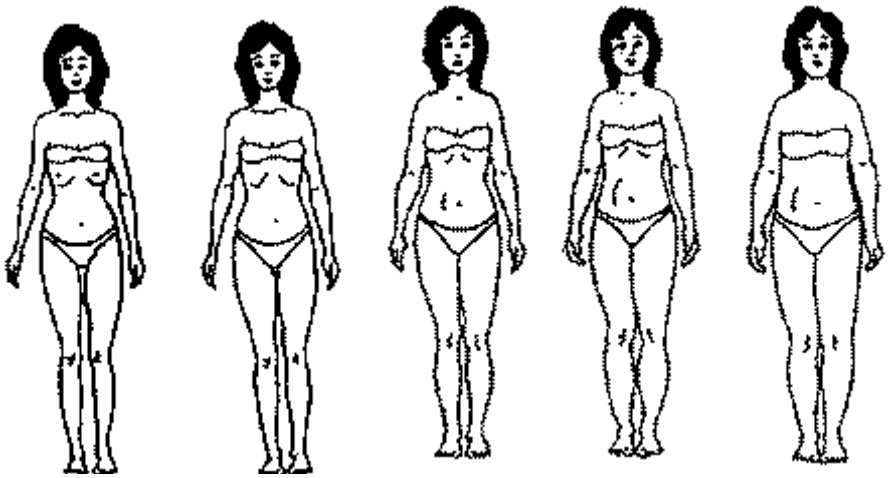
Question	1	2	3	4	5	6	7	8	9
8. What size would you like to be?									

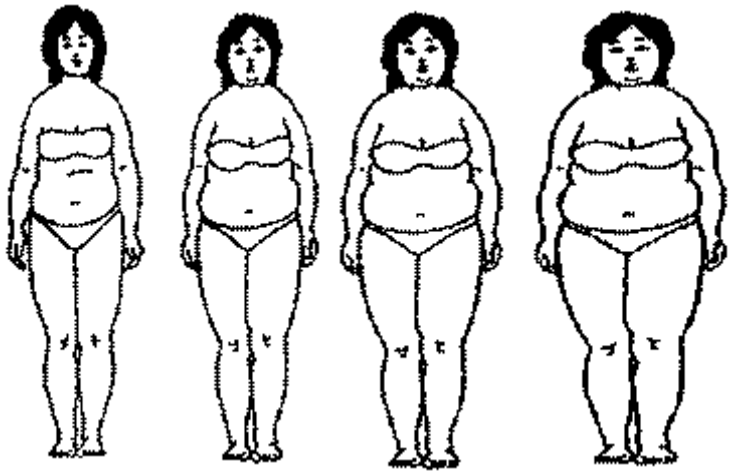
a. What made you choose this size over the others?

9. Now that you have participated in this study, what have you learned about diabetes and Indian women that you didn't know before?

What is the best way this information could be useful to other Indians not involved in this study? (How would you like to learn about diabetes?)

Appendix O
Body Images for Weight Valuation





Appendix P
Food Sort 2 Recording Form

Interviewer name:_____ Subject #:_____

Date:_____

Food Sort 2

Directions:
1. Randomly sort the set of 53food cards and conduct three, three-way, sorts of all the cards. The three sorts that will be done are: healthy/not healthy/not sure; low fat/high fat/not sure; and low sugar/ high sugar/ not sure.
2. When each sort is done, turn the cards over and record the number from the back of the card onto the data recording sheet. Then randomly sort the cards again and continue the next sort until you have completed the three sorts and recorded the information below.
3. Finish the session with questions concerning the dietary information and ask what the participant liked or disliked concerning the card sorting activity. This information will be useful to develop more appropriate programs for the participants.

HEALTHY	NOT HEALTHY	NOT SURE

LOW FAT	HIGH FAT	NOT SURE

LOW SUGAR	HIGH SUGAR	NOT SURE

Appendix Q

Parent Code Words Used in Initial Coding of Verbatim Transcripts

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
AWARENESS	Lack or increased awareness in terms of diabetes
BAR DM	Barriers in controlling diabetes
BAR EXER	Perceived barriers preventing exercise
BAR FOOD	Perceived barrier to eating a healthy diet
CONTROL	Methods used to control diabetes
DEF DIET	Cultural definition of a healthy diet
DEF DM	Cultural definition of diabetes
DEF EXER	Cultural definition of exercise
DEF HEALTH	Cultural definition of health
DENIAL	Denial experienced post-diagnosis of diabetes
DM CAUSES	Perceived causes of diabetes
DM CONCERN	Concerns and fear about diabetes
DM DIET	Perceived diabetic diet and dietary changes required by diabetes diagnosis
DM LT COMP	Perceived long-term complications of diabetes
DM PREVENT	Methods to prevent or delay onset of diabetes
DM SYMPTOM	Perceived symptoms of diabetes onset
DM TREAT	Perceived treatments for diabetes
FAMILY	Role of family in diabetes prevention and treatment
HEALTHCARE	Issues in quality and continuity of healthcare
MEN HEALTH	Perceptions of men and health
NA DEATH	Perceived leading causes of death for American Indian women
NA WOMEN	Perceived health issues of other American Indian women
PERSONAL	Personal health concerns
SOCIAL	Social aspects of diabetes care and prevention
SOURCE	Sources of health and nutrition knowledge
TRAD DIET	Cultural definition of a “traditional diet”
TRIBE	Role of tribe/community in diabetes prevention and treatment

Appendix R

Transcripts Memo Narratives for Cultural Structure of Health Questions

DEF HEALTH:

Predominantly, the Native American women in our sample defined health in terms of lifestyle behaviors. Individuals performing specific behaviors are considered healthier than those who do not. The activities that reflect healthy behaviors, including consuming a healthy diet, exercising and not smoking. Furthermore, one's health is often defined in terms of physiological presence of diseases. For example, when asked to define one's current health, responses circulated around the presence or absence of diabetes, heart disease, cancer or other disease. Despite a clinical diagnosis, one's health does not suffer unless there is a physical feeling of illness. One woman indicated, *"I haven't been like throwing up sick in like years, but a little cold here and there."* Being overweight was also considered to reflect negatively on health status. Individuals requiring medication are considered less healthy than those who do not. Conversely, individuals taking their medication have the power to restore health status. Despite these tangible concerns, achieving good health requires more frequent visits to a doctor or health care provider. The ultimate verdict often lies in clinical diagnoses made therein.

Another indicator of health status was defined through physical functionality. Poor health is considered to impair one's ability to perform daily tasks. Additionally, being healthy is having the energy to perform these tasks and other activities. However, there are certain reservations made for age. Health is expected to decline with age; many defined their health status compared to their expectations for their current age.

DEF DM:

Diabetes was defined most commonly in terms of the long-term complications, which were often tied to fear and concern. A thread of fatalism toward diabetes and its complications was found among these women. Diabetes is devastating *"because it'll ruin their health. It ruins*

your health, and ultimately it'll kill you." Diabetes is considered a malicious disease. One woman stated:

"I think diabetes is scary. It's a scary process. It's demeaning. I think it is, it's just a very, very cruel breakdown of your system."

Being of Native American descent leads to increased susceptibility to diabetes, feeding into the fatalism toward diabetes. The social network found in the Native American communities feeds this perception, as much of the information about the causes, care and outcomes of diabetes is commonly obtained from those close to them.

The body being "out of balance" causes diabetes. An error in the inner workings of the body creates an imbalance of blood sugar. Confusion exists in the perception of hyperglycemia and hypoglycemia. The thought is that hypoglycemia is the initial physiological response and then it converts to a hyperglycemic state of diabetes.

Upon diagnosis of diabetes, there is the impression that life must then change. The lack of healthy lifestyle behaviors prior to clinical diagnosis elicits the knee-jerk response of the need for monumental changes. Resistance to these changes is likely tied to the perceived inevitability to diabetes. Diabetes is a disease that requires intensive care. Care revolves around eating right, taking your medicine and doing what the doctor tells you to do. Diabetes care is the responsibility of the individual. This aspect will be discussed in detail when reporting diabetes treatment text segments.

Health, defined as physically feeling sick, provides a strong barrier to diabetes care and prevention. A perception exists that as long as you are taking your medication and you don't feel sick you are adequately caring for the disease. *"I guess maybe I don't have it bad enough, I don't know, but I just… I mean, nothing was bothering me. I couldn't tell that I had it."* Care of diabetes, including taking medication, is neglected in the absence of physical symptomology. If diabetes is not controlled, the disease will destroy your health, decrease quality of life and ultimately take over your life. Certain reservations are made in health for advancing age; however, Native American women felt diabetes was an ageless disease. Moreover, an overall

concern for children developing diabetes is expressed in the description of those at risk for this disease.

DM TREAT/CONTROL:

Text segments coded to identify specific treatments of diabetes and methods to control diabetes displayed a high level of congruency, therefore, they will be discussed herein together. Responses have been aggregated to three primary categories: intrinsic mechanisms; extrinsic mechanism; and skills/actions.

Diabetes care lies solely in the intrinsically within the patient. This reflects directly to the definitions of health and diabetes, as physiological conditions are the responsibility of the individual. To maintain adequate control, one must exhibit a strong will power to regularly perform the actions necessary for adequate control. These actions are considered to require a great deal of work or effort on the part of the individual.

Extrinsic factors also play a role in the ability for one to control their diabetes. Despite the internalized nature of diabetes care and the personal nature of health, a social support system, positive or negative, can alter one's ability to control their diabetes. Family and occupational obligations may provide the impedance to optimal care. This support system may exist in the family setting or through close friends or coworkers. In addition, a strong reliance on the healthcare professional is seen in terms of care. Often, the patient relies on the healthcare professional as an informational source and as the ultimate judge of health status and care and what to do to take care of them. Furthermore, the healthcare professional is responsible for providing the skills necessary for control of diabetes. The functional skills required for adequate control includes self monitoring of blood glucose, medication use, weight management and appropriate lifestyle changes, including alcohol consumption, eating a healthy diet and smoking cessation.

BAR DM:

Factors expressed as barriers to controlling diabetes can be further explained through two subclassifications, lifestyle change and self-care. As seen in the definition of diabetes, being

diagnosed requires an individual to spontaneously adopt a specific profile of lifestyle changes. Perceivably, all dietary habits must change; this phenomenon appears to be the greatest barrier to care. One woman indicated *"most people that I know that are diabetics have had a poor diet in the past and then all of a sudden have to (sound affect) change their diet."* Once diagnosed with diabetes, the person must give up the foods they like for foods they perceive to be more healthy to follow the "diabetic diet." (Perceptions of the most commonly consumed foods may provide insight into the link of perceptions and diabetes status – triangulation). Refusals to change life-long habits therefore provide a considerable barrier to diabetes care and prevention.

In addition to lifestyle change, the skills and time required caring for their condition serves as an additional barrier to care. Monitoring blood glucose levels requires time, resources and attention to one's physiological condition is required, often without adequate skills provided by healthcare professionals.

In the absence of the aforementioned lifestyle behaviors one is prone to resist, medication becomes the adequate means of control. As mentioned in the definition of health, the need for medication is indicative of compromised health. However, once prescribed, the medications are often relied to provide protection from the disease in lieu behavior changes.

DM CONCERN:

As seen in its definition, diabetes is defined by and thought of in terms of its complications. Women indicated an overall concern for each of the many long-term complications caused by poor control of diabetes. The most commonly noted complication was amputation. Similarly, others indicated a fear for diabetes, calling a "scary disease." Furthermore, diabetes is a *"silent killer"* perceived to end in death. This string was present directly and provided a constant undertone of concern throughout the interviews. One woman stated:

"I just don't want to get it. Don't want to be a diabetic. I've seen what it does to my family."

Another prominent concern among the Native American women was the propensity of their family or themselves to be diagnosed with diabetes. Interestingly, there was a greater indication of concern for the children in comparison to one's own propensity for diagnosis. Following concern for child and self, the women were concerned about other members in their family, including their siblings and parents. While considering themselves at-risk, there is a fear of having diabetes for an extended period of time without being diagnosed.

Additional concerns about diabetes centered on the topic of control. The women were uncomfortable with the thought of needing medication. There is an overall fear of insulin, needles and shots. Incorrectly or inadequately injecting oneself is of major concern in this population. Also, keeping blood glucose levels under control is a prominent concern. These are achieved through eating right and taking your medication.

DENIAL/AVOIDNACE:

Another perplexing phenomenon exists similar to the perceived barrier to diabetes control. Issues of denial and avoidance of diagnosis were evident, providing an additional wrinkle in diabetes prevention and treatment. Despite efforts for diabetes screening and increased awareness, an avoidance of screening surfaced. One is considered to be in good health with no clinical diagnosis of a chronic disease in addition to the absence of feeling ill. By avoiding the visit to the healthcare professional, one has freed themselves from the diagnosis of diabetes (often despite a personal suspicion of having diabetes) and thus delayed the need to care for it by making lifestyle changes. One woman mentioned "*(t)here might be a tendency for people to suspect it but not want to have it confirmed maybe...*" In this case, care for diabetes is delayed and the increased likelihood of long-term complications rises.

Furthermore, awareness of diabetes as a major personal health concern is not considered until one is facing diagnosis. If a positive diagnosis has been made, a strong sense of denial appears to be prevalent. A participant mentioned a family member, "*she's in denial, and won't go to the doctor, and then it gets worse, and then they'll go after it starts getting too bad.*" In

the absence of feeling ill, one must not have diabetes. Care is often postponed until a physically ailment is perceived, likely indicative of long-term complications.

AWARENESS:

There is a considerable lack of knowledge about various aspects of diabetes. At various points in the interviews, the lack of knowledge became evident, which ranged from an overall lack of knowledge of the disease to specific areas of understanding. Several NA women were unable to identify causes and preventative measures of diabetes. The misinformation or lack of knowledge extended to diabetes or identification of those at risk for disease development. A lessened awareness of the symptomology and consequences of poor diabetes control in some may prove detrimental to the quest for care for individuals at high risk or who may have developed diabetes.

DM SYMPTOM:

Many of the women were able to identify established symptoms of diabetes. Responses included frequent urination, excessive thirst, dry mouth and lethargy. Increased hunger was also noted, often accompanied by an increased craving for sugar. A physical feeling of illness also was considered to preclude diabetes diagnosis presented in the form of not looking healthy, feeling of nausea and overall “not feeling good.” Diabetes was also associated with both weight loss and weight gain. Dizziness and blurred vision were also attributed to diabetes onset. Emotional changes were also considered to be indicative of the onset of diabetes as one may experience mood swings and depression.

There appears to be confusion regarding the symptoms exhibited when one is developing diabetes. Many of the responses were derived from their personal experiences or of those close to them. Many of the warning signs of diabetes were considered to be deviations from the norm without direct indication of the established symptomology. One woman indicated dialysis as a necessary treatment of diabetes.

DM CAUSES:

As also seen in the definition of diabetes, being of Native American descent provides a strong propensity toward diabetes diagnosis. A strong interplay with prevention is noted in this population. In the event of a strong family history, it is perceived that it may be impossible to prevent the onset of diabetes, regardless of lifestyle behaviors. There is minimal mention of the ability of changing lifestyle behavior to aid in delaying the onset of diabetes.

Dietary habits were also labeled as a cause of diabetes. Food intake patterns established over a lifetime relying predominantly on carbohydrates are blamed for the onset of diabetes. Overconsumption and a high sugar diet were attributed to the rise in diabetes in this population. Also, the propensity toward obesity and a lack of exercise was considered to lead to the development of diabetes.

DM PREVENT:

When asked about the ability to prevent diabetes, many responded in terms of personal behaviors that may help delay the onset of diabetes, centering on the avoidance of behaviors considered to cause diabetes. Some possessed a perception that diabetes could be prevented through healthy lifestyle behaviors. In others, the fatalistic view seen in the definition of diabetes made evident the inevitability of diabetes in individuals with a strong family history of diabetes. However, we probed on the when these potential preventative behaviors should begin, a considerable portion indicated the need to reach the children at a young age.

Confusion exists in this population about diabetes and its long-term complications. Some indicated frequent visits with their healthcare professionals were an appropriate method of diabetes prevention. In the absence of changing lifestyle factors, the act of screening could serve as a method of diabetes prevention. This demonstrates a passive approach to diabetes prevention, coupled with the reliance on the healthcare provider as the final confirmation of health status. Following a medication regimen was also considered a means of diabetes prevention.

AT RISK:

Individuals exhibiting the traits perceived to cause diabetes, as previously mentioned, were considered to be at greater risk for diabetes. However, this presents the magnitude at

which individuals apply the knowledge of causation and apply it to individuals. There was an increased awareness of diabetes development in children; this data suggests that they have taken the increased risk for diabetes to heart and are concerned about their own children. This almost goes against the sense of denial found in this group. For themselves, their seems to be little action in changing lifestyle behaviors on their own behalf for diabetes prevention but they are much more ready to aid their children. This demonstrates less of a "wait until there are symptoms [or complications]" attitude commonly discussed previously, at least for NA children.

DM LT COMP:

Overall there appears to be an intense understanding of the consequences of poor control of diabetes. The most commonly sited complication of diabetes was amputation, followed by impaired vision, renal dysfunction and death. Fewer individuals noted the circulatory and neural consequences of diabetes or the impact on wound healing. Obesity, thyroid problems and organ transplants were also considered to be long-term complications of diabetes.

HEALTHCARE:

Various concerns surfaced throughout the interview process in regards to the quality and continuity of healthcare received. The most prominent of these was a failure of the healthcare team to provide the appropriate skills necessary for self-care of health and diabetes. This was manifested by those with diabetes primarily in the administration of medications, namely insulin injections. An example of this concern was expressed as:

> *"…You just put a little capsule like this in the medicine, just put in there and give yourself a shot. Well, then I had to draw that, and I was oh, I'm gonna get a bubble in there and kill myself, you know…"*

This also ties into a perception of inadequate education of other aspects of health and nutrition. Patients were often encouraged to promote health and diabetes care through a healthy diet and preventative lifestyle behaviors, such as increased exercise, without imparting the necessary knowledge and/or skills to support such changes. Furthermore, follow-up on these behaviors is often lacking in a system lacking continuity in patient care. This is manifested

through the common inability to see the same healthcare provider on consecutive visits. In such a system, the healthcare provider is viewed as a medication dispenser and not as a source of prevention information. Additional concerns in the healthcare system include the lack of use of traditional care. Despite these concerns, the women relied on the healthcare provider for decision-making.

Furthermore, the training of the health care professionals appeared to be out-dated. Many health care professionals continued to convey the diagnosis of borderline diabetes and that no action is required at that time. Still, a lack of screening has provided the avenue by which many have gone undiagnosed until complications arise. Several individuals mentioned they were diagnosed when they were seeking treatment for a seemingly unrelated health problem, such as heart disease or physical trauma.

SOURCES:

The Native American women were asked to identify their sources information about various aspects of health, diabetes and nutrition. It is evident that the most common source of health-related information was derived from those close to them. These individuals included immediate and extended family, friends, elders and coworkers. Predominantly, the list was comprised of mostly feminine acquaintances. Fewer mentioned of healthcare providers as a source of health information.

Various programs were also mentioned as a source of health-related information. These included various educational programs, health fairs, clinics, conferences and workshops. Also, various media contributed to information among this group. Particular media sources included pamphlets, magazines, books, library resources, medical and research literature, newspaper articles, public ads and the internet. In addition to hearsay and media, many individuals attributed their knowledge of health, diabetes and eating right to personal experiences or observation of those around them.

SOCIAL:

The social aspects of health and diabetes exist as a paradoxical phenomenon. A strong sense of personal responsibility is held in terms of health and diabetes. Health is a personal problem; one is expected to maintain their own health without burdening those around them, including family members. Only the affected individual can provide their care in the event of diabetes diagnosis. This is often modulated by the overall attitude of the individual towards health and their perceived capability to control their diabetes.

In addition to the intrinsic motivation to care for one's health, an external environment may serve to moderate personal health. Despite an individual's personal responsibility for care of their health, external factors may play a pivotal role in affecting lifestyle behaviors. Extrinsic support may be seen from several avenues as well as promoting or impeding self-care. of own health and diabetes

Family and friends may also provide either a positive or negative support environment. When diabetes was thought to bring about dietary modification and specific restrictions, it was considered rude to refuse food prepared by another.

"And you have to apologize you know cause well, I'm diabetic and I can't eat this. But sometime I will take maybe just a spoonful, you know, of something, just not to be, not to be, how do you say, if somebody's cooked a dinner?"

Conversely, one woman indicated that when a coworker was diagnosed with diabetes, her office staff was educated on how to react in the event of hypoglycemia.

"Well, we had to know in case she was going down what we needed to do for her. You know, we kept candy bars around and pop and stuff. Cause at first, she would have lows and she'd just start crying. So we had to learn what to do real fast."

This concern can also extend into social occasions shared at the workplace.

"Right, and you have that consideration for your other co-workers because on birthdays you don't just bring birthday cake because the diabetics can't have birthday

cake so you bring strawberry shortcake with cool whip and there's no sugar added. Or something like that."

Sometimes the family may impede care. In one instance, a woman suspected she may have diabetes but was deterred from screening by family members.

"But, and I always wanted them to check me and they all said I'm okay, you're not diabetic."

Religious beliefs may also alleviate one's worry about health and provide a positive outlook through faith.

"There's not a day goes by that I don't think about having diabetes, and that it's not like controlling my life because I won't let it, and God won't let it."

FAMILY:

Promotion of behavior changes for health promotion could also occur within the family unit. Creation of a family exercise program was considered to potentially aid in weight maintenance as well as the potential for physical activity to persist. Parental responsibility extends to limitations of television viewing time and computer use and emphasizing the importance of increased physical activity levels. One woman indicated that:

"I think if we could all, if we could all as a family sit down and discuss what could happen to you if you did get the diabetes. Like me, they know that I'm borderline, and they know that I have to watch my diet and what I eat and everything. And if I could get them to do what I'm doing, to follow some kind of diet, and get the exercise that we need, I think we would be better off in the long run."

Furthermore, family focus on screening for diabetes, though not preventative per se, may increase the likelihood of being diagnosed early with pre-diabetes. If a diagnosis is made, the family could work together in behavior changes that may ultimately delay the onset of frank diabetes.

In addition to the lifestyle changes made by the family unit, familial education may help prevent diabetes. Group attendance at diabetes education or healthy lifestyle programs may

provide support for family members at greater risk for developing diabetes. Also, the sharing of print materials with the family may facilitate discussion of diabetes risk.

The strength of the family unit may also provide the impetus for sustained change in lifestyles to promote health and prevent diabetes. Motivation and support is important in assisting a family in diabetes prevention. As seen in the definition of diabetes, individuals learn about the causes, care and complications of diabetes from those close to them. Family and friends have the ability to encourage and motivate individuals at risk for diabetes to adopt healthy lifestyle behaviors to prevent diabetes. This may also surface in the ability to watch for warning signs or symptoms of diabetes and encourage health care visits.

Additionally, the presence of the family indirectly provides motivation for diabetes prevention and care. Increasing one's lifespan is often desirable on the basis of being around longer to enjoy the family.

"I just think its up to the person. If they care enough about their family, wanting to live for them and watching what they eat and, you know, how they live then I think they can have a healthy life. If they don't care, you know, its just like…death, you know…"

Seeing family members around them die early may warn an individual about the need for taking care of their health.

"No, but see he died early I think. He was only sixty-seven and I think he could have lived longer had he taken care of his body and he understood that after he got old."

TRIBE:

The goal of this endeavor was to gather information to be used by the tribes for development of targeted nutrition education and public health programs. To identify the most desirable avenue for these programs, participants were asked what the tribe or community could do to help prevent diabetes. Educational programming proved to be the most desired avenue. However, the recommended avenues of education could be divided into two major types, active and passive. Active educational strategies include holding classes, workshops, health fairs and community discussions about diabetes. Conversely, pamphlets, videos and other forms of

literature were indicated to be acceptable sources of diabetes information for the community. Other possible ways for the community to promote health and diabetes prevention were provided, such as community exercise programs and facilities and the availability of counseling by a health professional.

DEF DIET:

In the quest for a cultural definition of a healthy diet, several issues surfaced. Primarily, the definition of healthy diet encompasses moderation and various portions of federal recommendations, focusing primarily on Food Guide Pyramid (FGP) serving and nutrient intakes. The following is a presentation of the specific statements defining healthy eating behaviors.

Many of the respondents indicated a need for variety to ensure a healthy diet. Following the FGP was considered an appropriate mechanism to achieve this goal. However, within the FGP, specific food groups were perceived to require more attention. Several participants indicated that one should increase their consumption of vegetables and fruits. Fewer individuals expressed a need for meat in the diet to be healthy while others indicated that meat consumption should be limited. Dairy consumption was also considered to be an integral portion to a healthy diet.

Other aspects of a healthy diet were founded upon an increased or decreased need for specific nutrients. Adequate intake vitamins, minerals, water and fiber were thought to contribute to a healthy diet and thus should be consumed at a greater level. Equally, increased intakes of certain nutrients were indicative of an unhealthy diet. High consumption of fat and cholesterol were considered detrimental to a healthy diet. Fatty foods, including chips, candy bars and fried foods, contribute to an unhealthy diet and should be avoided. This is a concern because the foods served at cultural functions like pow-wows are considered to be high fat foods.

"And, um, they eat a lot of greasy foods, and it's at pow-wows and feasts and stuff like that. And they're more high risk eating that stuff."

Potato chips were also targeted for their contribution to a high-salt intake, another indicator of an unhealthy diet.

With the rise of diabetes rates in this population, an increased focus on carbohydrate consumption has emerged. This avoidance has manifested itself to the extent of carbophobia. To further define this carbohydrate phobia, an aversion to high-starch food was necessary to consume a healthy diet. Of note is the dichotomy of following the FGP as a framework for consuming a healthy diet, of which grains provide the foundation, while also exhibiting a carbohydrate phobia.

"Food pyramid diet, with little carbohydrates and sugar. It's one of the easiest diets, disease to control. But it's the hardest. A human being wants to eat, wants to eat that all the time.anyway."

Furthermore, several women indicated a concern about sugar intakes. Elevated intakes of sweets, desserts, candies and soda are considered to denote a poor diet.

"They should. McDonald's is not healthy. (Laugh) Cut down on like the grease and the fatty foods and snack foods like chips and candy bars and stuff. It's not good for you."

Food consumption and preparation behaviors are also considered to be important in the consumption of a healthy diet. Several women indicated that eating at home and avoiding fast foods would aid in the consumption of a healthy diet. Furthermore, when eating at home, food preparation methods also contribute to the overall quality of the diet; frying of foods should be decreased with a concurrent increase in baking and boiling of foods. Additionally, eating two or three meals was considered to be indicative of a healthy diet. The women also felt that skipping meals was considered an unhealthy behavior.

Certain foods are also thought to play a key role in a healthy diet. An increased consumption of commodities and processed foods are deleterious to health while an increase in natural foods is encouraged. Food preferences served as the mediator of food selection behaviors. These preferences were said to be established during childhood that have endured

into adulthood. The diet consumed while growing up tended to shape the perceptions of a healthy diet as adults.

BAR FOOD:

After describing how NA should eat, the women were asked to speculate on the reasons why a healthy diet is not consumed. These rationales included various internal and external perceived barriers that may inhibit healthy food selections. The most prominent barrier involved a perceived lack of time and convenience. A busy lifestyle and the unwillingness to allow time for meal preparation, easier, less-healthy methods of food procurement are initiated. The various roles of the woman in family and society often do not allow for additional time to prepare a healthy meal and thus alternative methods are sought.

There is also a perception that eating healthy is more expensive. Fast foods and convenience foods are considered to be more readily available and cost effective than preparing foods from scratch at home. Inconsistencies on resource availability throughout the month and spoilage of fresh foods further exacerbate the problem. In addition, other members of the family may resist changing current dietary habits to a more healthy diet, undermining a woman's responsibility to provide a healthy meal. Also, cultural acceptance and history of food intake compete with current perceptions of healthy eating habits. Perceived traditional diets were higher in fats and low in vegetables and fruits. The definition of a traditional diet will be discussed in the following section.

In addition to the various external factors in food selection and preparation commands, internal factors influence food selection and efficacy to follow a healthy diet. Frankly, some individuals enjoy food and do not care to change eating habits despite the potential health benefits. Many would not change eating behaviors, even with the financial resources were available. Others feel they lack the self-control, knowledge or awareness to select or prepare a more healthy diet. Therefore, poor dietary habits remain unchanged

TRAD DIET:

As we reviewed transcripts early on, a thread of confusion over the real definition traditional diet became evident. The questioning route was then modified to ascertain an individual's perception of a "traditional diet" with no further explanation of answers expected. This provided the participants to provide an unbiased account of their definition of what a traditional diet was. From this discussion, three different definitions were obtained: a current (*cultural*) diet; and a pre-white man diet (*historical*).

The *cultural* diet consists of foods that are consumed during social gatherings, such as holidays and powwows. Connection with distant historical relevance appears to be devoid of this classification. Foods mentioned as foods in the *cultural* traditional diet were corn, meat pie, fry bread, boiled potatoes, corn soup, dumplings, beans, steam fry, meat, fried potatoes, gravy, tacos, kool aid, corn bread, sweets and a lot of soda. Many of these foods are the result of increased consumption of commodities, after removal and currently. An overall concern about the fat and sugar content of this diet warranted an apprehension to shift dietary habits to this *cultural* diet for disease prevention.

"And I love all of that. I love meat pies and corn soup and a lot, there was a lot of fat too, as well as carbohydrates. And the servings were big."

When asked about the potential outcomes of switching on diabetes prevention:

"Yeah, I really do because they put so much fat and stuff in corn soup and the fry bread. I don't know, it might even be a little worse."

The other prominent perception about a traditional diet focused on dietary habits prior to contact with whites and relocation. When the white men brought sugar and fat and the beginning of commodities marked the end of the *historical* diet.

"That traditional diet was put together right after that we were given flour. We didn't used to make fry bread. You know, we used to make a tortilla out on the oven, you know. And that's, I mean, the white's taught us how to cook like that."

This *historical* diet was focused primarily on the hunting and gathering principle.

"Like they had lean meat, I meant they killed it and you know it was very lean. They didn't have sugar. They didn't have, well they had flour, but they didn't have the sugar."

Foods constituting the *historical* diet included elk, deer, berries, buffalo, natural foods, low fat, no sugar, no added salt, no additives. This diet was considered to be a healthy diet.

"Well, it, like for Indians, you know how they ate a long time ago, before they got the (commodities), before the (commodities)were given to them, they were eating pretty healthy. Then they thought, oh, we'll help these Indians."

Mixed responses were received when asking if a shift from current dietary habits toward this traditional diet would aid in disease prevention, namely diabetes; however, more women were optimistic about the potential health benefits of reversion to this diet. Substantial barriers were mentioned in rebuttal to such a switch, including the time, energy and availability of resources to return to hunting and gathering activities.

DEF EXER:

To gauge the current perspective on physical activity and exercise, questions were added to the questioning route to define what exactly encompasses exercise. Walking was the most common response when asked what kind of exercise should people do. Often it is going walking with other members of the family. There is no indication of intensity therefore strolling may not be providing the intended benefit. In terms of frequency, the women indicated exercise should commence daily while a slightly higher number felt three to four times per week was adequate.

Another interesting phenomenon was the indication that performing daily activities was equivalent to exercise. There is a perception that performing household chores constitutes a considerable portion of one's need for physical exertion. Therefore, in the absence of being sedentary, one is active.

"Especially when you cook and you set your table and you go from the cabinet to table you know. That's exercise. Even in my little place."

Furthermore, there was a perception that getting exercise required involvement in organized activities, typically involving equipment. Examples are these included basketball, softball and weight training.

BAR EXER:

Many reasons were provided as to what barriers exist that prevent NA women from exercising. The primary reasons encompassed a common theme of motivation and priority. Many indicated they were too lazy or lacked the motivation to generate and adhere to a constant routine. One woman lamented:

"Because a long time ago when I was younger, we walked all the time, you know. You didn't think nothing of walking clear across town, you know. 'Cause back then, there weren't as many people having cars as there is now. Too lazy, you know."

Entwined in the matrix of the lack of commitment lies the roles ordained to womanhood. Family responsibilities often are thought to consume a woman's available time for exercise. Additionally, exercise serves a less enticing roll than less strenuous activities like watching television. In light of these circumstances, exercise is often compromised in lieu of other more important or more enjoyable activities.

Other reasons inhibiting the establishment of an exercise routine included the physical inability to perform manifested through obesity, pain due to movement or impaired ambulation due to amputation or confinement to a wheelchair. There is also a perception that exercise requires intense planning and financial resources. Additionally, there is a psychological and emotional link to exercise program initiation and compliance. The NA women indicated that they lacked the self-confidence to exercise sometimes tied to obesity. Concerns also exist in the efficacy or perceived benefits to be expected from regular exercise.

PERSONAL:

When asking about the status of their current, the woman indicated various ailments and health concerns they personally experienced. The concerns ranged from various physiological conditions, such as diabetes, arthritis, obesity and heart disease, to lifestyle behaviors, including

a lack of exercise and poor dietary habits. These ailments constituted a large proportion of the health concerns of the women.

NA WOMEN/ NA DEATH:

The women were asked what they perceived to be the health concerns of other NA women. The list included several physiological conditions including diabetes, cardiovascular disease, hypertension, high blood cholesterol, cancer and arthritis. In addition to the diseases indicated above, complications of diabetes, such as dialysis and vision problems were also addressed. Several lifestyle indices were considered to be health concerns. These behaviors were an overall poor care of health, poor dietary habits, smoking and alcohol and drug abuse.

Responses regarding the leading causes of death centered on various chronic diseases. The major causes were considered to be diabetes, heart disease, cancer and high blood pressure. The other causes of death included being overweight, smoking, alcoholism and not taking care of yourself.

Appendix S
Consent Form for Assessment Tool Administration

Voluntary Consent Form to Sign
Validation of Assessment Tool

Oklahoma State University

Individual's Consent to Voluntary Participation in a Research Project

I, _____, voluntarily consent to participate in the research study entitled: Development of a Native Americans diabetes prevention tool. This study is sponsored by the Nutritional Sciences Department in the College of Human Environmental Sciences at Oklahoma State University.

PURPOSE: The purpose of this study is to create and validate an assessment tool to measure beliefs, attitudes and knowledge about health, diabetes, and healthy eating. The information gathered during this research study will be shared with tribal leaders to aid in the development of diabetes prevention programs appropriate to tribal needs.

PROCEDURES AND DURATION: I will meet with undergraduate or graduate Nutritional Sciences students one time to complete two surveys. This will take approximately 20 minutes. The first survey is for personal information (demographic) and the second survey (assessment tool) is a series of questions about attitudes, beliefs, knowledge about health and diabetes.

RISKS: A possible risk is I might feel uncomfortable answering some of the questions about my feelings about health and diabetes. If I am uncomfortable, I can voluntarily decide to not answer those questions or I may withdraw from the study.

BENEFITS: I will receive $10.00 for answering questions on both surveys. This research is beneficial in that it provides information about health and diabetes of Native Americans and can be used to assist in the development of educational programs to improve the health of Native Americans in Oklahoma.

ALTERNATE TO PARTICIPATION: I have the right to withdraw from this study at any time. I may stop participating in the study at any time without penalty or loss of benefits that I am otherwise entitled to receive.

CONFIDENTIALITY: My name will not appear on any of the 2 surveys. An ID number is used to identify across the 2 surveys for analysis purposes. The ID number does not appear on the consent form and the consent form cannot be identified with the 2 surveys. All surveys are kept in a locked file cabinet and will be shredded after the group information has been shared with the tribal leaders and journals articles published.

I understand that by signing this consent form I have not waived any of my legal rights or released this institution for liability or negligence.

I understand that records from this study will be held confidential and that I will not be identified by name in any report or publication resulting from this study. My responses will be reviewed and analyzed by the project director or her authorized representatives. Surveys will be filed in the project director's office until completion of the study when they will be destroyed by shredding them.

I understand that if I have questions about this study, or need to report adverse effects, I may contact Dr. Kathy Keim at (405) 744-8293. If I have any question about my rights as a research subject, I may contact Dr. Carol Olson at the Office of University Research Services, 305 Whitehurst, Oklahoma State University, Stillwater, OK 74078 at (405) 744-1676.

SIGNATURES: I have read this consent form and understand its contents. I freely consent to participate in this study as described herein. I will receive a copy of this consent form.

Date _____ Time_____

Volunteer's Name (Please Print)_____

Volunteer's Signature_____

I certify that I have personally explained all parts of this form to the volunteer before requesting the vounteer to sign it.

Signature _____(Project Director or Authorized Representative)

Printed Name_____(Project Director or Authorized Representative)

Witness

Signature _____ Date _____

4

Appendix T
Diabetes Assessment Tool

Topics were taken from interviews done with Native men and women here in Oklahoma. You do not have to answer anything you are uncomfortable with,.

I am going to read you a list of statements about your perceptions of health. Tell me how much you agree or disagree with the following statements.

Strongly Agree 1	Agree 2	Somewhat Agree 3	Somewhat Disagree 4	Disagree 5	Strongly Disagree 6

Health:

1. I am unhealthy when my body is out of balance
2. I am healthy if I do not have a disease
3. I am healthy when I take care of myself
4. I can prevent health problems if I take care myself
5. I need a strong will to eat a healthy diet
6. I need a strong will to be physically active
7. I know when I am not healthy because I feel sick
8. I only need to go to the doctor when I feel sick
9. I can stay healthy if I go visit the doctor on a regular basis
10. I can be healthy even if I am overweight
11. I need to start taking care of my health when I start to feel sick
12. I only need to take medicine when I feel sick
13. I expect my health to get worse as I get older
14. Unhealthy people are irritable
15. Unhealthy people are depressed
16. Being healthy means I can physically do all the things I want to do
17. I am the only person who can take care of my health
18. Taking care of my heath should not burden others
19. Taking care of my health is expensive
20. Taking care of my of health takes a lot of time
21. My eating habits and physical activity do not need to change until I get sick
22. I should start early in life to take care of my health
23. I should start early in life to eat a healthy diet
24. I should start early in life to be more physically active
25. It would be hard for me to change my diet
26. It would be hard for me to be more physically active
27. It is hard for me to eat a healthy diet
28. Eating a lot of starches (like breads, potatoes and pasta) is bad for me
29. Eating a lot of fat is bad for me
30. It is expensive to eat healthy foods
31. Doing my daily tasks is getting physical activity

Now I am going to read you a list of statements about your perceptions of diabetes. Tell me how much you agree or disagree with the following statements. We will use the same 6-point scale as we just used.

Strongly Agree 1	Agree 2	Somewhat Agree 3	Somewhat Disagree 4	Disagree 5	Strongly Disagree 6

Diabetes:

1. I could be healthy even if I have diabetes
2. Indians are at higher risk of getting diabetes
3. Indians can't do anything about diabetes because they'll get it anyway
4. I did not think about diabetes until it happened to me
   I won't think about diabetes until I get it
5. Diabetes is a scary disease
6. I am afraid of diabetes
7. Diabetes is a death sentence
8. Diabetes ruins your health
9. Diabetes attacks your organs
10. Diabetes means taking insulin shots
11. Only a doctor can tell me if I have diabetes
12. I can tell someone has diabetes just by looking at them
13. I avoid diabetes screening so I wouldn't have to care of it
    I avoided diabetes screening so I wouldn't have to care of it
14. Diabetes can be controlled
15. I don't want to get my blood checked because I don't want to know if I have diabetes
16. Diabetes requires a lot of daily life changes
17. Daily life behaviors do not need to change until one gets diabetes
18. People with diabetes need to eat different foods than people without diabetes
19. People with diabetes can take their medicine to control diabetes without having to change their diet
20. People with diabetes can take their medicine to control diabetes without having to be more physically active
21. Children are at risk of getting diabetes
22. I think I am at risk for diabetes
    Before I got diabetes, I thought I was at-risk
23. I can prevent myself from getting diabetes
    Before I got diabetes, I thought I could have prevented it.

I am going to read you a list of traits that may or may not help someone prevent diabetes. Using the same 6-point scale, tell me how much you agree or disagree about how these can prevent diabetes.

Strongly Agree 1	Agree 2	Somewhat Agree 3	Somewhat Disagree 4	Disagree 5	Strongly Disagree 6

Ways to Prevent Diabetes:

1. Eating a healthy diet can prevent diabetes
2. Doing more physical activity can prevent diabetes
3. Getting one's blood sugar checked regularly can prevent diabetes
4. Diabetes cannot be prevented

Now I'm going to ask you about some ways someone can tell they have diabetes. Tell me how much you agree or disagree with the following signs and symptoms.

Symptoms of Diabetes:

1. Irritability
2. Depression
3. Feeling very tired
4. Being very thirsty
5. Feeling very hungry
6. Having to urinate a lot
7. Having blurry eyesight
8. Needing dialysis
9. Having sores that heal slowly
10. Losing weight without trying
11. Needing an amputation/losing limbs
12. There are no symptoms

Next I'm going to read you a list of traits. Would you tell me how much you agree or disagree that these items cause diabetes.

Causes of diabetes:

1. Family history
2. Not enough of physical activity
3. Being overweight
4. Being Indian
5. Drinking lots of soda pop
6. Eating a lot of fat
7. Eating a lot of sugar
8. Eating a lot of salt
9. Drinking alcohol
10. There are no known causes

This last section covers items related to your social environment. Please tell me how much you agree or disagree with these statements.

Strongly Agree 1	Agree 2	Somewhat Agree 3	Somewhat Disagree 4	Disagree 5	Strongly Disagree 6

Social

1. My family will help me take care of my health
2. Families should discuss health together
3. Family members should do healthy behaviors (like eating healthy and getting physical activity) together
4. My family should encourage me to take care of myself
5. Taking care of my family means I have less time to take care of my own health
6. Changes in health behaviors will last longer if the family changes together
7. Family blood sugar screening would help prevent diabetes
8. It is hard to keep a child from eating, even if he or she is eating too much
9. Parents should gather pamphlets, fliers and booklets on diabetes for their family
10. My family should encourage me to be more physically active
11. My family should encourage me to make healthy food choices
12. Parents should limit their children's TV watching and computer time
13. The priority of the family cook is to provide what the family wants to eat, even if it is unhealthy
14. Healthy eating habits should be learned at home
15. I learned about diabetes from my family
16. I learned about diabetes from my friends
17. Public education would prevent diabetes
18. Taking care of my health allows me to live longer for my family
19. It is rude to refuse foods that are offered to me, even if they are unhealthy
20. Schools should teach children about diabetes
21. Schools should teach children about eating a healthy diet
22. Schools should teach children about being physically active
23. Spirituality helps me deal with my health problems
24. I shouldn't bother other people with my health problems
25. People with diabetes should not let others know they have it
26. Poor health affects my ability to carry out my role in the family
27. It is easier for me to take care of my health if I have support from friends and family

Appendix U

Demographic Questionnaire for Assessment Tool

Keeping the Balance Assessment Tool

A little about YOU

1. How old are you (in years)? _____ (Must be 18-65)
2. What is your degree of Indian blood? _____ (Must be > ¼)
3. What is your current marital status? (Please circle one)
    a. Married / Not married but living with a partner
    b. Widowed
    c. Divorced / Separated, or
    d. Never married
4. With which tribe are you an enrolled member? _____
5. What is your zip code: _____
6. Total number of persons in your household including yourself.
    _____Number of adults
    _____Number of children (under age 18)
7. Which category best describes your total household or retirement income over the past year?
    a. Less than $10,000
    b. $10,000 - $14,999
    c. $15,000 - $19,999
    d. $20,000 - $24,999
    e. $25,000 - $29,999
    f. $30,000 - $34,999
    g. $35,000 - $39,999
    h. Over $40,000
8. What is the highest level of education you have completed? (Please circle one)
    a. Some high school or less
    b. High school graduation / GED
    c. Some college / Some technical school
    d. A 4-year college degree
    e. A postgraduate degree
9. Which of the following describes you current work status? (Circle one)
    a. Employed full time
    b. Employed part time
    c. Homemaker
    d. Unemployed (not working)
    e. Retired

10. Has a doctor ever told you that you have (Circle all that apply):
    a. Diabetes
    b. High Blood Pressure/Hypertension
    c. Heart Disease
    d. Osteoporosis
    e. High blood cholesterol
    f. Stroke
11. How often do you participate in any physical activities or exercises, such as running, calisthenics, gardening, or walking, vigorously enough to work up a sweat? (Please circle one)
    a. Daily
    b. 5-6 Times per week
    c. 2-4 times per week
    d. Once a week
    e. 1-3 times per month
    f. Rarely or never
12. Do you consider yourself (Please circle one):
    a. Underweight
    b. Appropriate weight
    c. Overweight
    d. Not sure
13. How would you define your current health?
    a. Excellent
    b. Good
    c. Fair
    d. Poor
14. What is your current height? _____
15. What is your current weight? _____
16. Have you ever had your blood sugar tested? Yes No
17. When you need healthcare, where do you go for help? (Circle all that apply)
    a. IHS clinic/hospital
    b. Tribal health clinic/hospital
    c. Non-IHS or non-tribal clinic
    d. Emergency room
    e. Traditional healer
18. How would you like to learn about health and diabetes? _____

    _____

Appendix V

Original Assessment Tool Response Recording Form

H1	SA	A	SwA	SwDA	DA	SDA
H2	SA	A	SwA	SwDA	DA	SDA
H3	SA	A	SwA	SwDA	DA	SDA
H4	SA	A	SwA	SwDA	DA	SDA
H5	SA	A	SwA	SwDA	DA	SDA
H6	SA	A	SwA	SwDA	DA	SDA
H7	SA	A	SwA	SwDA	DA	SDA
H8	SA	A	SwA	SwDA	DA	SDA
H9	SA	A	SwA	SwDA	DA	SDA
H10	SA	A	SwA	SwDA	DA	SDA
H11	SA	A	SwA	SwDA	DA	SDA
H12	SA	A	SwA	SwDA	DA	SDA
H13	SA	A	SwA	SwDA	DA	SDA
H14	SA	A	SwA	SwDA	DA	SDA
H15	SA	A	SwA	SwDA	DA	SDA
H16	SA	A	SwA	SwDA	DA	SDA
H17	SA	A	SwA	SwDA	DA	SDA
H18	SA	A	SwA	SwDA	DA	SDA
H19	SA	A	SwA	SwDA	DA	SDA
H20	SA	A	SwA	SwDA	DA	SDA
H21	SA	A	SwA	SwDA	DA	SDA
H22	SA	A	SwA	SwDA	DA	SDA
H23	SA	A	SwA	SwDA	DA	SDA
H24	SA	A	SwA	SwDA	DA	SDA
H25	SA	A	SwA	SwDA	DA	SDA
H26	SA	A	SwA	SwDA	DA	SDA
H27	SA	A	SwA	SwDA	DA	SDA
H28	SA	A	SwA	SwDA	DA	SDA
H29	SA	A	SwA	SwDA	DA	SDA
H30	SA	A	SwA	SwDA	DA	SDA
H31	SA	A	SwA	SwDA	DA	SDA

D1	SA	A	SwA	SwDA	DA	SDA
D2	SA	A	SwA	SwDA	DA	SDA
D3	SA	A	SwA	SwDA	DA	SDA
D4	SA	A	SwA	SwDA	DA	SDA
D5	SA	A	SwA	SwDA	DA	SDA
D6	SA	A	SwA	SwDA	DA	SDA
D7	SA	A	SwA	SwDA	DA	SDA
D8	SA	A	SwA	SwDA	DA	SDA
D9	SA	A	SwA	SwDA	DA	SDA
D10	SA	A	SwA	SwDA	DA	SDA
D11	SA	A	SwA	SwDA	DA	SDA
D12	SA	A	SwA	SwDA	DA	SDA
D13	SA	A	SwA	SwDA	DA	SDA
D14	SA	A	SwA	SwDA	DA	SDA
D15	SA	A	SwA	SwDA	DA	SDA
D16	SA	A	SwA	SwDA	DA	SDA
D17	SA	A	SwA	SwDA	DA	SDA
D18	SA	A	SwA	SwDA	DA	SDA
D19	SA	A	SwA	SwDA	DA	SDA
D20	SA	A	SwA	SwDA	DA	SDA
D21	SA	A	SwA	SwDA	DA	SDA
D22	SA	A	SwA	SwDA	DA	SDA
D23	SA	A	SwA	SwDA	DA	SDA

KP1	SA	A	SwA	SwDA	DA	SDA
KP2	SA	A	SwA	SwDA	DA	SDA
KP3	SA	A	SwA	SwDA	DA	SDA
KP4	SA	A	SwA	SwDA	DA	SDA

KS1	SA	A	SwA	SwDA	DA	SDA
KS2	SA	A	SwA	SwDA	DA	SDA
KS3	SA	A	SwA	SwDA	DA	SDA
KS4	SA	A	SwA	SwDA	DA	SDA
KS5	SA	A	SwA	SwDA	DA	SDA
KS6	SA	A	SwA	SwDA	DA	SDA
KS7	SA	A	SwA	SwDA	DA	SDA
KS8	SA	A	SwA	SwDA	DA	SDA
KS9	SA	A	SwA	SwDA	DA	SDA
KS10	SA	A	SwA	SwDA	DA	SDA
KS11	SA	A	SwA	SwDA	DA	SDA
KS12	SA	A	SwA	SwDA	DA	SDA

KC1	SA	A	SwA	SwDA	DA	SDA
KC2	SA	A	SwA	SwDA	DA	SDA
KC3	SA	A	SwA	SwDA	DA	SDA
KC4	SA	A	SwA	SwDA	DA	SDA
KC5	SA	A	SwA	SwDA	DA	SDA
KC6	SA	A	SwA	SwDA	DA	SDA
KC7	SA	A	SwA	SwDA	DA	SDA
KC8	SA	A	SwA	SwDA	DA	SDA
KC9	SA	A	SwA	SwDA	DA	SDA
KC10	SA	A	SwA	SwDA	DA	SDA

S1	SA	A	SwA	SwDA	DA	SDA
S2	SA	A	SwA	SwDA	DA	SDA
S3	SA	A	SwA	SwDA	DA	SDA
S4	SA	A	SwA	SwDA	DA	SDA
S5	SA	A	SwA	SwDA	DA	SDA
S6	SA	A	SwA	SwDA	DA	SDA
S7	SA	A	SwA	SwDA	DA	SDA
S8	SA	A	SwA	SwDA	DA	SDA
S9	SA	A	SwA	SwDA	DA	SDA
S10	SA	A	SwA	SwDA	DA	SDA
S11	SA	A	SwA	SwDA	DA	SDA
S12	SA	A	SwA	SwDA	DA	SDA
S13	SA	A	SwA	SwDA	DA	SDA
S14	SA	A	SwA	SwDA	DA	SDA
S15	SA	A	SwA	SwDA	DA	SDA
S16	SA	A	SwA	SwDA	DA	SDA
S17	SA	A	SwA	SwDA	DA	SDA
S18	SA	A	SwA	SwDA	DA	SDA
S19	SA	A	SwA	SwDA	DA	SDA
S20	SA	A	SwA	SwDA	DA	SDA
S21	SA	A	SwA	SwDA	DA	SDA
S22	SA	A	SwA	SwDA	DA	SDA
S23	SA	A	SwA	SwDA	DA	SDA
S24	SA	A	SwA	SwDA	DA	SDA
S25	SA	A	SwA	SwDA	DA	SDA
S26	SA	A	SwA	SwDA	DA	SDA
S27	SA	A	SwA	SwDA	DA	SDA

Demographics Recording Form

q1	_____ must be 18-65							
q2	_____ Must be at least 25% (1/4)							
q3	a	b	c	d				
q4	_____							
q5	_____							
q6a	_____							
q6b	_____							
q7	a	b	c	d	e	f	g	h
q8	a	b	c	d	e			
q9	a	b	c	d	e			
q10a	No	Yes						
a10b	No	Yes						
a10c	No	Yes						
q10d	No	Yes						
q10e	No	Yes						
q10f	No	Yes						
q11	a	b	c	d	e	f		
q12	a	b	c	d				
q13	a	b	c	d				
q14	_____ inches							
q15	_____ lbs							
q16	No	Yes						
q17a	No	Yes						
q17b	No	Yes						
q17c	No	Yes						
q17d	No	Yes						
q17e	No	Yes						
q18	_____							
	_____							
	_____							

Appendix W

Revised Assessment Tool Response Recording Form

HEALTH QUESTIONS

H1	SA	A	SwA	SwDA	DA	SDA
H2	SA	A	SwA	SwDA	DA	SDA
H3	SA	A	SwA	SwDA	DA	SDA
H4	SA	A	SwA	SwDA	DA	SDA
H5	SA	A	SwA	SwDA	DA	SDA
H6	SA	A	SwA	SwDA	DA	SDA
H7	SA	A	SwA	SwDA	DA	SDA
H8	SA	A	SwA	SwDA	DA	SDA
H9	SA	A	SwA	SwDA	DA	SDA
H10	SA	A	SwA	SwDA	DA	SDA
H11	SA	A	SwA	SwDA	DA	SDA
H12	SA	A	SwA	SwDA	DA	SDA
H13	SA	A	SwA	SwDA	DA	SDA
H14	SA	A	SwA	SwDA	DA	SDA
H15	SA	A	SwA	SwDA	DA	SDA
H16	SA	A	SwA	SwDA	DA	SDA
H17	SA	A	SwA	SwDA	DA	SDA
H18	SA	A	SwA	SwDA	DA	SDA
H19	SA	A	SwA	SwDA	DA	SDA
H20	SA	A	SwA	SwDA	DA	SDA
H21	SA	A	SwA	SwDA	DA	SDA
H22	SA	A	SwA	SwDA	DA	SDA
H23	SA	A	SwA	SwDA	DA	SDA
H24	SA	A	SwA	SwDA	DA	SDA
H25	SA	A	SwA	SwDA	DA	SDA
H26	SA	A	SwA	SwDA	DA	SDA
H27	SA	A	SwA	SwDA	DA	SDA
H28	SA	A	SwA	SwDA	DA	SDA
H29	SA	A	SwA	SwDA	DA	SDA
H30	SA	A	SwA	SwDA	DA	SDA
H31	SA	A	SwA	SwDA	DA	SDA

DIABETES QUESTIONS

D1	SA	A	SwA	SwDA	DA	SDA
D2	SA	A	SwA	SwDA	DA	SDA
D3	SA	A	SwA	SwDA	DA	SDA
D4	SA	A	SwA	SwDA	DA	SDA
D5	SA	A	SwA	SwDA	DA	SDA
D6	SA	A	SwA	SwDA	DA	SDA
D7	SA	A	SwA	SwDA	DA	SDA
D8	SA	A	SwA	SwDA	DA	SDA
D9	SA	A	SwA	SwDA	DA	SDA
D10	SA	A	SwA	SwDA	DA	SDA
D11	SA	A	SwA	SwDA	DA	SDA
D12	SA	A	SwA	SwDA	DA	SDA
D13	SA	A	SwA	SwDA	DA	SDA
D14	SA	A	SwA	SwDA	DA	SDA
D15	SA	A	SwA	SwDA	DA	SDA
D16	SA	A	SwA	SwDA	DA	SDA
D17	SA	A	SwA	SwDA	DA	SDA
D18	SA	A	SwA	SwDA	DA	SDA
D19	SA	A	SwA	SwDA	DA	SDA
D20	SA	A	SwA	SwDA	DA	SDA
D21	SA	A	SwA	SwDA	DA	SDA
D22	SA	A	SwA	SwDA	DA	SDA
D23	SA	A	SwA	SwDA	DA	SDA

PREVENTION QUESTIONS

KP1	SA	A	SwA	SwDA	DA	SDA
KP2	SA	A	SwA	SwDA	DA	SDA
KP3	SA	A	SwA	SwDA	DA	SDA
KP4	SA	A	SwA	SwDA	DA	SDA

SIGNS OF DIABETES QUESTIONS

KS1	SA	A	SwA	SwDA	DA	SDA
KS2	SA	A	SwA	SwDA	DA	SDA
KS3	SA	A	SwA	SwDA	DA	SDA
KS4	SA	A	SwA	SwDA	DA	SDA
KS5	SA	A	SwA	SwDA	DA	SDA
KS6	SA	A	SwA	SwDA	DA	SDA
KS7	SA	A	SwA	SwDA	DA	SDA
KS8	SA	A	SwA	SwDA	DA	SDA
KS9	SA	A	SwA	SwDA	DA	SDA
KS10	SA	A	SwA	SwDA	DA	SDA
KS11	SA	A	SwA	SwDA	DA	SDA
KS12	SA	A	SwA	SwDA	DA	SDA

CAUSES OF DIABETES QUESTIONS

KC1	SA	A	SwA	SwDA	DA	SDA
KC2	SA	A	SwA	SwDA	DA	SDA
KC3	SA	A	SwA	SwDA	DA	SDA
KC4	SA	A	SwA	SwDA	DA	SDA
KC5	SA	A	SwA	SwDA	DA	SDA
KC6	SA	A	SwA	SwDA	DA	SDA
KC7	SA	A	SwA	SwDA	DA	SDA
KC8	SA	A	SwA	SwDA	DA	SDA
KC9	SA	A	SwA	SwDA	DA	SDA
KC10	SA	A	SwA	SwDA	DA	SDA

SOCIAL QUESTIONS

S1	SA	A	SwA	SwDA	DA	SDA
S2	SA	A	SwA	SwDA	DA	SDA
S3	SA	A	SwA	SwDA	DA	SDA
S4	SA	A	SwA	SwDA	DA	SDA
S5	SA	A	SwA	SwDA	DA	SDA
S6	SA	A	SwA	SwDA	DA	SDA
S7	SA	A	SwA	SwDA	DA	SDA
S8	SA	A	SwA	SwDA	DA	SDA
S9	SA	A	SwA	SwDA	DA	SDA
S10	SA	A	SwA	SwDA	DA	SDA
S11	SA	A	SwA	SwDA	DA	SDA
S12	SA	A	SwA	SwDA	DA	SDA
S13	SA	A	SwA	SwDA	DA	SDA
S14	SA	A	SwA	SwDA	DA	SDA
S15	SA	A	SwA	SwDA	DA	SDA
S16	SA	A	SwA	SwDA	DA	SDA
S17	SA	A	SwA	SwDA	DA	SDA
S18	SA	A	SwA	SwDA	DA	SDA
S19	SA	A	SwA	SwDA	DA	SDA
S20	SA	A	SwA	SwDA	DA	SDA
S21	SA	A	SwA	SwDA	DA	SDA
S22	SA	A	SwA	SwDA	DA	SDA
S23	SA	A	SwA	SwDA	DA	SDA
S24	SA	A	SwA	SwDA	DA	SDA
S25	SA	A	SwA	SwDA	DA	SDA
S26	SA	A	SwA	SwDA	DA	SDA
S27	SA	A	SwA	SwDA	DA	SDA

VITA

Christopher Alan Taylor

Candidate for the Degree of

Doctor of Philosophy

Dissertation: AN APPROACH TO DIABETES PREVENTION AMONG NATIVE AMERICANS IN OKLAHOMA

Major Field: Human Environmental Sciences

Biographical:

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Professional Memberships:
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Oklahoma Dietetic Association