

New Beginnings: Living with Diabetes among an Urban American Indian Community

Carolee Dodge Francis, Ed.D
Associate Professor
4505 S. Maryland Parkway Box 453064, Las Vegas,
NV 89154-3064
702-895-5586, carolee.dodgefrancis@unlv.edu

Eudora Claw, MPH

Abstract

The purpose of this qualitative study was to examine how urban American Indian/Alaska Natives (AI/ANs) cope and manage their daily life with type 2 diabetes. A culturally responsive American Indian adaptation of a single module within the National Diabetes Education Program (NDEP), *New Beginnings: A Discussion Guide for Living Well with Diabetes* toolkit was utilized to facilitate this conversation. This study analyzed responses from participants diagnosed with type 2 diabetes, pre-diabetes, or had family members with the disease. A qualitative focus group with a phenomenological research design and thematic analysis was utilized. Eight female respondents were interviewed using a semi-structured interview guide. The in-depth focus group's dialogue was audio-taped and transcribed verbatim. It was followed by line-by-line coding and included an inter-coder process. Four themes associated with the quality of life emerged from these interviews: impact of type 2 diabetes, disease knowledge and perceptions, health behaviors, and family/social support. Diabetes management programs must consider psychosocial aspects of patients' as they are closely associated with their quality of life.

Key words: American Indian, type 2 diabetes, curriculum adaptation, qualitative research

Introduction

Type 2 diabetes is currently at epidemic proportions for American Indian/Alaska Natives (National Center for Health Statistics, 2015). American Indian/Alaska Natives (AI/AN) have the highest rates of type 2 diabetes in the United States of any specific population (U.S. Department of Health and Human Services, 2014). Based upon the 2009 Indian Health Services' (IHS) National Patient Information Reporting System, the Centers for Disease Control and Prevention (CDC) reported that "14.2% of American Indians and Alaska Natives aged 20 years or older who received care from IHS had diagnosed diabetes" (CDC, 2011, p.3). It should be noted that once IHS adjusted for population age differences, 16.1% of the total adult population had a diagnosis of diabetes (CDC, 2011). Rates vary by region, with lower rates within Alaska Natives adults, 6.0%, and 24.1% among American Indians in the southern Arizona (CDC, 2012). Although diabetes is the sixth leading cause of death in the United States for the total population (Harris & Pokorny, 2012), diabetes ranks fourth among American Indian and Alaska Natives (AI/AN) (O'Connell, Yi, Wilson, Manson, & Acton, 2010).

The IHS serves a section of the overall AI/AN population to provide diabetes health care services for individuals who come from a federally recognized tribe (Trombino, 2005). In total, IHS consists of 12 area offices, and 168 local service units provide care to AI/ANs (Roubideaux, 2013). Urban AI/ANs might find it difficult to seek IHS health care services for diabetes management on or near reservations because they are no longer in the same areas as the service units (Mendenhall et al., 2010). The U.S. Census Bureau (2010) showed that 71% of AI/AN's reside in urban areas. These urban AI/ANs makeup 67% of the nation's 4.1 million self-identified American Indian and Alaska Natives population (Urban Indian Health Commission, 2007). 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. However, recent studies have documented that urban AI/AN population still have poor health and limited options for health care (Urban Indian Health Commission, 2007).

A diabetes curriculum that addresses AI/AN 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. Diabetes self-management education (DSME) is a crucial component of reducing the risk of diabetic complications as well as sustaining and improving quality of life. Finucane and McMullen (2008) found that to 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. One strategy aimed at bridging the gap would be providing culturally competent content directed towards preventing, delaying, and disease management of type 2 diabetes among AI/AN's.

New Beginnings: A Discussion Guide for Living Well with Diabetes was originally created through the National Diabetes Education Program (NDEP), a partnership between the National Institutes of Health (NIH) and the Centers for Disease Control and Prevention (CDC) for the African American population (CDC, 2005). *New Beginnings: A Discussion Guide for Living Well with Diabetes (New Beginnings)* guide fits the standards of a DSME tool. The eight module guide focuses on assisting individuals with diabetes and the role families might play to manage the emotional impact of diabetes along with creating positive, supportive relationships. The original *New Beginnings* guide was intended to be used within a variety of group settings such as, but not limited to: diabetes support groups, faith-based groups, and worksite groups.

Social Cognitive Theory

The Social Cognitive Theory (SCT) provided an appropriate theoretical framework, as it represents a triadic reciprocal causation model where the interaction between behaviors, personal and environmental factors that are interacting (Bandura, 1977). Further considerations within behavioral constructs of SCT included behavioral capability, self-efficacy, outcome expectations, perceived behavior of others from observation, and environment (Bartholomew, 2011). Another construct of the SCT that is utilized in the results of this study is outcome expectations and individual's judgment of the likely consequence that a certain behavior will produce (Bandura, 2004). Finally, SCT triangulates the effect of environment, where all factors affect a person's behavior, but only those that are external to the person (Bartholomew, 2011). Physical environments might include the availability of nutritional foods, safe environments for exercising, air quality, and so forth. Social environments can include family members, friends, or neighbors. Research has found that people may or may not be aware of how strong an influence the environment can have in determining their behavior (Bartholomew, 2011).

Purpose of the Study

This study utilized a half-day CDC curriculum adaptation of *New Beginnings: A Guide for Living Well with Diabetes* to have a discussion focused on the management of diabetes with urban AI/ANs who are currently living with pre/diabetes or have family members with the disease. Therefore, the purpose of this study was to examine how do urban AI/ANs cope and manage their daily life with type 2 diabetes.

Methods

This section will provide an overview of the research methodology used and the adaptation of curriculum that facilitated the conversation for this qualitative phenomenological study.

Adaptation of the New Beginnings Curriculum

This study utilized an adaptation of the National Diabetes Education Program toolkit, *New Beginnings: A 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 discussed with the urban AI/AN participants due to the short implementation window. The *New Beginnings* modules were initially developed to help acknowledge and better understand the importance of diabetes self-management in African American population. Prior to data collection, the *New Beginnings* guide was blended with other educational texts in order to deliver face-to-face instruction during the focus group.

The modifications made to *New Beginnings*, Module #1: Overview: Living Well with Diabetes toolkit, included: podcasts and handouts geared toward *The Debilitator*, a faith-based film, were removed as part of the adapted version of the toolkit because they were created to target African American populations. It should also be noted that, *The Debilitator* is no longer available from NDEP as part of the toolkit. For the modification, *The Debilitator* was exchanged for a NDEP podcast audio of a Hualapai Tribal member discussing his ability to control his diabetes. Additional NDEP and CDC handouts were utilized, these included: *The American Indian/Alaska Native Fat and Calorie Counter*, *Living a Balanced Life with Diabetes*, and other culturally responsive materials.

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 a phenomena, uncovering the links among concepts and behaviors, which create and refine theory and practice. Qualitative research provides an avenue to explore the potentially missing components of information about wellbeing and illness within communities. Phenomenology is described as a shared meaning found among several individuals who have lived the experiences of a concept or a phenomenon (Creswell, 2013). This describes what the participants have in common with a certain phenomenon, e.g. living with diabetes.

This study used focus group structure with semi-structured questions as a qualitative technique of gathering data about participants' thoughts and experiences with diabetes. The discussions during the focus group helped to examine the research question of how urban AI/ANs cope and manage their daily life with type 2 diabetes.

Recruitment and Eligibility

Recruitment procedures included web-based contact methods with notifications delivered via electronic mail to American Indian organizations within the Las Vegas, Nevada area. All emails and notifications included a brief description of the study and potential respondents were invited to contact the investigators if interested. Interested respondents indicated their desire to participate through a telephone call or email. The investigators then discussed requirements of participation. A study summary was sent to each potential respondent, and they were notified of the focus group date. The review of Consent to Participate form and written consent was obtained the day of the focus group.

Participants had to meet the inclusion criteria to participate in this study. The inclusion criteria for the study targeted AI/ANs that are enrolled members of a federally recognized tribe or descendants of. The participant criteria also included currently having pre-diabetes, type 2 diabetes, or a family member that is diagnosed with type 2 diabetes. The exclusion criteria included individuals not enrolled in a federally recognized tribe or descendants of, not diagnosed with pre-diabetes or type 2 diabetes, or did not have family members with type 2 diabetes. Individuals 17 years old and younger were excluded from this study.

Data Collection

Data collection occurred primarily through in-depth interviews at the end of the *New Beginnings* Module 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. The moderator conducted thematic analysis by hand coding for emerging themes and identifying supporting quotes separately.

***New Beginnings* Module.** 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 audio taped. 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.

Focus Group Interviews. The focus group consisted of eight eligible respondents; all were AI/AN females who reside within the city of Las Vegas, Nevada. The age range included ages 18-65 years old. Within the eight participants, 40% identified themselves to be pre-diabetic or diagnosed with type 2 diabetes. The remaining 60% of participants in the group identified themselves as non-diabetic, but having at least one family member with diabetes. The focus group was facilitated at the University of Nevada, Las Vegas (UNLV). This research project did receive UNLV IRB approval, # 711580-2.

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. All participants in the focus group were audio taped. Interview questions were semi-structured so the facilitator could ask further questions into the topic. The following questions were asked:

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?

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, and a lunch voucher to use at the campus dining hall. Email addresses and phone 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 transpired as the action of disassembling the research data into

thematic pieces. The first step in the *New Beginnings* data analysis process was the immersion into the narrative data to grasp the entirety of what was divulged during the interviews. Once the data was collected, researchers reviewed auditory data for a clearer understanding of preliminary key concepts and meanings.

The next step involved transcribing the interviews into documents to allow for transcription analysis. The transcriptions were carefully examined multiple times by both researchers for concise translation thus, ensuring the accuracy of transcriptions for data analysis. The researchers performed manual transcription to allow for data immersion at an intimate level. The in-depth focus group's dialogue was audio taped and transcribed verbatim. It was followed by line-by-line coding and included an inter-coder process to resolve any differences through consensus agreement (Schreier, 2012). There was 90% agreement between coders and all differences were resolved.

The analysis of themes allowed researchers to aggregate information into large clusters of ideas and provide details that supported the themes. The collected narrative data that shared a relationship created interrelated categories. The researchers grouped central categories and essential topics together. The analysis led to the emergence of similar key perspective that final narrowed into common themes. The common themes transcend the participant cases and provide an understanding of the diabetic social support complexity found within the data (Creswell, 2007).

Results

The study's emerging themes aligned with structural concepts within the Social Cognitive Theory (SCT) framework. These concepts included three areas: personal factors, environmental factors, and behavioral factors. It should be noted that while all three influences may be present, this does not preclude that they are symmetrical. In-depth data analysis and synthesis provided 4 major emerging themes: (1) Impact of type 2 diabetes, (2) Disease Knowledge and Perceptions, (3) Healthy Behaviors, and (4) Family/social support. The qualitative data contributed reliable information from the perspective of the participant rather than the perspective of the researcher.

Theme 1: The Impact of Type 2 Diabetes

Understanding how participants perceived diabetes and the everyday struggles of living with diabetes helps anchor the direction of the diabetes

education curriculum. When asked if diabetes was an issue for American Indians, the study participants agreed that indirectly or directly, it has an impact for American Indians and their families. One focus group member stated:

I feel like the ball is in my court and... I see the writing on the wall with both parents being both type 2 and it's up to me! I need to dance more, I need to exercise more, I need to do portion control, [and] I need to cut out Dr. Pepper!

The 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 AI/AN's may be at higher risk to develop type 2 diabetes. One respondent commented about the status of her family's health:

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.

Similar to the findings of other studies (Jones et al., 2012; Lautenschlager & Smith, 2006), participants of this study believed genetics was one of the major causes of diabetes. "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."

Theme 2: Diabetes Knowledge and Perceptions

Many urban-dwelling AI/ANs seek health care services from those that work directly or indirectly with the population, e.g. Indian Health Services (IHS) or other urban Indian health organizations. Some participants described their status of health based solely on what they heard from their healthcare provider. Participants who were previously diagnosed with diabetes and living with the disease had more knowledge about diabetes than those that had not been diagnosed. The study found one participant who was not receiving the satisfactory services she expected from her doctor. This participant disclosed that she was not getting the response she wanted:

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 [the doctors] 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.

Theme 3: Lack of Healthy Behaviors

Managing type 2 diabetes can be time consuming and extremely challenging. For the participants in this study, time was seen as a barrier. Most of the participants of this study are mothers and reported having to balance their work schedules while taking care of household responsibilities. It was reported that these demands often make it difficult to actively care for one's self. Other studies had seen similar results from other ethnic groups such as African Americans (Chlebowy, Hood, & LaJoie, 2010), Mexican Americans (Afaible-Munsuz, Mayeda, Pérez-Stable, & Haan, 2013) and First Nations peoples in Canada (Hernandez, Antone, & Cornelius, 1999) all of whom perceived time as a barrier to health.

Healthy eating and food intake education is one of the foundational elements of diabetes management (CDC, 2017). The focus group participants were knowledgeable about the healthy and unhealthy food choices they should be making. Portion control was one of the topics of concern to the focus 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 necessary skill that is vital to all diabetic patients and their families. One participant said, "Not that I don't know how [to eat], I just get out of control when it's something I like." Some participants found portion control difficult because they reported cooking in bulk size to help with their budget. One participant added, "I'm not a very good cook unfortunately, to stretch money I tend to make big meals that will last a few days and a lot of that consists of pastas, rice, [or] breads."

Theme 4: Family and 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 individuals with type 2 diabetes to stay motivated and make appropriate health choices. 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 diagnosis allowed for her to change her lifestyle.

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!"

Conversely, a few participants indicated they were receiving little family support mainly because they did not want their issues to be a burden on others. Likewise, one participant from the current study indicated she had little support from her family said, "...they have their own life, their own business, with their kids and stuff like that."

Empowering others about diabetes. A key theme that stemmed from the discussion about diabetes was the empowerment to self-manage diabetes for themselves and family members. Empowerment and self-management of diabetes includes independently making the correct decisions about health and lifestyle. The participants in the study were able to hear from others whom had learned from their mistakes. One participant concerned about her medical information from her health care provider stated, "I guess I feel more strength to tell them, 'No, you have to tell me.'"

Another 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. The participant reported:

[My 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 got to

go to the library to check out books on these things, it's the only way I'm going to learn.

Follow-up Results

After concluding the study, two pre-diabetic participants were contacted via email or by telephone to ask follow up questions in regards to the decisions they have been making to help reduce their chances of getting the disease. All the participants were sent an email requesting if they could comment about the changes made after the study. One participant responded in an email about her current status:

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. A late resolution of mine [was] 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.

As the email suggested, subsequent to the study, the participant made some behavioral modifications in her daily routine. She eliminated soda from her diet and made the effort to be healthy and active by enrolling herself in "The Biggest Loser Kickoff" competition sponsored by the Las Vegas Paiute Tribal Clinic.

A second participant was contacted by telephone for an interview and was asked several questions. The first question asked was, "I wanted to know if you made any changes after the diabetes discussion we had?" The participant said,

Yes. Within 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 every day 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 [soy] milk. We started eating more salads. Instead of using sour cream we went to a Greek yogurt. Instead of ice cream we switched to [soy based] frozen yogurt, just switching little things you know. We are just getting healthier foods into [our] 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. She is also making sure the surgery does not inhibit her activity. The second question asked, “Was it hard to make that transition?” She then replied,

No, because the [foods] 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 [soy] milk, but it gets used and it is 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 asked 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!” The final question for the participants was, “Is there any additional comments you would like to make?” The participant said,

I did make some notes after. It’s 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 we’re doing smaller portions. Before, we would have a big steak to ourselves. Now, it is

one steak cut into two, and now that’s plenty. It was helpful coming to the meeting and learning more things and [discovering] that there are healthier food choices out there.

The participant utilized a key point made during the diabetes discussion group: portion control was crucial to maintaining a healthy diet. This participant’s self-motivation to exercise has changed her attitudes and behaviors towards being healthier and being more physically active.

Discussion

Focus group discussions with urban AI/ANs who are currently living with diabetes and/or have family members with diabetes were conducted to better understand how they cope and manage life with type 2 diabetes. The study identified four key themes that emerged from these discussions including: the impacts of diabetes on their lives, how they perceived their knowledge of the disease, their health behaviors, and importance of family and social support. Various facets of urban-dwelling AI/AN’s personal, behavioral, and environmental factors can hinder or enhance positive health practices when trying to prevent or manage diabetes.

Individual responsibility in the prevention and management of diabetes was one of the facets identified relating to first two themes. Those individuals who were currently living with type 2 diabetes believed it was about the self; the responsibility of the individual to set their intentions to seek diabetes care, and educate themselves about the disease. However, the self-efficacy and empowerment of AI/ANs plays an important role in understanding how they will handle management of their diabetes. Studies suggest 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 et al., 2014). There can be a positive and significant relationship between health literacy (trusting healthcare providers), family, as well as social support and adherence to diabetes treatment (Miller & DiMatteo, 2013). Having access and knowledge about the nutritional and dietary skills is important for diabetes prevention and management.

Participants understood how important it was to make healthy food choices in managing diabetes. They 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. The brief education session provided by this study was seen as beneficial for bringing

awareness about the disease. Multiple studies have highly recommended utilizing culturally appropriate diabetes education when trying to target and aid particular lifestyle behaviors among AI/AN populations with type 2 diabetes (Cavanaugh, Taylor, Kiem, Maureen, & Geraghty, 2008; Dodge Francis & Chino, 2012; Struthers, Hodge, Geishirt-Cantrell, & De Cora, 2003).

However, some participants reported still finding it difficult to make the right choices or purchase the appropriate foods for living a healthy lifestyle because of money constraints. This is not uncommon. A study of type 2 diabetes interventions with two Northern Plains Indian reservations found that their participants also needed more exercise, more knowledgeable about the disease, and lacked appropriate actions for management of their own diabetes (Struthers, Hodges, Geishirt-Cantrell, & De Cora, 2003). This study's participants, living in an urban environment, were also faced with an even higher concentration of fast food chains, and are more prone to a sedentary pattern of life. Additionally, some participants expressed how crucial portion control is when trying to manage their diabetes. Portion size was seen as a barrier to positive lifestyle change. It is an important component for weight loss and controlling glucose levels. They mentioned overindulge in foods that they are fond of which were all high in sugars, carbohydrates, and fat. Previous studies have also found AI/AN adults who were diabetic were consuming higher-fat foods, possibly because of the lack of nutrition education efforts (Story et al., 1999; Lauthenschlager & Smith, 2006). Continued efforts to use culturally appropriate diabetes education can help bridge these gaps in nutrition knowledge and provide additional resources. Also, AI/AN culture considers food to be a traditional component rooted in spiritual and social circles of life. Many AI/ANs believe food is sacred and important to maintain harmony and balance. Reviving this concept of food could be a motivational tool to bring awareness to AI/AN communities in order to turn to traditional foods and live a healthier lifestyle.

Another area of discussion was how social support was associated with the participant's self-management proficiency and ability to cope with diabetes complications. When family members are not supportive, the participants reported facing challenges in managing their diabetes. A study by Mayberry and Osborn (2012) also noted this phenomenon where participants were frustrated with family members and their non-supportive behaviors; taking away from the participant's ability to self-manage and feel empowered. Having a social support system assisted participants in overcoming barriers

and managing type 2 diabetes. The participants share a true relationship of social support that is seen beyond this study; they became aware of each other's barriers and triumphs while managing their diabetes.

This social support is especially important for the participant's physical, mental, and emotional health. Social support and familial support allows for knowledge and information to be circulated. This focus group's findings have been consistent with previous studies showing a positive relationship between social support and diabetes self-management (Schiotz Bogelund, Almdal, Jensen, & Willaing, 2012; Shaw, Brown, Khan, Mau, & Dillard, 2013; Chlebowy, Hood, & LaJoie, 2010; Huang & Goran, 2003).

The participants were also seeking a deeper purpose and meaning to the disease and strived to be healthier and active on behalf of their children. As a result from the follow-up, a participant 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. Another participant 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 in the long run it would be the better choice.

Biases and Limitations

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

Despite these limitations, this study adds to the knowledge base about diabetes education in urban settings. It also makes a case for the importance of gathering qualitative data to support and gain insight

to urban AI/AN population about diabetes prevalence and incidence.

Conclusion

The findings from this study help to illuminate personal, environmental, and behavioral factors that affect health behaviors when trying to manage and cope with diabetes. 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.

Empowering at the individual and community levels is exceedingly needed because it can assist the urban AI/ANs to focus on their goals and gives them a sense of control over their health. Empowerment can provide a way to seek motivation and social support to improve their quality of life. Urban AI/AN populations have not received equal amounts of attention compared to AI/ANs who live on reservations. However, creating well designed, effective, and culturally appropriate diabetes education materials, through further research, and culturally sensitive public health professionals we can better serve urban AI/AN dwellers. Developing culturally appropriate diabetes material that focuses on empowerment will help encourage AI/ANs to keep striving towards healthier lifestyles; hopefully eliminating or reducing type 2 diabetes among urban AI/ANs.

References

- Afable-Munsuz, A., Mayeda, E. R., Pérez-Stable, E. J., & Haan, M. N. (2013). Immigrant generation and diabetes risk among Mexican Americans: The Sacramento area Latino study on aging. *American Journal of Public Health, 103*(5), e45-E52. doi:10.2105/AJPH.2012.300969
- Bandura, A. (1977). Self-efficacy: Toward a unifying theory of behavioral change. *Psychological Review, 84*(2), 191-215. doi:10.1037/0033-295X.84.2.191
- Bandura, A. (2004). Swimming against the mainstream: The early years from chilly tributary to transformative mainstream. *Behaviour Research and Therapy, 42*(6), 613-630. doi:10.1016/j.brat.2004.02.001
- Bartholomew, L. K. (2011). *Planning health promotion programs: An intervention mapping approach*. San Francisco, CA: Jossey-Bass.
- Bradley, E. H., Curry, L. A., & Devers, K. J. (2007). Qualitative data analysis for health services research: Developing taxonomy, themes, and theory. *Health Services Research, 42*(4), 1758-1772. doi:10.1111/j.1475-6773.2006.00684.x
- Cavanaugh, C., Taylor, C., Keim, K., Clutter, J., & Geraghty, M. (2008). Cultural perceptions of health and diabetes among Native American men. *Journal of Health Care for the Poor and Underserved, 19*(4), 1029-1043. doi:10.1353/hpu.0.0083
- Centers for Disease Control and Prevention, & National Institute of Health. (2005). *New Beginnings: a discussion guide for living well with diabetes*. Retrieved from: <http://www.cdc.gov/diabetes/ndep/pdfs/132-new-beginnings.pdf>
- Centers for Disease Control and Prevention. (2011). *National diabetes fact sheet: national estimates and general information on diabetes and prediabetes in the United States*. Retrieved from: https://www.cdc.gov/diabetes/pubs/pdf/ndfs_2011.pdf

- Centers for Disease Control and Prevention. (2012). *Data and statistics*. Retrieved from <https://www.cdc.gov/diabetes/data/index.html>
- Centers for Disease Control and Prevention. (2017). *Diabetes basics*. Retrieved from <https://www.cdc.gov/diabetes/basics/index.html>
- Chlebowy, D. O., Hood, S., & LaJoie, A. S. (2010). Facilitators and barriers to self-management of type 2 diabetes among urban African American adults: Focus group findings. *The Diabetes Educator*, 36(6), 897-905. doi:10.1177/0145721710385579
- Creswell, J. W. (2013). *Qualitative inquiry and research design: Choosing among five approaches* (3rd ed.). Thousand Oaks, CA: Sage Publications.
- Dodge Francis, C., & Chino, M. (2012). Type 2 diabetes science and American Indian/Alaska Native culture: Creating a national K-12 curriculum prevention strategy for native youth. *Diabetes Spectrum*, 25(1), 23-25. doi:10.2337/diaspect.25.1.23
- Finucane, M. L., & McMullen, C. K. (2008). Making diabetes self-management education culturally relevant for Filipino Americans in Hawaii. *The Diabetes Educator*, 34(5), 841-853. doi:10.1177/0145721708323098
- Harris, S. T., & Pokorny, M. E. (2012). Living with diabetes: What patients are saying. *Care Management Journals*, 13(2), 46-50.
- Hernandez, C. A., Antone, I., & Cornelius, I. (1999). A grounded theory study of the experience of type 2 diabetes mellitus in First Nations adults in Canada. *Journal of Transcultural Nursing : Official Journal of the Transcultural Nursing Society / Transcultural Nursing Society*, 10(3), 220-228. doi:10.1177/104365969901000313
- Huang, T. T., & Goran, M. I. (2003). Prevention of type 2 diabetes in young people: A theoretical perspective. *Pediatric Diabetes*, 4(1), 38-56. doi:10.1034/j.1399-5448.2003.00022.x
- Jones, E. J., Appel, S. J., Eaves, Y. D., Moneyham, L., Oster, R. A., & Ovalle, F. (2012). Cardiometabolic risk, knowledge, risk perception, and self-efficacy among American Indian women with previous gestational diabetes. *Journal of Obstetric, Gynecologic, and Neonatal Nursing : JOGNN / NAACOG*, 41(2), 246-257. doi:10.1111/j.1552-6909.2012.01339.x
- Lautenschlager, L., & Smith, C. (2006). Low-income American Indians' perceptions of diabetes. *Journal of Nutrition Education and Behavior*, 38(5), 307-315.
- Mayberry, L. S., & Osborn, C. Y. (2012). Family support, medication adherence, and glycemic control among adults with type 2 diabetes. *Diabetes Care*, 35(6), 1239-1245.
- Mendenhall, T. J., Berge, J. M., Harper, P., GreenCrow, B., LittleWalker, N., WhiteEagle, S., & BrownOwl, S. (2010). The family education diabetes series (FEDS): Community-based participatory research with a Midwestern American Indian community. *Nursing Inquiry*, 17(4), 359-372. doi:10.1111/j.1440-1800.2010.00508.x
- Miller, T. A., & DiMatteo, M. R. (2013). Importance of family/social support and impact on adherence to diabetic therapy. *Diabetes, Metabolic Syndrome and Obesity: Targets and Therapy*, 6, 421-426. <http://doi.org/10.2147/DMSO.S36368>.
- National Center for Health Statistics. (2015). *Health, United States, 2014: With special feature on adults aged 55-64* (DHHS Publication No. 2015-1232). Washington, DC: U.S. Government Printing Office.
- O'Connell, J., Yi, R., Wilson, C., Manson, S. M., & Acton, K. J. (2010). Racial disparities in health status: A comparison of the morbidity among American Indian and U.S. adults with diabetes. *Diabetes Care*, 33(7), 1463-1470. doi: 10.2337/dc09-1652
- Rabiee, F. (2004). Focus-group interview and data analysis. *The Proceedings of the Nutrition Society*, 63(4), 655-660. doi:10.1079/PNS2004399

- Roubideaux, Y. (2013). *Statement of the Indian Health Services*. Retrieved from website: http://www.ihs.gov/newsroom/includes/themes/newihsthem/display_objects/documents/IHSFY2014InteriorAppropsHearing_031913FINALtestimony.pdf
- Schiotz, M. L., Bøgelund, M., Almdal, T., Jensen, B. B., & Willaing, I. (2012). Social support and self-management behaviour among patients with type 2 diabetes. *Diabetic Medicine*, 29(5), 654-661. doi:10.1111/j.1464-5491.2011.03485.x
- Schreier, M. (2012). *Qualitative Content Analysis in Practice*. Thousand Oaks, CA: SAGE Publications, Inc.
- Shaw, J. L., Brown, J., Khan, B., Mau, M. K., & Dillard, D. (2013). Resources, roadblocks and turning points: A qualitative study of American Indian/ Alaska Native adults with type 2 diabetes. *Journal of Community Health*, 38(1), 86-94. doi:10.1007/s10900-012-9585-5
- Story, M., Evans, M., Fabsitz, R. R., Clay, T. E., Rock, B. H., & Broussard, B. (1999). The epidemic of obesity in American Indian communities and the need for childhood obesity-prevention programs. *The American Journal of Clinical Nutrition*, 69(4), 747S-754S.
- Struthers, R., Hodge, F. S., Geishirt-Cantrell, B., & De Cora, L. (2003). Participant experiences of talking circles on type 2 diabetes in two northern plains American Indian tribes. *Qualitative Health Research*, 13(8), 1094-1115. doi:10.1177/1049732303256357
- Trombino, C. (2005). Changing the borders of the federal trust obligation: The urban Indian health care crisis. *New York University Journal of Legislation and Public Policy*, 8(1-2), 129.
- Tucker, C. M., Lopez, M. T., Campbell, K., Marsiske, M., Daly, K., Nghiem, K., ... & Patel, A. (2014). The effects of a culturally sensitive, empowerment-focused, community-based health promotion program on health outcomes of adults with type 2 diabetes. *Journal of Health Care for the Poor and Underserved*, 25(1), 292-307.
- Urban Indian Health Commission. (2007). *Invisible tribes: Urban Indians and their health in a changing world*. Seattle, WA: Urban Indian Health Commission.
- U.S. Census Bureau. (2010). *American Indian and Alaska Native summary file, Census 2010*. Retrieved from <https://factfinder.census.gov/faces/tableservices/jsf/pages/productview.xhtml?src=bkmmk>
- U.S. Department of Health and Human Services. (2014). *Trends in Indian health 2014 edition*. Retrieved from https://www.ihs.gov/dps/includes/themes/newihsthem/display_objects/documents/Trends2014Book508.pdf