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New Beginnings: A Discussion Guide Adaptation for Living with Diabetes among an Urban American Indian Community

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NEW BEGINNINGS: A DISCUSSION GUIDE ADAPTATION FOR LIVING WITH
DIABETES AMONG AN URBAN AMERICAN INDIAN COMMUNITY

By

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Bachelor of Arts in Evolutionary Anthropology
University of New Mexico
2012

A thesis submitted in partial fulfillment
of the requirements for the

Master of Public Health

Department of Environmental and Occupational Health
School of Community Health Sciences
Division of Health Sciences
The Graduate College

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August 2014

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THE GRADUATE COLLEGE

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Eudora Lynette Claw

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August 2014

ABSTRACT

New Beginnings: A Discussion Guide Adaptation for Living Well With Diabetes among an Urban American Indian Community

By

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Diabetes is a chronic disease where the body has the inability to control the sugar levels in the blood to convert into to usable energy needed to fuel the body's cells. Some common diabetic complications include heart disease, stroke, amputations, and possibly blindness. It can be successfully managed with routine care of monitoring of sugar levels, eating a healthy diet, and daily exercise. The occurrence of type 2 diabetes is rising rapidly worldwide, but is a burden for AI/ANs (American Indian/Alaska Natives) at a substantially disproportionate rate. The purpose of this pilot study was to participate in a one-day curriculum assessment, focusing on the management of AI/ANs who are currently living with diabetes. The goal of the curriculum assessment was to help facilitate discussions among AI/ANs about living with diabetes, identifying support from family and other social outlets, and developing coping skills for the management of diabetes. The information resulting from the assessment will benefit AI/ANs living with type 2 diabetes, as well as assist diabetes educators/health professionals in providing quality resources and support services which incorporate emotional and self-management skills, and ways to communicate effectively with family members about the disease.

Keywords: Urban American Indians, type 2 diabetes, diabetes curriculum, qualitative research, social cognitive theory

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CHAPTER 1

INTRODUCTION

Globally, diabetes mellitus is one of the most prevalent diseases that affect many individuals around the world in epidemic proportions. Today, there are 382 million people aged between 40 and 59 living with diabetes and the numbers are projected to rise (International Diabetes Federation, 2013). In the United States (U.S.), approximately 25.8 million people (8.3 percent of the population) are affected by diabetes and, of those, 18.8 million have been diagnosed (“National diabetes fact,” 2011). The risk factors for diabetes include obesity, physical inactivity, and a diet that is rich in saturated and trans fats (“Eat right,” 2014). Diabetes affect many parts of the body and can lead to serious health complications, such as heart disease and stroke, hypertension, blindness, nervous system disease, dental disease, and amputations (“Diabetes overview,” 2014). The economic costs, both directly and indirectly for treating the disease amounted to \$116 billion (“Diabetes research and,” 2012). It is evident that this disease needs to be addressed.

There are three main types of diabetes: type 1 diabetes, type 2 diabetes, and gestational diabetes. For the context of this paper, the type 2 diabetes in the United States will be discussed because it is by far the most common form of diabetes and has been detrimental for American Indian/ Alaska Native (AI/AN) populations. About 90 to 95 percent of people with diabetes have type 2 diabetes, most commonly found among older age individuals, those with a family history of diabetes, and members of certain ethnic and racial groups, such as American Indians, African American, Hispanic/Latino, and Asian/Pacific Islanders (“Diabetes overview,” 2014). Ethnic and racial minority

populations are twice as likely to be diagnosed with diabetes than non-Hispanic whites (“2011 national diabetes,” 2011).

Diabetes and other leading health complications are among the most serious chronic health problems facing AI/ANs. Centers for Disease Control (2012) reports 15.3 percent of AI/AN adults suffer from diabetes, which is twice the rate of the national average, which is 7.3 percent. 16.1 percent of AI/ANs who are 20 years or older, who seek medical services through the Indian Health Service (IHS), have been diagnosed with diabetes (“2011 national diabetes,” 2013). AI/ANs are 2.3 times more likely to have diabetes diagnoses compared with non- Hispanic whites (16.1 percent vs. 7.1 percent) (“2011 national diabetes,” 2013). Additionally, diabetes is a condition that can also be prevented, managed, and controlled at any state of the disease, thus giving hope that others can live a healthy life.

The health and well-being of an individual can be influenced by biological, environmental, economic, and social factors. AI/AN populations have been impacted with a high prevalence of chronic diseases, such as diabetes. It is important that individuals diagnosed with diabetes must to learn how to manage the disease. People living with diabetes must also be mindful about their everyday choices, since they carry with them an additional identity from those without diabetes.

Purpose of Study

The purpose of this study is to evaluate the adaptation of a single module of the Centers for Disease Control and Preventions, “New Beginnings: A Discussion Guide for Living Well with Diabetes” toolkit. The setting site was within the urban American Indian/Alaska Native population of Las Vegas, Nevada. The curriculum focused on

module 1 disease management sessions for urban AI/ANs who are currently living with diabetes. Approval for this study was obtained from the University of Nevada Las Vegas Human Research Review Committee.

Significance to Public Health

Urban AI/ANs represent over 566 federally recognized nations and those tribes who are waiting recognition. The Indian Health Service (IHS) serves a section of the overall AI/AN population to provide comprehensive health care services for individuals who come from a federally recognized tribe (Trombino, 2005). The IHS was established in 1955 as an agency within the Department of Health and Human Services (HHS) and with its foundation of upholding the federal government's obligation to promote, honor, and protect tribes. IHS consists of 12 area offices, and deeper within the area offices, 168 service units provide care to AI/ANs at the local level (Roubideaux, 2013). Urban AI/ANs might find it difficult to seek IHS health care services on or near reservations since majority identify themselves as living in urban areas (62%) than on reservations and other rural areas (Bertolli et al., 2008). Because of the movement towards cities, programs such as the Urban Indian Health Program were put in place to improve health care access for AI/AN people living in urban areas. Recent studies have documented urban AI/AN population have poor health and have limited options for health care specifically for AI/AN group (Urban Indian Health Commission, 2007)

AI/ANs they are entitled federal health dollars, which are then supposed to be used for services provided only by their respective reservations. Hence, this makes funding difficult for AI/ANs living in metropolitan settings who seek primary and preventive health-care off the reservation. There is a need to build upon and implement a

diabetes curriculum especially for those living with diabetes that are residing near urban settings. As public health professionals, we must make strides towards implementing best practices to better serve hard-to-reach populations such as urban AI/ANs.

Definition of Terms

American Indian or Alaska Native: Someone who has blood degree from and is recognized as such by a federally recognized tribe or village (as an enrolled tribal member) and/or the United States (“Frequently asked questions,” 2014).

Diabetes: Is a chronic disease that occurs when the pancreas does not produce enough insulin, or when the body cannot effectively use the insulin it produces. (“Diabetes,” 2014)

Type 2 diabetes: The most common form of diabetes, in which the body does not produce enough insulin, or the cells ignore the insulin, Type 2 diabetes is commonly known as “adult-onset diabetes” or “non-insulin dependent diabetes.” (“Indian health diabetes,” 2009).

Federally recognized tribe: It is a American Indian or Alaska Native tribal entity that is recognized as having a government-to-government relationship with the United States, with the responsibilities, powers, limitations, and obligations attached to that designation, and is eligible for funding and services from the Bureau of Indian Affairs. (“Frequently asked questions,” 2014).

Body Mass Index: is a number calculated from a person's weight and height. BMI provides a reliable indicator of body fatness for most people and is used to screen for weight categories that may lead to health problems (“Body mass index,” 2013).

CHAPTER 2

LITERATURE REVIEW & THEORETICAL FRAMEWORK

Literature Review

Type 2 diabetes

Type 2 diabetes, often referred to as non-insulin dependent diabetes mellitus and has become a global health epidemic and is impacting indigenous populations around the world. Type 2 diabetes is a chronic condition characterized by how the body improperly breaks down glucose (sugar) for the body to use as energy. Consequently, individuals with type 2 diabetes will have high glucose levels (fasting plasma glucose ≥ 126 mg/dl (or 7.0 mmol/l) or plasma glucose ≥ 200 mg/dl (or 11.1 mmol/l) 2 hours after a 75g glucose load (American Diabetes Association, 2014). Those who develop type 2 diabetes will show symptoms of frequent urination, excessive thirst, and feeling fatigued. Other symptoms could also include weight loss, blurred vision, more infections than usual, and wounds or sores that heal slowly (“Basics about diabetes,” 2014).

According to the American Diabetes Association, 25.8 million children and adults in the United States (8.3 percent of the population) have diabetes; 18.8 million people are diagnosed and 7.0 million are undiagnosed; furthermore, 79 million people are considered pre-diabetic ("Diabetes statistics," 2012). Although, diabetes is the sixth leading cause of death in the United States (Harris & Pokorny, 2012), it ranks fourth among AI/AN (O’Connell, Yi, Wilson, Manson & Acton, 2010). Type 2 diabetes, specifically, is one of the most prevalent chronic diseases in the United States (Winer & Sowers, 2004). Importantly, type 2 diabetes is increasing in large numbers in AI/AN communities.

Type 2 diabetes is the most common type of disease affecting an estimated 12 percent of the 40 to 70 year old individuals in the United States (Bray, Culbert, Champagne & Dawson, 1999). American Indians are among those that are at high risk and, depending on the tribe, prevalence of type 2 diabetes is 2 to 4 times higher than among non-Hispanic whites (Thompson, Allen, Helitzer, Qualls, Whyte, Wolfe & Herman, 2008). Risk factors for this disease include obesity, physical inactivity, and family history of type 2 diabetes, and being a member of a high-risk racial or ethnic group for diabetes. Within the last 1-2 generations among American Indians, obesity is on the rise from consuming high fat foods that are readily available and accessible. As a result of this, AI/ANs have seen a drastic change in lifestyle from their traditional diet possibly due to the residency of AIs living on or near urban areas (Story, Evans, Fabsitz, Clay, Holy Rock & Broussard, 1999).

Diabetes was first diagnosed among AI/ANs in the 1930s and has since become a major cause of morbidity and mortality (Story et al., 1999). One of the major primary healthcare facilities available for AI/ANs is the Indian Health Service (IHS) provided under the US Public Health Service, which spends approximately 1 of every 3 IHS dollars on treatment for services for adults with diabetes (Sanderson, Little, Vasquese, Lomadafkie, Brings Him Back, Trujillo, Jarratt-Snider, Teufel-Shone, Brown & Bounds, 2012). Findings by Acton, Burrows, Moore, Querec, Geiss, and Engelgau (2002), from 1990 to 1998, found that AI/AN children, adolescents, and young adults combined who utilized the IHS or tribal health facilities, showed a 71 percent increase of their services.

Risk factors associated with type 2 diabetes also include environmental, economic, genetic, and lifestyle choices (Mundra, 2013). Environmental factors include where a

person resides. Some of the American Indian tribes are located in rural areas where they have limited resources and funding to support tribal facilities. An example is how a person's environment can have affect on their health. In the Navajo community, their built environment, which includes all of the physical parts of where they live and work, can have an influence on how they manage their diabetes. According to "Welcome to Navajo", 2012, there are estimated to be more than 16,000 Navajo families on the Navajo Reservation who still do not have access to electricity and running water. Without electricity individuals are not able to store their insulin and keep healthy foods available. Economic factors include those who already have a low social economic position (SEP) are at risk for poor health outcomes (Story et al., 1999). Further, people with low SEP are also more likely to consume food high in fats rather than those with lower fats such as fruit and vegetables (Story et al., 1999).

The findings by Shaw, Brown, Khan, Man and Dillard (2013) give a clear insight into the psychological experience of AI/AN adults with type 2 diabetes. Their participants reported that knowledge and education about diabetes was one of the central resources that helped with managing their illness. Participation in groups helped the individuals cope with the diabetes and encouraged following a nutritional plan. Participants described their "turning point" with the disease as being confronted by others to recognize and accept their disease. In another study Olshansky and his colleagues (2008) found their participants had a connection with others who had diabetes because they have lived the experience and are able to understand each other's feelings. A study by Harris and Pokorny (2012), called, "Living with Diabetes: What Patients Are Saying," noted how spirituality was influenced in helping the participants cope with their disease;

in addition to controlling their diabetes by eating healthy.

Urban-dwelling AI/ANs have often been overlooked in diabetes efforts, even though a majority of AI/ANs currently live in urban areas (Mendenhall, Berge, Harper, GreenCrow, Little Walker, WhiteEagle & BrownOwl, 2010). In 2007, the Urban Indian Health Commission, reported nearly 7 out of very 10 AI/ANs (2.8 million) live in or near cities, and the number continuously grows. Urban AI/ANs makeup 67 percent of the nations 4.1 million self-identified American Indian and Alaska Natives (Urban Indian Health Commission, 2007). Obtaining health statistics on urban AI/ANs is very difficult, possibly due to misclassification and little research on this special population. For urban AI/ANs, a diabetes curriculum that is able to address their needs and concerns in the context of their everyday environments is greatly needed to increase the quality of life and health status for those living with diabetes.

Curricula

To understand a need for a diabetes relevant curriculum for urban AI/ANs, it is necessary to have an understanding of The Diabetes Prevention Program (DPP), that conducted a major clinical study that has now become the gold standard for diabetes prevention. DPP was the first major clinical trial that showed that people with impaired glucose tolerance, an intermediate category between normoglycemia and diabetes, can lower their risks by diet and exercise, and treatment of oral drug metformin (NIDDK, 2013). There were three interventions groups to which a participant could possibly be randomly assigned: 1) an intensive lifestyle intervention group that received counseling and motivational support on diet, exercise and behavior modification, 2) standard lifestyle recommendations combined with metformin, or 3) standard lifestyle

recommendations combined with the placebo (Bray et al., 1999). They found participants in the intensive lifestyle intervention reduced their incidence of developing type 2 diabetes by 58 percent. On average, this group maintained their physical activity at 30 minutes per day, through moderate intensity exercise e.g. walking or bicycling. Participants taking metformin reduced their incidence of developing type 2 diabetes by 31 percent as compared with the placebo (Knowler, Barrett-Connor, Fowler, Hamman, Lachin, Walker, Elizabeth, & David, 2002). They found participants who were assigned to the intensive lifestyle intervention had much greater weight loss and greater increase in physical activity than the participants who received metformin or the placebo. Metformin was most effective among older populations, and those with a high body mass index (BMI). This study has added to the evidence that supports type 2 diabetes can be prevented and delayed in individuals who are at high risk of getting the disease.

In Indian Country, type 2 diabetes has been on the rise and shows no distinct signs of slowing down. AI/ANs have the highest rates of type 2 diabetes in the United States of any specific population (IHS, 2014). According to the Agency for Healthcare Research and Quality (2013), diabetes was seen less commonly among Alaska Natives (8.1 percent) and most commonly among American Indians, specifically in the southern U.S. and in southern Arizona (26.7 percent and 27.6 percent respectively). Although AI/ANs have been hit with this disease, there have been some successes in adapting diabetes curriculum for specific populations. Two examples of successful diabetes curriculum that have been adapted to a specific group is the Diabetes Empowerment Education program (DEEP), that targeted Hispanics/Latinos with type 2 diabetes, and the Power to Prevent (P2P) Diabetes curriculum, that targeted rural African Americans.

DEEP self-management diabetes education program was originally developed by the Midwest Latino Health Research Training and Policy Center at the University of Illinois in Chicago at Chicago's Jane Adams School of Social Work (Castillo et al., 2010). The purpose of the DEEP pilot study conducted by Castillo et al. (2010) was to deliver and evaluate the impact of the diabetes program among Southeast Chicago communities led by community health workers (CHWs) to help educate the community about improving diabetes self-management behavior and provide information of improving glycemic control among persons living with type 2 diabetes. The DEEP has 2 components: The Training of Trainers Program, and the Diabetes Patient Education Program. The Training of Trainers Program is a 20-hour workshop that prepares CHWs to use the educational curriculum in their communities. The Diabetes Patient Education Program, is a sequence of educational sessions that discuss topics such as self-care needs for persons living with or at risk of diabetes, nutrition, physical activity, and ways to access community diabetes resources (Castillo et al., 2010). The DEEP study supports that it is possible to implement a diabetes self-management program led by CHWs in a community setting. The diabetes curriculum met the diabetes self-management education (DSME) guidelines and the national medical care recommendations.

The development of the diabetes curriculum, P2P, was a joint collaboration between the Centers for Disease Control and Prevention (CDC), National Institutes of Health (NIH), and the National Diabetes Education Program (NDEP) who wanted to target African Americans using the findings found from the DPP study (Cené et al., 2013). Cené and colleagues conducted a feasibility study using a community-based participatory research (CBPR) approach to implement the P2P diabetes prevention

education curriculum among rural African Americans in both faith and non-faith based settings. P2P consists of 12 60-90 minute sessions that address lifestyle modifications to prevent or delay the onset of diabetes, and for those already living with the disease to learn skills to better control their blood glucose levels. The results from this study suggest P2P has the capacity to be implemented in African American community settings, and the CBPR approach was feasible for this study.

There are several type 2 diabetes programs that have been effective and specific for AI/AN populations. An example is the implementation of the K-12 Diabetes-Based Science Education for Tribal Schools (DETS) curriculum that has been developed to increase the understanding of diabetes and health by interweaving local native diabetes science, indigenous wellness, and western and traditional knowledge of understanding as efforts to decrease the incidence of type 2 diabetes among AI/ANs (Dodge-Francis, Coulson, Kalberer, et. al. 2010, Dodge-Francis & Chino, 2012). Furthermore, the curriculum wanted to inspire AI/AN youth to pursue science and health careers. The DETS curriculum can be utilized by teachers and health educators who work directly with the youth in grades K-12. The curriculum met the National Science Education Standards and can be accessed at no cost through Indian Health Services website therefore making it a valuable prevention tool for tribes.

Started in 1997, The National Diabetes Education Program (NDEP) is sponsored by the NIH and CDC (“About NDEP,” 2014). NDEP partners with “over 200 partners at the federal, state and local levels, working together to improve the treatment and outcomes for people with diabetes, promote early diagnosis, and prevent or delay the onset of type 2 diabetes” (Funnel, 2011). From the results from the DPP clinical trial,

NDEP and with its partners released “messages and materials” to help explain the science of diabetes prevention for health care professionals, community organizations, schools, and worksites. Most importantly these materials help to bring awareness to individuals who are high risk for the disease. It is important to also note, the people who are experts in their respective fields are developing the materials. They have piloted, evaluated, and specifically designed culturally appropriate educational materials for a given target population (Funnell, 2011). NDEP offers from its variety of publications and resources from toolkits, videos, fact sheets, to diabetes articles (can be searched by age, diabetes status, ethnicity/race, and language). First and foremost, NDEP educational materials can be accessed online and documents can be downloaded and ordered if need be.

Through the works of NDEP many materials have been adapted and created for specific groups including children, older adults, Asian Americans, Hispanic/Latino Americans, AI/ANs, Pacific Islanders, and African Americans. For this study, “New Beginnings: A Discussion Guide for Living Well with Diabetes” toolkit was applied. This toolkit was initially developed to help bring diabetes prevention and control to African American communities.

Theoretical Framework

To study type 2 diabetes in AI/AN populations, Social Cognitive Theory provides an appropriate theoretical framework. Albert Bandura’s Social Cognitive Theory (SCT) represents human functioning from a triadic reciprocal causation model where the interaction between behavior, personal and environmental factors are interacting (Bandura, 1977). The major behavioral constructs of SCT include behavioral capability, self-efficacy, outcome expectations, perceived behavior of others from observation, and

environment (Bartholomew, Parcel, Kok & Gottlieb, 2011). Behavioral capability refers to the knowledge and skill needed to perform a given behavior (Bartholomew, Parcel, Kok & Gottlieb, 2011). Self-efficacy is a judgment of a person's capability to accomplish a certain level of performance (Bartholomew, Parcel, Kok & Gottlieb, 2011). Another construct of the SCT is outcome expectations and individual's judgment of the likely consequence that a certain behavior will produce (Bandura, 2004). Humans are by nature social beings and learn through observation. By observing others, individuals are able to form rules for behavior, and thus refer to another construct called perceived behavior (Bartholomew et al., 2011).

The final construct for SCT is environment, where all factors affect a person's behavior, but only those that are external to that person, e.g. physical and social environments (Bartholomew et al., 2011). Physical environments could include such things as the availability of certain foods and the air quality. Social environments can include family members, friends, or neighbors. It is important to note, people may or may not be aware of how strong an influence the environment can have in determining their behavior (Bartholomew et al., 2011).

SCT has the capacity to be implemented into "New Beginnings" diabetes curriculum. It is a framework that has shown to have a high degree of acceptability in many American Indian contexts as it allows for integration of AI/AN cultural elements in prevention implementation (Weaver, 2010). Self-efficacy, one of the key constructs of SCT, is a major element in implementing the diabetes curriculum among AI/ANs.

Expected outcomes from utilizing a curriculum grounded in SCT are developing or strengthening participants' self-efficacy through positive experiences, which will

provide opportunities for social support, promote diabetes skills training, and provide opportunities to participants to learn from one another about living and managing their diabetes. For example social modeling by others in a discussion group is a way to reinforce behaviors. SCT has the ability to give individuals control of their own behavior (Bandura, 2005).

Culturally Relevant Curricula

Among ethnic and minority groups there exists disparities in the prevalence and burden of type 2 diabetes. Finding ways to reduce these disparities is of great importance in the United States. By providing culturally relevant content about preventing and delaying type 2 diabetes is strategy to reduce the prevalence of type 2 diabetes among AI/ANs. From a 1990-2001 review of community-based programs, to help bridge the gap between western and traditional health beliefs, it is essential to involve members from the targeted population to help create culturally relevant materials (Finucane & McMullen, 2008). One approach found in the literature was including cultural concepts of AI customs and practices into their obesity intervention program because they believed health behaviors was had a strong relationship with the culture. Ultimately, by drawing from traditional beliefs and values one is most certain to see the success of a diabetes program that involves promoting healthier lifestyles and reflects the native culture.

Qualitative Design

Qualitative research was best appropriate for this study. Qualitative research in health is essential because it enables a person to tell their story and as public health professionals, we are able to explore those stories for inferences and metaphors, and recognize meanings as it brings forth a new level of knowledge and insight (Morse,

2012). Qualitative research can offer health professionals important missing pieces of information about the knowledge of health and illness (Morse, 2012). Research by Saks and Allsop (2013) imply qualitative data can contribute reliable information because research is being documented from the viewpoint of the people studied rather than the perspective of the researcher. To understand metaphors, meaning, and phenomena, it requires flexibility and fluid methods employed by qualitative research (Saks & Allsop, 2013).

Qualitative research stemmed from the works of anthropologists and sociologists during the early decades of the 15th century as an attempt to understand other cultures and groups (Hays & Singh, 2012). As time surpassed, qualitative research began to develop more focused approaches but still was struggled for legitimacy (Morse, 2012). Today, qualitative research is not being ignored and taken into account as it continues to break down boundaries and introduce new traditions. Above all, qualitative research has been seeing greater attention among indigenous studies and non-Western approaches (Hays & Singh, 2012). As the United States is becoming more culturally diverse, researchers and health professionals can benefit from using qualitative research to help them better explain and understand the underlying complexities of the human experience (Hays & Singh, 2012).

In qualitative research, focus groups is a technique used for “describing and understanding perceptions, interpretations and beliefs of a select population to gain understanding of a particular issue from the perspective of the group’s participants” (Hays & Singh, 2012). Focus groups stimulate discussion, and provide a collective prospective on a topic in greater depth (Bowling, 1997). Additionally, focus groups have

the potential to advance our understanding of the root causes of health disparities facing urban AI/ANs (Ruff, Alexander & McKie, 2005). Focus groups are useful when studying underrepresented and marginalized populations and can provide an opportunity to focus in on the racial/cultural issues specific for the group under study (Liamputtong, 2013).

Focus group discussion brings power back into the hands of the participants to communicate their views about health and illness and brings issues to the table that might have been overlooked or unforeseen by the researcher (Saks & Allsop, 2013). Some examples of focus group studies conducted in health research was studying of knowledge, attitudes and practices of contraception, gain limited knowledge about AIDs among the gay community, and also improving the effectiveness of intervention programs in public health (Rice & Ezzy, 1999).

CHAPTER 3
METHODOLOGY

Research Design

A qualitative design, specifically a descriptive, phenomenological approach, was used for this study to gather information of the experiences of AI/ANs who are living with type 2 diabetes or have family members with this chronic disease. Bradley, Curry and Devers (2007) describe how qualitative research sets itself up for understanding phenomena, uncovering the links among concepts and behaviors, which create and refine theory. Qualitative research can help generate information where quantitative research might not answer, e.g. decision making, cultural and health beliefs, and health disparities. Phenomenology, is described as a shared meaning found among several individuals who have lived the experiences of a concept or a phenomenon (Creswell, 2013). The focus describes what the participants have in common with a certain phenomenon, e.g. living with diabetes. Descriptive phenomenology's main focus is to gain dense amount of information that represents the individuals experience and to come to an unbiased understanding of a phenomenon (Liamputtong, 2013). An assumption of this approach is that the unit of analysis is a group of individuals who have shared or lived a common experience, and as Liamputtong put it, "the descriptive phenomenologist develops detailed concrete descriptions of experience." Phenomenology in qualitative research is seen as a preferred method in studies done among American Indian populations because it was attuned to the native ways of knowing and looks deeper into the relationships between all beings (Struthers, Hodge, Geishirt-Cantrell & Cora, 2003; Crazybull, 1997).

This study used focus groups as a qualitative technique of gathering data about participants' thoughts and experiences with diabetes. Focus groups stimulate similar and different perspectives between individuals (Rabiee, 2004). Another benefit of focus groups is they provide an abundant amount of information in a short period of time (Rabiee, 2004).

Research Question

The research question for this study is, "How do urban American Indians cope and manage their daily life with type 2 diabetes?" The discussion group took an hour and half with a maximum of 8 participants from the Las Vegas and surrounding areas. The focus group took about an hour to interview all participants. During the focus group session participants were asked the following questions:

1. Can you explain to me why diabetes is an issue for American Indians?
2. How do you think this disease impacts tribal families?
3. What were some of your thoughts when you were told you had diabetes?
4. How do you manage your diabetes?
 - a. Was it difficult in the beginning?
5. Are there food choices that help you maintain your lifestyle?
6. How do your family members view your diabetes?
7. When you visit the doctor, are you able to ask questions about your diabetes?
8. Have there been issues that arose in your diabetes care? If so, could you explain?
If not, why?
9. How confident are you in managing your diabetes?
10. What kind of recipes do you like to prepare at home?

11. Can you describe to me about the different types of physical activities you like to do at home?
12. Can you talk about how diabetes affects your life? How do you feel about it now?

Adaptation of the New Beginnings Curriculum

This study assessed an adaptation of the National Diabetes Education Program toolkit, “New Beginnings: A Discussion Guide for Living Well with Diabetes.” The toolkit discussion guide contains 13 modules. Of those, only Module 1 (an overview of living with diabetes) was reviewed and assessed with the urban AI/AN participants. Due to the short implementation window the diabetes curriculum module 1 was utilized for the focus group. The New Beginnings modules were initially developed to help acknowledge and better understand the importance of diabetes self-management in African American population. Topics that were covered included diabetes ABCs, managing diabetes, and supporting a loved one with diabetes. The original discussion guide page was divided into two columns: instructions for leading the sessions were in the left column, while discussion questions and key talking points were in the right column.

There were 5 modifications made to the toolkit for this research study. “The Debilitator” a faith-based film was not shown as part of the adapted version of the toolkit because the population to be addressed was AI/ANs and not African Americans. Plus the film was not culturally relevant to the population within this study. Also, “The Debilitator,” was not going to be available from CDC in the future. A video vignette could be developed that would address the struggles of urban AI/ANs in managing their diabetes; it is important to highlight the struggles of urban AI/ANs living in cities who

are also trying to discover a path that works for them. Therefore, “The Debilitator,” was removed and exchanged for a NDEP podcast audio in Module 1 of the toolkit called Managing Diabetes. A man from the Hualapai Tribe discusses how he took control of his diabetes. Since family members play a concrete role in the management of diabetes of their loved ones, family members were not excluded from the participation in this study. Finally, handouts were provided from the NDEP “Living a Balanced Life with Diabetes” toolkit as an AI/AN specific resource. The American Indian/Alaska Native Fat and Calorie Counter, produced by NDEP, that lists foods commonly eaten by AI/ANs, was also provided.

Recruitment

Recruitment of participants was completed through the circulation of informational flyers, and with the help of community health representatives at the Las Vegas Paiute Clinic. Participants were also recruited from the Native Women’s Circle. Staff and stakeholders worked closely with study facilitators to recruit potential participants. Flyers were provided to AI/AN participants met the eligibility requirements. The AI/AN participants called the contact phone number on the flyer to sign-up for the discussion group. Each participant would receive a \$20 grocery gift card incentive at the completion of the focus group. A purposeful criterion sampling was most appropriate for this phenomenological study. Criterion sampling refers to the researchers sampling participants who were selected because they met a predetermined criterion, and were important for the study (Hays & Singh, 2012). Typically, this sampling method has an established criterion before beginning the study, which is in this case, is the following.

Participants had to meet the inclusion and exclusion criteria to participate in this study. The inclusion criteria for the study targeted American Indian/Alaska Natives who are currently an enrolled member of a federally recognized tribe or descendants of, and currently have Type II diabetes or a family member that is diagnosed with the disease. The exclusion criteria were individuals who were not American Indian/Alaska Native and did not have Type II diabetes or family members with the disease. Children 17 and younger were excluded from this pilot study.

Study Participants

All participants were female and from the Native Women's Circle who resided in the Las Vegas community who were over the age of 18 and were diagnosed or at risk for type 2 diabetes. The participants included the young to elderly and identified as being AI/AN. All of the participants were women. Several were parents and two participants brought along their child to the study. It should be noted that the parents felt it was important for their children to receive the information too. Participants were able to bring family members to this half-day interactive diabetes curriculum study.

Native Women's Circle

The Native Women's Circle, offered through The Health and Family Services department at the Las Vegas Paiute Clinic, has been providing support to AI/AN women since 2010. Las Vegas appears to be a hub for AI/AN families who have left their reservation in surrounding states to find work and affordable housing. At the Native Women's Circle, AI/AN women can find strength and support to deal with life's struggles. The group organizes cultural and family activities that promote positive interactions and provides a reminder of the native spirit, missed by many AI/ANs in the

Las Vegas community. Women can invite their sisters, mothers and daughters to participate in the Native Women's Circle. Native women have similar backgrounds in areas of family history, relationships, substance abuse, reservation life and personal hardships. The Women's Circle acts as a helpful resource to free the spirit and promote individuality, as well as provides consistent reminder to have fun and nurture one's self worth.

Data Collection Process

A discussion guide in the toolkit was used to gather information from participants during the first part of the study. Data collection occurred primarily through in-depth interviews at the end of the study during the focus group session with participants. In-depth interviews gave an opportunity for the interviewer to get to know the participants; learn about their feelings and personal experiences, and identify factors that help or hinder their lives. Participant observations were taken during the entire study. Thematic analysis was conducted by the moderator by hand coding for emerging themes and identifying supporting quotes separately.

The discussion group was held in a classroom in the Bigelow Health Sciences building on the University of Nevada Las Vegas campus. The discussion took the form of a guided semi-structured group session in an informal setting. A professional native facilitator unknown to the group assisted in facilitating the curriculum and group discussions. Before the discussion began, participants signed a consent form, acknowledging that they understood and agreed to participate in the study. The discussion began with brief introductions, identification of individual's tribal affiliations, and some participants also mentioned their diabetes diagnosis. The focus group

discussion for Module 1 was audiotaped. Folders were given to the participants that included handouts that were to be discussed during the implementation of the toolkit. During the final activity, the facilitator revealed to the participants her diabetes story about living with type 2 diabetes. Participants' were able to share in depth feelings and thoughts about the disease from their perspectives. This part of the session took approximately 1 hour, which allowed enough time for a break before continuing on to the second part of the study: focus group interviews.

The focus group of an n=8 was assembled as a method to explore different views, opinions, and experiences in a group setting. The focus group took place around a circular table, where the facilitator and the participants could both interact and speak about their experiences with diabetes and to address the focus of the study: How do urban American Indians cope and manage their daily life with type 2 diabetes? Interview questions were semi-structured so the facilitator could ask further questions into the topic. All participants in the focus group were audiotaped.

The focus group session lasted about 2 hours. All participants were then given a \$20 gift card as a token of appreciation for their participation in the study. All participants were given a lunch voucher to use at the campus dining hall. Email addresses and phones numbers from the session leaders and facilitators were given to the participants if they had any additional questions or comments they forgot to mention during the study.

To gain more information from participants after the study, two participants were contacted about what they had been doing since the focus group discussions. One participant found emailing me her responses was easier than a phone interview to discuss

the changes she made since the study. Follow up interviews were either tape-recorded or sent via email, all interviews were transcribed, and analyzed for content analysis.

Data Analysis

Qualitative data analysis is taking apart, separating, and disassembling the research material into pieces. Qualitative researchers are searching for patterns from the resulting data to induce final conclusions (Hays & Singh, 2012). Data Analysis is a systematic process that entails sorting and classifying the data collected which starts long before the initial process of data collection (Green, Hughes, Small, Gibbs & Daly, 2007). From the time the researcher starts listening to the descriptions of the interviewees, analysis is occurring, and so these two processes (qualitative data collection and analysis) are inseparable (Speziale & Carpenter, 2007; Hays & Singh, 2012).

The first step in the data analysis process was the immersion into the data to better grasp the entirety of what is being said during the interviews. Because data analysis begins before data collection, it was necessary to limit my data analysis to a selected topic, conceptual framework, and research question which will then lead to the important concepts from the findings (Hays & Singh, 2012). Data immersion helps bring about clarity and lays the groundwork for connecting fragmented ideas (Green et al., 2007).

The second step was collecting data from the focus group interviews. Collecting data from a focus group is a natural method of data collection in clinical and educational settings (Hays & Singh, 2012). A focus group was used because its application and purpose of use supports the research question, as well as the target population.

Once the data was reviewed and collected to provide a clearer understanding of the key concepts and meanings discovered during the study, the third step involved

transcribing the interviews into documents to allow for transcription analysis. The transcriptions were carefully examined and were accurate of what was recorded during the interview to ensure accuracy in the data analysis. The recordings were also listened to several times, alongside the transcriptions to ensure nothing was missed (LoBiondo-Wood & Haber, 2002). Manual transcription was done for the researcher to get to know the data at an intimate level (Holzemer, 2010).

The final step was coding the information embedded in the interviews. Coding has an important role in data analysis. Coding is a way of categorizing the data for assigning meaning to the descriptive information gathered during the study (Basit, 2010). The final step was finding collected information that shared a relationship – these points were highlighted using markers. The researcher then grouped certain topics together that represented similar meanings into common themes (Bradley, Curry & Devers, 2007).

Protection of Human Subjects

All information gathered in this study was kept completely confidential by the researchers, however, this cannot be guaranteed within the participant group setting. No references were made in written or oral materials that could link specific participants to this study. All records are stored in a locked facility at UNLV for five years after completion of the study. After the five years mark the information gathered will be destroyed. Researchers and community members will have ownership of the data that will be acquired through this study. The researcher obtained permission from the Institutional Review Board at the University of Nevada, Las Vegas prior to initiation of the study. The study involved minimal risk for the participants. The main identified risk could be that a participant may have felt uncomfortable when answering focus group

questions in a small group setting. To minimize psychological risk, participants were informed if they were not comfortable with responding to a question, they could decline to respond. Participants were informed that they could withdraw from the study at any time, all information gathered from the study would be confidential, and their identities would remain private, and would not be shared with anyone. There were no direct benefits to participants in this study but participants were compensated for their time, as all participants received a \$20 gift card. The hope was that participants were satisfied in contributing valuable information and personal experiences to an important health issue among urban AI/ANs living with diabetes.

Validity & Reliability

The terms for assessing the quality of the research study is validity and reliability. Validity and reliability are ways of establishing and communicating the rigor of research methods, procedures, and the trustworthiness of research findings (Roberts et al., 2006). Validity describes the truthfulness in the study findings for a phenomenon that it is intended to describe or explain (Hays & Singh, 2012). Reliability makes sure the research procedures and data is trustworthy (Roberts et al., 2006). Reliability is more concerned with showing similar findings in different settings. For this study validity was established by taking field notes and observations throughout the study. To enhance internal validity, this study used triangulation of data sources to understand the phenomenon (Hays & Singh, 2012). To provide a more accurate picture of the lived experiences of the participants, data collection and analysis were gathered simultaneously so valuable knowledge about the diabetes curriculum would not be missed. Peer debriefing took place on a continuous basis with the principle investigator to ensure rigour in the study.

An audit trail was logged for this study to provide evidence of data collection and analysis procedures, e.g. transcriptions, timeline of research activities, participant contact information, copies of emails with participants, and audio recordings of the entire study was also kept for evidence.

CHAPTER 4

RESULTS & ANALYSIS

Participant Demographics

The focus group consisted of 8 participants, which were all AI/AN women who resided in the Las Vegas community and were ages of 18-65 years old. Participants were encouraged to bring family members to the session, and not all participants were diagnosed as having diabetes. Of the 8 participants, 12.5 percent identified themselves to be pre-diabetic, 25 percent identified themselves to be diabetic, and 50 percent identified themselves as non-diabetic.

Themes

The emerging themes were discovered through what the participants said during the study were structured based on the concepts of Social Cognitive Theory: personal factors, environmental factors, and behavioral factors (see Figure 1).

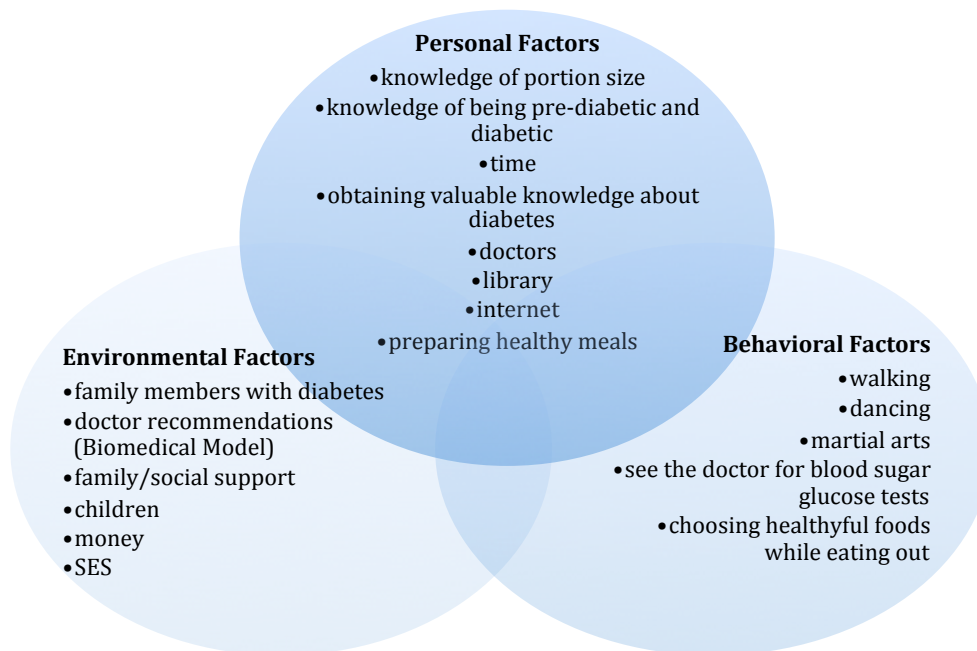


Figure 1: Themes organized by the Social Cognitive Theory concepts

Focus Group Results

The focus group data analysis resulted in 5 major themes: (1) family/social support, (2) diabetes knowledge, (3) disease perceptions and struggles, (4) food choices and preferences among diabetics, and (5) empowering others about diabetes.

Family/Social Support

Participants indicated that family support was critical in managing their type 2 diabetes. Having family members as active contributors to the success of their health allows them to stay motivated to make appropriate health choices. There were also participants who expressed having very little family support in managing their diabetes.

One participant discussed how her daughter recently moved in with her. One evening, the participant's daughter commented to her mother about decreasing her soda consumption. The daughter stated, *"This is going to be limited these Dr. Peppers – we're going to see less and less of these!"* The participant replied with, *"I'm very glad!"* Some participants indicated they were receiving little family support because they did not want their issues to be a burden on others. This phenomenon was also noted in a study by Mayberry and Osborn (2012). Some of Mayberry and Osborn's participants were also seeing the frustration in family members and their non-supportive behaviors, either by not helping the participant perform diabetes self-care behaviors or unhelpful behaviors that produced conflict. One participant from this study indicated she had little support from her family, she said,

"...they have their own life, their own business, with their kids and stuff like that you know."

Having social support while living in an urban setting is important for the participants. This allows for knowledge and information to be circulated, but most importantly, groups of individuals help to encourage one another regarding successes and failures of living with diabetes. These groups also offer reassurance that individuals are not alone in their struggle. These findings have been consistent with previous studies that have documented a positive relationship between social support and diabetes self-management (Schjøtz Bøgelund, Almdal, Jensen & Willaing, 2012; Shaw, Brown, Khan, Mau & Dillard, 2013; Chlebowy, Hood & LaJoie, 2010; Huang & Goran, 2003). As an example, a participant from the focus group stated,

“Here we’re all of different race - not a different race, but a different tribe and it seems to be that the information is absorbed, and I don’t know if it has to do with having an education in life to understand what we’re talking about or just the fact we click together very well.”

Most participants expressed having motivation to stay healthy for their children. One of the participants told her story about being diagnosed as a diabetic when she was pregnant. This allowed for her to change her lifestyle.

“When I was diagnosed with diabetes or as pre-diabetic, I was pregnant. And I thought ‘Oh my gosh, how is this going to affect my baby?’ And prior to that, I was drinking, partying, smoking - not cigarettes, but pot - and carrying on like a maniac...so I stopped drinking, stopped doing the pot, and started cleaning up my act a whole lot. This was in 72’ and I did pretty good, I thought, and when I came to Vegas in 76’...I was pretty heavy into martial arts and that was my form of exercise.”

Diabetes Knowledge

Participants reported that they were knowledgeable about the differences between being pre-diabetic and having diabetes. Participants that were previously diagnosed with diabetes and living with it had more knowledge about diabetes than those that had not been diagnosed. Participants were informed during the discussion guide session about the foods they should and should not consume, as well as the importance of living an active lifestyle. One participant was driven to educate herself and search for up-to-date information about the disease. Education was seen as beneficial in preventing and bringing awareness about the disease. It has been suggested that culturally appropriate diabetes education is highly recommended when trying to aid and target particular lifestyle behaviors, specifically among AI/AN populations with type 2 diabetes (Cavanaugh, Taylor, Kiem, Maureen & Geraghty, 2008; Struthers, Hodge, Geishirt-Cantrell & Cora, 2003; Dodge Francis et al., 2012). A participant from the discussion group took on the responsibility to be active in managing and coping with her diabetes. She said,

“I want to cook something that I can eat. I bought all these cookbooks and everything and when I go to the garage sales when people are throwing out all their diabetic stuff, I pick those things up.”

She is also proactive in trying to understand what the doctor gives her and utilizes library resources to educate herself about diabetes.

“She (her doctor) is very honest with me and she gives me information to look into and she gave me a food chart. She’s very upfront with me. The only thing is that I have to do it, I have to go back home and do it, I got to

go look into it. I have to make time to look into it. I got to go to the library to check out books on these things, it's the only way I'm going to learn."

Disease Perceptions & Struggles

Understanding how the participants perceived diabetes and the everyday struggles of living with diabetes is important because it helps anchor the direction of the diabetes education curriculum. When asked if diabetes was an issue for American Indians, participants agreed that indirectly or directly, it has an impact for American Indians and their families. One focus group member stated,

"I think it's an issue because it really just affects our families a lot and it's in our genes."

Some participants agreed there is a personal responsibility in managing their diabetes.

One participant mentioned,

"I feel like the balls are in my court and...I see the writing on the wall with both parents being both type 2 and it's up to me! And so I need to dance more, I need to exercise more, I need to do portion control, I need to cut out Dr. Pepper, I wish they would just ban it, it would be a lot easier."

A type 2 diabetes intervention with two Northern Plains Indian reservations found that their participants talked about their own personal changes that they had to make (Struthers et. al., 2003). Some of the responses found that they were: needing more exercise, being more knowledgeable about the disease, and taking the appropriate actions for management of their own diabetes. Participants from Struthers' study discussed the

responsibility and time that diabetes management entails (2003). This was also seen in this study.

These study participants reported chronic health problems linked to their family history, especially those of close kin, e.g. mother, father, brother, or sister. They recognized the signs of developing diabetes and were well aware that, being AI/AN, they may be at higher risk to develop diabetes, particularly type 2 diabetes. One respondent commented about the status of her family's health and questioned why they were not very concerned about the disease.

“I’ve seen what it has done to my family, my father, my mother, and how my father has gotten blind, and my mother...it affected her heart and also when she would get sores on her feet, her feet would turn black and her sores would just never heal. And to me, that was really scary because I couldn’t understand, why was it doing that? What were the doctors doing about it and why didn’t it scare her? Because it didn’t really seem to scare her because she looked at it as something, ‘Well, I’m used to it now.’”

Similar to the findings of other studies (Jones, Appel, Eaves, Moneyham, Oster, & Ovall, 2012; Lautenschlager & Smith, 2006), participants of this study believed genetics was one of the major causes of diabetes. The facilitator asked another participant her status of being pre-diabetic and how that impacts her life. She responded with,

“Well, I just thought, ‘I’m not surprised’ and I just accepted it like that was my fate, but now I feel like maybe I can do something about it. But where before I just kinda of thought, ‘Okay, I can get it sooner or later,’ but now, ‘Wait a minute, maybe I can try.’”

She constructed this idea that she will one day be diagnosed with diabetes. She recognizes the prevalence of diabetes and its threats. However, she was also able to be optimistic about preventing diabetes.

Many urban AI/ANs seek health care services from those that work directly or indirectly with the population, e.g. Indian Health Services or other urban Indian health organizations. Some participants described their status of health based on what they heard from their healthcare provider. One participant mentioned,

“My doctor said, ‘Something might pop up and it might pop up fast and you’re going to be in more problems and you’re going to have more problems.’”

Another participant who lived in California before moving to Las Vegas was persistent about her health and changed for lifestyle because of what her doctor told her. She said,

“I think a lot of it I learned through my doctor I had in California, when he told me I was borderline and I was pregnant at the time. All the info he gave me there changed a lot of the things I was doing.”

There was one participant who was not receiving the services she expected from her doctor and was not getting the response she was wanted. She said,

“Because what happened to me was that when I would ask questions they said, ‘We can’t just give you this. (We) would have to sit with your file with a medical provider and we have to go over it because we don’t want to. You’re not able to really understand what’s in there because you’re not a medical professional. We don’t want to upset you and scare you and so we would have to schedule an appointment.’ And then I just said, ‘Oh

okay.’ And so I know they have to do their certain things they have to do, but...I didn’t know what I was really getting into when I asked that and I don’t really know to ask for that they can readily give me.”

Later she commented,

“I wouldn’t even know what to ask, I didn’t even know to ask for that stuff (blood work tests).”

Several of the participants conceptualized their diabetes condition with their current health status. One participant had a previous injury that restricts her ability to maintain her diabetes. She said,

“Because I had a back injury, I have a lot of problems with my right side and my doctors are never sure that the pain I have on my right leg is neuropathy or not, or if it’s caused from my cyanotic nerve and that’s a block for me.”

Another participant, who identifies herself as pre-diabetic, said when she was younger she had radial keratotomy which affects her eyes to this day. She said,

“I have gone for an eye exam over at the clinic. I had radial keratotomy surgery before Lasik was an option... he (the doctor) had the clinic do the A1C. He was like, ‘If I didn’t know any better, I’d say you’re a diabetic,’ and he says, ‘It will affect your eyes.’ I just know from having that surgery with my eyes, the eyes are a very sensitive portion of your body and I think it tells us, if we were to pay attention to that a lot of times, what’s going on.”

As previous studies have shown, participants utilize Western forms of healthcare services for many reasons (Ghosh, 2012; Grazywacz, Arcury, Ip, Kirk, Bell & Quandt, 2011). In Ghosh's study (2012), participants in the older age group among the First Nations people of Eastern Ontario were using western medicine because it was easily accessible in the urban settings.

Managing type 2 diabetes can be time consuming. For these participants, since most of them were mothers and had to balance their work schedules while taking care of household responsibilities, time was seen as a barrier – making it difficult to actively care for one's self. Other studies had seen similar results from other ethnic groups such as African Americans (Chlebowy et al. 2010), Mexican Americans (Afable-Munsuz, Mayeda, Pérez-Stable & Haan, 2013) and First Nations peoples in Canada (Hernandez, Antone & Cornelius, 1999) that time was a perceived barrier. One participant from the focus group discussed her biggest problems in staying healthy and active. She explained that her barrier was exercising,

“I used to do it and you get so busy. But you know what, you make time for what we want to do.”

Another participant identified the barrier that keeps her from being healthy and that is not having the time to exercise. She said,

“I feel like I don't get enough exercise. I baby sit all day long 10-12 hours a day.”

Food Choices & Preferences among Diabetics

Food education is one of the foundational elements of diabetes management (Savoca & Miller, 2001). The focus group participants were knowledgeable about the

healthy and unhealthy food choices they should be making and mentioned they should be eating more vegetables, minimizing bread and meat intake, and reducing sodium content.

One participant highlighted an important point that,

“We (AI/ANs) always eat a lot of potatoes. I think a lot of our problem is our can goods. There’s so much poison in them that 3/5 of our nation is diabetic because of it. Be more conscious about what you’re eating and how you’re eating and being Latter Day Saints, we always talked about eating very little just enough to live more or less, and not living to eat.”

Another participant compared food to a drug. This belief is a mechanism that allowed for her to conceptualize how carbohydrates can have a negative connotation to her health. She said,

“Well, for me I would changing the carbohydrates to look at food as something that is like a drug, like a drug or alcohol you just avoid it. You can really think of it (food) as a drug, but it’s a drug that you can’t abstain from and that’s what makes it hard for me.”

This participant brought up a point about food addiction and how food choices are a struggle, particularly for those with diabetes. It becomes a personal responsibility to maintain good health behaviors when one is living with diabetes.

Portion control was one of the topics of concern to the group. Some participants understood why portion control matters when living with type 2 diabetes. Being able to monitor calories and carbohydrates that affect blood sugar is a skill. Studies done by (Story, Evans, Fabsitz, Clay, Holy Rock & Broussard, 1999; Lauthenschlager & Smith, 2006) have found AI adults who were diabetic, were consuming higher-fat foods,

possibly because of the lack of nutrition education efforts and that they had a pleasing taste. One participant said,

“Not that I don’t know how, I just get out of control when it’s something I like.”

Others find portion control difficult because they cook in bulk size to help with their budget. One participant said,

“I’m not a very good cook, so unfortunately to stretch money I tend to make big meals that will last a few days and a lot of that consists of pastas and rice and breads.”

It was also mentioned,

“When Indians get together, they always eat.”

Food is not just seen as bringing nourishment to bodies, but holds an important part in the AI/AN culture because eating together holds a form of communication and meaning when shared among family, neighbors, and friends. Food is also deeply tied to the land, ceremony, and spirituality of indigenous peoples (Edwards & Patchell, 2009); just as reflected in Navajo traditions of the burial of the child’s umbilical cord is intricately attached to a special site that resembles the child’s future endeavors, when one disrupts traditional food systems, everything that is attached to AI/AN teachings, language, and culture is also disrupted.

Empowering Others About Diabetes

A key theme that stemmed from the discussion about diabetes was the empowerment to self-manage diabetes and to independently make the right decisions, as well as to hear from others that made mistakes and learned from their choices. One

participant was not informed about requesting her blood work from her provider, but from the input of others she learned that she could request her information from her health care provider. She responded,

“I guess I feel more empowered to tell them, ‘No you have to tell me.’

Numerous studies suggest having culturally sensitive, empowerment focused programs have a greater impact for improving the health outcomes among minority populations and low-income adults who have type 2 diabetes (Tucker, Patel, Lopez, Campbell, Marsiske, Daly, Nghiem, Rahim-Williams, Jones & Hariton, 2014).

Follow-up Results

After the conclusion of the study, 2 participants were contacted via electronic mail or by telephone to ask a few follow up questions in regards to the decisions they have been making to help reduce their chances of getting the disease. I emailed this participant requesting if she could speak about the changes she has made after the study. This participant was able to send an email response about her status. She wrote,

“I had started my "NO" soda's routine prior to the "Biggest Loser Kickoff" at the Las Vegas Paiute Tribe Health and Human Services Clinic. In fact it was a late resolution of mine, to quit Dr. Peppers and see if my A1C goes down. I only changed my “NO” soda routine and this was my choice. In essence my A1C did decline by 50 percent and I am not sure but I think I was upgraded to Very Good. I don't feel any different, except that I'm not swelling. I can see some reduction of fluid retention.”

The participant made some behavioral modifications in her daily routine such as eliminating soda from her diet and making the effort to be healthy and active by enrolling

herself in The Biggest Loser competition sponsored by the Las Vegas Paiute Tribal Clinic.

The second participant was contacted by phone to schedule a phone interview that was most convenient for her. During the interview I asked her several questions. The first question I asked her was, *“I wanted to know if you made any changes after the diabetes discussion we had?”* Participant said,

“Yes. With in the past few weeks we haven’t been really doing it because I’ve been trying to recover from a hip procedure. But prior to that yes. We did a few things some simple things in your diet. I did some things through the Paiute Clinic. They were doing an event where you were paired with a partner and they will give you something you have to do everyday or every week. I was exercising 30 to 40 minutes a day so that was a switch. I have been doing it 3 times a week. I was doing the stationary bike for about 10 to 30 minutes a day. I did little things for my daughter like changing up our diet. We switch from whole milk to silk milk. We started eating more salads. Instead of using sour cream we went to a greek yogurt. Instead of ice cream we switched to frozen yogurt soy based, just switching little things you know. We are just getting more healthy foods into your diet instead of the high fats.”

This participant regardless of her injury has been making small changes in her daily routine to help keep her family healthy and making sure the surgery does not inhibit her to being active. The second question I asked, *“was it hard to make that transition?”* She then replied,

“No because the things actually taste a lot better! They’re a little bit pricier but as long as you’re using it in moderation and they actually taste better. Well sometimes what ends up happening is we would end up throwing the milk away because we didn’t even use it and sometimes we would have to spend a dollar more on the silk milk but it gets used and its also better for us.”

This participant believes healthful foods costs more than unhealthful foods. She found this transition to be better for her family and surprisingly enough the food she purchases gets eaten and not wasted. The third question I asked her was, *“Do you feel more confident now as far as taking care of your health and knowing a little bit more knowledge about how to prevent illnesses?”* She responded with, *“Yes I do feel more confident!”* My final question was, *“Is there any additional comments you would like to make?”* She said,

I did make some notes after. Its funny because when you said exercise 10 to 30 minutes a day, at the time, I was like ugh but actually when I get on my bike and I started doing it I can’t just do 10 minutes I have to do more. It’s just doing it and realizing it’s not that big of a deal. We changed what we eat and were doing smaller portions. Before we would have a big steak to ourselves now its one steak cut into two and now that’s plenty. It was helpful coming to the meeting and learning more things and that there are healthier food choices out there.”

Her self-motivation to exercise has changed her attitude and behavior towards being healthier, and being more active. The participant recalled a key point made during the

diabetes discussion group session about how portion control was important to maintaining a healthy diet.

Curriculum Adaptation Results

The overall purpose of this part of the study was to assess the efficacy of a modified version of the CDC “New Beginnings” diabetes curriculum among urban AI/AN individuals who are living and coping with the disease. Based on this current study of the diabetes curriculum, the focus group provided insightful feedback of what might be beneficial to include in the discussion guide. A female native professional facilitator led the final format of the diabetes discussion guide. The native facilitator played an important role in keeping participants engaged, and guided the discussion and focus group process. There was a strong connection from participants’ to the facilitator.

Diabetes Curriculum

In Module 1 of the diabetes curriculum, managing diabetes podcast audio was played and used as a discussion aide to discuss Rudy, a Hualapai tribal member, who took certain actions and gain control of his diabetes. From the audio, participants were able to learn that diabetes management is essential and this provided an opportunity for participants to reflect and talk about their own stories related to diabetes. Sharing stories about their family members and their own personal experiences brought them closer to each other. The participants declare that they were “comfortable with other natives” or being comfortable because they knew of someone in the study. Key points that were mentioned by participants in regards to the audio were: Rudy increased his physical activity to manage his diabetes, he took time for himself to realize how to control his

disease, he recognized had to do something different to manage his diabetes, and realized he had a lot of family support.

Participants were able to find detailed information about diabetes in folders provided to them. Many appreciated the knowledge given by the facilitator about her diabetes knowledge in explaining questions they might have. Some questions were raised about what is considered to be a normal blood pressure range, how much exercise is recommended to stay healthy, signs of having diabetes, and what an A1C fasting test involves. The handouts provided up-to-date information that was culturally specific for AI/ANs with type 2 diabetes. The folder contained factsheets, tips about healthy eating, a resource list of where they can get additional information, and steps to control their diabetes.

Focus Group

The pilot study included a focus group structure to assess the value of the discussion guide as a tool for urban AI/ANs. The participants were asked a multitude of questions that can support the main research question: How do urban American Indians cope and manage their daily life with type 2 diabetes? Focus group participants individually chose their own made up names for this section of the study for confidentiality purposes.

Although all participants actively engaged in the discussion within the focus group, there were some participants who had more input than others. Age and experience with diabetes could have been reasons why there was limited participation from certain participants. The process of sitting in a circle seemed to work well for both the discussion and focus group sessions.

The focus group gave the participants the chance to elaborate and share their feelings about diabetes that did not get to say during the discussion. The participants agreed that the take home information resources would be useful. Other suggestions were that audible and visual aids are effective in retaining the knowledge. Another participant suggested being informed about the basic definitions associated with diabetes without all the scientific jargon was helpful. Another important point was that participants were more comfortable in sharing information when a female American Indian facilitator guided the discussion process.

CHAPTER 5

DISCUSSION & IMPLICATIONS

Discussion

The purpose of this study was to assess a half-day CDC curriculum adaptation to “New Beginnings: A Guide for Living Well With Diabetes,” which focused on the management of urban AI/ANs who are currently living with diabetes. The goal of the curriculum research project was to help facilitate discussions about living with diabetes, identifying support from family and other social outlets, and develop skills with coping with diabetes. This study highlights the need of a diabetes curriculum specifically designed for urban AI/ANs living with diabetes. Although one-fourth of participants identified themselves as having type 2 diabetes, the remaining participants had similar responses to those living already with diabetes.

Participants shared their stories of shock, denial, and fear when they were told they were pre-diabetic or diagnosed with diabetes. Participants shared their concerns, and risks of getting the disease. Some of the participants felt they could do better in controlling their weight and be more physically active. Those that were diagnosed with type 2 diabetes went from denying it to finding the ways to understand and most importantly manage their disease on a daily basis.

The study revealed the many facets of what urban AI/ANs face when understanding the personal, behavioral, and environmental factors that may hinder or enhance positive health practices when trying to prevent or manage diabetes. The SCT framework asserts that people learn by observing from the action of others. Participants in this study indicated some form of physical activity they were involved in during the

study. As found from the follow up interviews, the 2 participants were able to process the information gained during the study (verbally or nonverbally) to take the necessary actions for their health. Because of their changes, they both seen positive reinforcements as a result of their changes e.g. reduction in A1C count and food preference for healthy foods. The participants in the study mentioned how valuable the input from family members was instrumental to controlling and managing the disease. Some participants received support from family about changing their diet, and exercise, and some reported being encouraged to exercise, which helped to make it easier for them to make necessary changes on behalf of their health.

Another finding our study was how social support was associated with self-management and coping with diabetes. The participants share a true relationship of social support that is seen beyond this study. Social support seemed to help in overcoming and managing type 2 diabetes. The participants have become a resource for one another to become aware of each other's barriers and triumphs in managing their diabetes.

Participants were also seeking a deeper purpose and meaning to the disease and therefore strived to be healthier and active on behalf of their children, seeing them as a motivation for staying healthy. Urban AI/AN populations have not received the greatest amount of attention compared to AI/ANs who come from reservations. Small efforts have been made towards research endeavors; hence, by creating well-designed, effective, and culturally appropriate diabetes education materials, we can better serve urban AI/AN dwellers (Urban Indian Health Institute, 2004).

One of the strongest themes among the participants was individual responsibility in the prevention and management of diabetes. Those individuals who were currently

living with type 2 diabetes believed it was about the self; it's the responsibility of the individual to set their intentions to seek diabetes care, and educate themselves about the disease. It was also important for the participant to eat properly and be physically active on behalf of their health. Diabetes creates personal strain on participants, but learning and having the right tools can help them overcome those challenges associated with controlling and managing type 2 diabetes.

Participants understood that diabetes was prevalent among AI/ANs and many had made references to the genetic predisposition to diabetes. Their risk perception for diabetes related to genetics and one participant said, "It runs in our family." As reflected in the themes section, the participants have seen first-hand from their family members the struggles and complications as a result of their diabetes. The participants understood the genetic risk for type 2 diabetes would lead them to believe they would someday develop the disease, regardless of they changed their lifestyle behaviors.

Participants in this study conceptualized their health status from a biomedical perspective, and therefore expressed a reliance on the biomedical model for treatment. There is limited access for urban AI/ANs to access health and wellness services with an AI/AN focus, specifically those that are seeking diabetes care. Some participants also sought other forms of health care from providers at the Indian Health Service facility in Las Vegas. From the transcriptions, there was no mention about the use of traditional medicine however, this does not necessarily mean that participants and other urban AI/ANs who did not participate in this study do not seek other approaches to care e.g. traditional medicine. Traditional medicine is a healing system that AI/ANs utilized before

European contact; where the people relied on medicinal plants, traditional healers, and ceremonies to harmonize one's health and wellbeing with their surroundings.

For urban dwelling AI/ANs, if IHS clinics are unavailable many will have to pay for their health care services as needed or travel great distances to receive care on their reservations. Mohammed (2011) highlights an important point that although the Indian Health Service carries the responsibility for providing health care services for AI/ANs, urban AI/AN health centers such as the one located in Las Vegas are receiving approximately 1 percent of the total Indian Health Services budget. Uncertain about how to provide the best comprehensive diabetes care for urban AI/ANs when there are limited or no support to build upon.

Urban AI/ANs are often navigating their own environments (e.g. political, physical, economic) and share experiences of historical trauma, and the influences of colonization, all of which are embedded in the AI/AN urban experience. Mitchell (2012) pointed out that health promotion programs and policies tend to emphasize individual behavior change without addressing the bigger factors that contribute and influence health inequalities e.g. social, environmental, economic, and political factors. As a result, we will continue to see new people being diagnosed, and the distribution unchanged unless we start to address the social influences that have caused the high rates of diabetes in the first place.

As discussed in the themes section, time was seen as a perceived barrier to preventive care among participants. The participants in this study expressed their inability to set aside time to properly manage the disease because of responsibilities they have to uphold at work, or in the home.

Participants understood how important it is to make healthy food choices in managing diabetes. Some found it difficult to make the right choices because of money constraints to purchase the appropriate foods for living a healthy lifestyle. By living in an urban environment our participants were faced with a higher concentration of fast food chains, and are more prone to a sedentary pattern of life while living in the city. Women are primarily the ones doing the grocery shopping for the family. Making bad food choices food dense in high fats and carbohydrates, family member's chances of developing type 2 diabetes will increase.

Some participants expressed how important portion control is when trying to manage their diabetes. Having access and knowledge about the nutritional and dietary skills is important for diabetes prevention and management. Portion size was seen as a barrier to positive lifestyle change. It is an important component for weight loss and controlling glucose levels. Some participants mentioned they would overindulge in foods that they like which were all high in sugars, carbohydrates, and fat. It is important to note, for AI/ANs, food is considered to be a traditional component of the culture, as it is rooted in the spiritual and social circles of life. Many AI/ANs believe food is sacred and important to maintain harmony and balance. This concept of how food is sacred, could be a motivational tool to bring awareness to communities and AI individuals to turn to traditional foods and live a healthier lifestyle.

Empowerment at the individual or community level was something the participants needed because it helped them focus of their goals, and gave them a sense of control over their health. It is a way to seek motivation, and social support to improve their quality of life. By developing culturally appropriate diabetes material that focus on

empowerment will help encourage AI/ANs to keep striving towards healthier lifestyles. This is just one strategy of going about eliminating or reducing type 2 diabetes among urban AI/ANs.

As a result from the follow-up, the first participant who sent the email, was able to pin point her struggles in being healthier. She identified what actions needed to happen to get to where she wanted to see herself. By signing up for a program through the Paiute Clinic to help her reach a personal goal and making little changes in her diet, she was able to see results in her A1C blood work. The second participant who did the phone interview, was responsive and working towards changing the foods her family ate. Although the food was more costly than the regular foods she would purchase she knew on the long run it would be the better choice. One cannot put a price on health, but sometimes policy and other environmental factors can make this an impossible endeavor.

Strengths & Limitations

There are several limitations of this study, one of which is that all participants were female. As a result of recruitment process, the women in the study were contacted through the tribal health service in Las Vegas that sponsor the Native Women's Circle. This produced an over-representation of females in this study. There needs to be a more effective and better way of recruiting men in diabetes research. Because this study used phenomenological methods to obtain the data, participants may have been influenced by other participant comments during the focus group. The study had a relatively small sample size (n=8) and was open to those who qualified to participate in the Las Vegas area. The findings are not generalizable to other urban settings where AI/ANs reside.

Despite these limitations, however, this pilot study adds to the knowledge about diabetes education in urban settings makes a case for the importance for the use of gathering qualitative data to support and gain insight to urban AI/AN population about diabetes prevalence and incidence.

Future Implications

There is a critical need to develop culturally appropriate diabetes education material for urban AIs because what might be working in tribal communities might not be similarly successful for AIs in urban settings. Roubideau, Moore, Avery, Muneta, Knight and Muchwald (2000) identified that there are over 550 federally recognized tribes who are distinct in their own ways. Therefore, developing culturally appropriate diabetes education materials needs to be specific and relevant to the culture, language, and traditions held in by AI/ANs in urban areas. This pilot study showed that educational structures and community members can work together to improve and contribute to the limited knowledge about urban AI/ANs with type 2 diabetes. Further research needs to be conducted through combining western ideologies of health with native ideas of health and with self-management of type 2 diabetes. Researchers and health professionals have a responsibility to contribute to the neglect of data to improve the quality of care for urban Indians and, most importantly, help reduce the ethnic/racial disparities of AIs living in cities. By adapting the diabetes curriculum to urban AIs, a few lessons were learned. Anyone from the clinical or community setting can pick up the discussion guide and use it to provide training, support, and resources to improve diabetes care among their participants. The inclusion of extended family members in group discussion and the focus group to listen in on the session was beneficial to increasing their knowledge and

informing them on the risks of diabetes and ways to prevent it. Future efforts in quantitative methods need to be considered for properly adapting and addressing the needs of urban AIs. Contributions from both a qualitative and quantitative research perspective will strengthen the data and better position this study to address the initial research questions.

Conclusion

The findings of this study help to illuminate personal, environmental, and behavioral factors that affect health behavior when trying to manage and cope with diabetes. Aspects such as diabetes information, time, nutritional knowledge e.g. portion size, were seen as barriers that need to be addressed when educating urban AI/ANs in our study. The participants expressed their concerns with environmental factors that hinder the management of their diabetes. Such environmental influences were family, social circles, and money. Managing and coping with diabetes can be a personal struggle and there is a need to not only look at the weaknesses of diabetes management, but also to identifying the strengths of where urban Indians exist so health professionals can start addressing and eliminating type 2 diabetes among urban Indian dwellers.

APPENDIX A

ADAPTED DIABETES DISCUSSION GROUP GUIDE

Purpose

You are invited to participate in a research study. The purpose of this pilot study is to participate in a one-day curriculum assessment that will focus on the management of American Indian and Alaska Natives (AI/ANs) who are currently living with diabetes. The goal of the curriculum research project is to help facilitate discussions about living with diabetes, identifying support from family and other social outlets, and developing skills with coping with diabetes. The data gathered will provide valuable insight into developing supplement diabetes self-management curriculum education and prevention tools to help AI/ANs manage their diabetes and help with specific training for health professionals who are working directly within the population. The use of this information will inform AI/ANs living with Type II and assist diabetes educators/health professionals to be more effective in providing quality resources and support services that incorporate emotional managing skills, understand the importance of diabetes care and self-management, and ways to communicate with family members about their diabetes. The goals of the discussion groups include:

- 1) Discussion related to the impact of living with Type II diabetes.
- 2) Identify family and social support needs for the individuals living with Type II diabetes.
- 3) Develop important steps in setting positive goals to improve their health.

Discussion Group Protocol

A total of one discussion will be conducted with AI/AN participants. AI/AN participant's discussion groups will be held at the University of Nevada, Las Vegas facilities. Recruitment of participants will be through flyers and community health representatives from the Las Vegas area and recruitment will be based upon the qualifying criteria. Flyers will be provided to AI/AN participants that are eligible. The AI/AN participant will then call the contact phone number on the flyer to sign-up for the discussion group. Discussion groups will be one and a half hour each; and will be audio taped and transcribed. All groups will tentatively take place the week of December 7st. The discussion will include two parts. The discussion is focused on the person with diabetes. The discussion page is divided into two columns. Instructions for leading the session are in the left column. Discussion questions and key talking points are in the right column.

Session Modules

The *New Beginnings* modules are developed for diabetes discussion groups. For this study will be looking at 1 module: Module 1 is an overview of living with diabetes. Topics that will be covered will be diabetes ABCs, managing diabetes, and supporting a loved one with diabetes.

Group Discussion

The discussion will be focused on the person with diabetes. The discussion page is divided into two columns. Instructions for leading the session are in the left column. Discussion questions and key talking points are in the right column.

Evaluation Methodology

This qualitative research will be conducted using traditional discussion group and interview methods. All discussions will be taped and transcribed. Analysis will be conducted by the moderator by hand coding for emerging themes and identifying supporting quotes separately.

Participants

Participants must fit the following criteria: currently an enrolled member of a federally recognized tribe, and currently living with Type II diabetes. Excluded from the study will be individuals who are not enrolled in a federally recognized tribe. Children will be excluded from this study.

Discussion Guide

Preliminary Comments

Thanks for coming today. I know how busy you are and I appreciate your time today. We're going to talk about a lot of topics, probably topics that you talk about daily with your friends. BUT you may not have shared openly about these topics with strangers like me. So let's start with some thoughts about how we can make this a safe time for us all. First, I want to tell you that no names will be attached to any comments made today. I am recording our conversation because I have the memory of a mosquito and I don't want to miss anything you say.

This is a pilot project that has the intentions of providing a safe space for creative dialogue about your experiences living with diabetes. So feel free to say exactly what you think or fear without any worries.

As you know, everyone feels and thinks differently in regards to their diabetes. What we're looking for today is the truth and that may be different for each person. So please share what you feel and also share if you feel or think differently than someone else.

Just so you know, my name is Eudora. I am from the Navajo Nation and part of the Cahone Mesa Community. I am a graduate student at the University of Nevada Las Vegas in the Masters of Public Health Program. I am honored to listen and learn from you today.

I may forget to take a break at the right time, so feel free to get up anytime and pour some soda or go to the rest room. I want you to be very comfortable.

Before we get started, please take a few minutes to review the consent form in front of you. Basically it says that we are recording the conversation so we don't miss any of your valuable thoughts and that your name will not be attached to any of your comments so you can be as open and honest as possible (all aspects of the consent form will be reviewed). I'll collect the forms now.

Projective Module Activities

Module 1. Overview: Living Well With Diabetes

Background

This module provides an overview of key concepts that are discussed throughout the *New Beginnings* sessions. It introduces participants to the steps involved in controlling diabetes and the important role of social support. It can be used to raise awareness of diabetes, teach people about action steps they can take to control it, and action steps loved ones can take to support a person who has the disease. Diabetes can wear down a person's energy and wellbeing, but this does not have to happen. A person can take charge and control their diabetes.

The key points for this module follow.

People with diabetes can take control of the condition by:

- Learning about diabetes.
- Knowing their ABCs.
- Managing their diabetes.
- Getting routine care.

Family members can support their loved ones with diabetes by:

- Learning about diabetes.
- Talking to their loved ones about coping with diabetes.
- Finding out what their loved one needs.
- Finding ways to help.

Module Objectives

By the end of this session, participants will be able to:

1. Name at least three actions a person can take to control type 2 diabetes.
2. Name at least three actions a loved one can take to support a person with diabetes.

Materials

Time needed for the session: minimum of 60 minutes.

Discussion Aides (choose one):

- [It Takes a Family](#) (about 3 minutes)
- [Managing Diabetes Podcast: Episode 1](#) (2 minutes)

Managing Diabetes Podcast - Episode 4

Hear how Rudy took control of his diabetes.



Rudy and his cousin, Faylynn Hualapai Tribe Peach Springs, AZ

- [Living with Diabetes: Finding the Support You Need](#) (about 3 minutes)

Handouts (one for each participant)

- [4 Steps to Control Your Diabetes for Life](#) or [Tips to Help you Stay Healthy](#) (an easier to read version of 4 Steps)
- [Help a Loved One With Diabetes](#)

Equipment

- Flipchart or blackboard.

Group Discussion

This discussion will provide an overview of the topics that will be discussed in *New Beginnings* and an introduction to diabetes management concepts.

Introductions

Group Leader Instructions	Talking Points and Discussion Questions
Say:	<p>Hello. I'd like to welcome you all here today for our group discussion on the effects of diabetes on people with the disease and their families.</p> <p>Before we get started, I'd like to ask you a few questions.</p> <ul style="list-style-type: none">• Do you either have diabetes or have someone in your family with diabetes? Please raise your hand. Okay, keep your hands raised.• Do you have a close friend or coworker with diabetes? Please raise your hand.
Say:	<ul style="list-style-type: none">• Look around the room at the number of people affected by diabetes.• According to the Centers for Disease Control and Prevention, there are more than 25 million people in the United States with diabetes.• I want you all to think about this fact for a minute.
Say:	<p>This disease is very serious and has complications that can cause heart disease, kidney failure, amputations, blindness, impotence, and many more health conditions.</p>

Group Leader Instructions	Talking Points and Discussion Questions
Say:	<p>But before we go more deeply into our discussion of diabetes, let's introduce ourselves.</p> <p>My name is _____, and I'll be leading our discussion today. I'm glad that you are here to share your story and learn more about managing diabetes.</p>
<i>Ask participants to introduce themselves.</i>	
Say:	Now, let's get back to the discussion.
Say:	<ul style="list-style-type: none"> • Some people do not realize how serious diabetes is. Did you know that diabetes is a leading cause of death in the United States, and that there is a strong link between diabetes and heart disease? • In fact, more people with diabetes die of heart disease than of any other cause. We have to do something to help educate ourselves about how to control diabetes in order to lower the chances of complications.
<i>Let the group know how much time you have planned for discussion.</i>	The discussion should last about ____ minutes or so.

Diabetes Management Discussion

Group Leader Instructions	Talking Points and Discussion Questions
<p><i>Hand out: 4 Steps to Control Your Diabetes for Life booklet or Tips to Help You Stay Healthy.</i></p> <p>Say:</p>	This booklet outlines 4 steps people diabetes should take to control their condition.

Group Leader Instructions	Talking Points and Discussion Questions
<p>Ask:</p>	<ul style="list-style-type: none"> • What is the first step? • What are some things the characters did to take this step? • Why do you think learning about diabetes is important? • How do you think it will help?
<p>Ask:</p>	<ul style="list-style-type: none"> • What is the second step? The ABCs are A1C, which is a measure of your blood glucose over the last 3 months; blood pressure; and cholesterol. • Controlling your ABCs will help lower your chances of having a heart attack or stroke. • We will talk more about controlling the ABCs during our sessions.
<p>Ask:</p> <p><i>Note: Participants may mention choices the characters made that they think were wrong. If so, ask why they think the character might have made those choices.</i></p>	<ul style="list-style-type: none"> • What is the third step? • Did you notice any actions the characters took to manage their diabetes? • What do you think made it easier for them? • What do you think made it harder? • We will spend time talking about small steps that people with diabetes can take to manage their condition. We will also talk about how loved ones can help.

Group Leader Instructions	Talking Points and Discussion Questions
<p style="text-align: right;">Ask:</p> <p><i>Note: Some participants may only think of doctors. Remind them that diabetes educators, nurses, pharmacists, and others are also part of their health care team.</i></p>	<ul style="list-style-type: none"> • What is the fourth step? • Do you remember any examples from the video of the characters getting routine care or talking about getting care from a health care professional? • What did you think about how well the characters related to members of their health care team? • During these sessions we will talk about how to make the most of your appointments with your health care providers.

Family Support Discussion

Group Leader Instructions	Talking Points and Discussion Questions
<p style="text-align: right;">Ask:</p> <p><i>Note: You may need to encourage the discussion by giving a few lead-in examples of the family's role; for example, a mother's choice of what to cook for dinner, children being physically active with their father, or the family making sure that character took their medicine or went to the doctor.</i></p> <p><i>Some participants may mention actions that family members took that were not helpful. Ask why they think the family member might have made those choices.</i></p>	<ul style="list-style-type: none"> • What roles did the family members play in the life of this person with diabetes? • How important were the family members in the video?
<p style="text-align: right;">Ask:</p> <p><i>Note: Discuss relationships within families, and ask members of the group to share their personal stories relating to a family member or close friend.</i></p>	<p>Can you relate to this family? In what ways?</p>

Group Leader Instructions	Talking Points and Discussion Questions
<p><i>Note: Do not ask more than five questions about the discussion aide. If your group is having a good discussion not related to the questions above, feel free to go with the flow—just as long as the comments add to the understanding of diabetes.</i></p>	
<p><i>Hand out: Help a Loved One with Diabetes fact sheet.</i></p>	
<p>Say:</p>	<p>Let’s take a look at this fact sheet. Just like there are 4 steps a person with diabetes can take to control their condition, there are 4 steps loved ones can take to help.</p>
<p>Ask:</p>	<ul style="list-style-type: none"> • What is the first step? • What are some examples of this from the story? • Why is it important for loved ones to learn about diabetes?
<p>Ask:</p>	<ul style="list-style-type: none"> • What is the second step? • Did you notice any examples of this in the story?
<p>Ask:</p>	<ul style="list-style-type: none"> • What is the third step? • Did you notice the ways the characters in the story talked about what they needed? • What can be difficult for a person with diabetes talking about what they need with loved ones?
<p>Ask:</p>	<ul style="list-style-type: none"> • What is the fourth step? • What are some things family members did in the story to help?
<p>Ask:</p>	<p>Does anyone have any suggestions on how to help someone in your family who is living with diabetes?</p>

Group Leader Instructions	Talking Points and Discussion Questions
<p><i>Optional</i> <i>Hand out: bookmarks or post cards.</i></p> <p>Say:</p>	<p><i>Here is a reminder for you about ways to help a loved one with diabetes. Use it to begin a discussion with family members or loved ones.</i></p>
<p>Say:</p> <p>Ask:</p>	<p>We're getting close to the end of the session now. We are almost finished. I just have one more question for you.</p> <p>Are there things that you will try to do differently in your own life or your family life now that you have watched this video and have attended this discussion?</p>

Close the Session

Group Leader Instructions	Talking Points and Discussion Questions
<p>Say:</p> <p><i>Note: Answer questions briefly. Explain homework (see Homework Exercises on page XX). Remind participants of next session. Ask participants to complete the session evaluation.</i></p>	<p>I want to thank each of you for participating in our group discussion.</p> <p>Does anybody have any questions before we wrap up?</p> <p>In our next session we will talk about ____.</p> <p>Do you have any specific questions about this topic that you would like to see addressed?</p>
<p>Say:</p>	<p>Thank you.</p>

Module 1 Exercise

A. Managing Diabetes Think-Pair-Share (12 minutes total)

- Ask participants to think about the their own story. What actions did the they take to manage his or her diabetes? What seemed to help? What seemed to be a barrier? What role did the family play? (3 minutes)
- Ask participants to pair up and discuss their answers. (5 minutes)
- Ask participants to share 2 or 3 key things they learned about managing diabetes and family support. (5 minutes)

Homework Exercises

- Ask participants to discuss the 4 Steps to Control Diabetes brochure with family members and friends.
- Ask participants to review the “Tips to Help You Stay Healthy” fact sheet and complete the “Take Action” section on the back of the sheet.
- Ask participants to review the “Help a Loved One With Diabetes” fact sheet and complete the goal setting exercise on the back.

Concluding Remarks:

- I’ve been asking all the questions today. Now it’s your turn to ask me or others questions or share something that we have not touched on yet tonight. Who would like to share?
Thank you.
- Provide incentive and ask them to sign incentive receipt form.
- Get into a focus group and ask questions about living with their diabetes.
- Ask them to sign the consent form for audio recording for the purposes of transcribing

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CURRICULUM VITA

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Academic Achievements

Native American Research Centers for Health (NARCH) Graduate Fellowship

- November 2013: Provides opportunity for conducting research, research training and development to meet the needs of American Indian/ Alaska Native (AI/AN) communities. The fellowship supports opportunities for capacity building and the possibility of reducing the many health disparities so prevalent in AI/AN communities.

Association of American Indian Physicians Cross Cultural Medicine Workshop Participant

- May 2012: Identified strategies to improve communications between American Indian/Alaska Native patients and health professionals; described current health issues affecting Indian communities in both reservation and urban settings.

Dean's List

- Fall 2010 and Spring 2011: must have earned a semester GPA of 3.5 or higher and completed at least twelve credit hours.

Indigenous Health Leadership Institute Participant

- Spring 2010: Learned about American Indian and Indigenous perspective on health from community leaders, traditional healers, political activists, and health professionals.

Ronald E. McNair Scholar

- 2008 - 2009: Designed to prepare undergraduate students for doctoral studies through involvement in research and other scholarly activities. Researched phylogeography of the nematode, *Soboliphym batrini*, across the Alexander Archipelago.

Work Experience

Graduate Student Worker, American Indian Research Center at UNLV Las Vegas, NV

Sept 2013-Dec 2013

- The American Indian Research student worker performs administrative assistant task associated with the NIH Build Grant, that includes syllabi and coursework collection from the Science & Health: Ascertaining Research Education (SHARE) partners, assisting with meetings and teleconferences, literature review, etc.

Graduate Research Intern, Albuquerque Indian Health Board Inc., Albuquerque, NM

June 2013-Aug 2013

- The American Indian Summer Research Interns (RI) was assigned to the Southwest Tribal NARCH. The RI assisted NARCH staff and other AAIHB staff in community assessments, technical assistance and administrative activities; conducted literature searches and participated in a journal club; help organized programmatic material and maintain project files, and assisted in the fulfillment of program initiatives.

Graduate Research Assistant, American Indian Research Center at UNLV, Las Vegas, NV

Feb 2013-Sept 2013

- Adapting of the National Diabetes Education Program toolkit: New Beginnings: A Discussion Guide for Living Well with Diabetes for the American Indian/Alask Native Population

Undergraduate Project Assistant, Center for Native American Health, Albuquerque, NM

Feb 2012-May 2012

- Assists the Center for Native American Health with general office duties, internet and library research, writing, drafting, and editing documents, assisting with special events, managing and archiving materials and files and other job-related duties that are assigned.

Program Researcher, Cycles of Life Program, Albuquerque, NM

June 2011-May 2012

- Explored communities by bicycles, gardening, and art while utilizing the natural and cultural landscapes. Cycles of life takes a holistic approach to health by stimulating the mind, body, and spirit.

Health Justice Intern, Native Health Initiative, Albuquerque, NM

June 2009-May 2012

- Addressing the health inequities identified by tribal leaders and their communities particularly in the Southwest.

Education

August 2014-May 2016 (expected)

University of Nevada Las Vegas, Las Vegas, NV

- Ph.D. in Pubic Health, Social & Behavioral Health

August 2012-May 2014

University of Nevada Las Vegas, Las Vegas, NV

- Masters of Pubic Health, Social & Behavioral Health

August 2009-May 2012

University of New Mexico, Albuquerque, NM

- B.A. Human Evolutionary Ecology

September 2006-June 2007

University of Washington, Seattle, WA

- Biology

August 2002-May 2006
The Knox School, St. James, NY

- High School Diploma

Skills

Strong customer service and people skills, experience in fund raising, experienced and capable of working in a diverse work force, served as a coordinator with Native Health Initiative, knowledge of SPSS, STATA, GIS, Link+, Microsoft Word, Excel, and PowerPoint.

Professional Memberships

American Public Health Association, 2013-present