

**Utilizing the Socioecological Model as a Framework for Understanding Elder  
Native Americans' Views of Type 2 Diabetes for the Development  
of an Indigenous Prevention Plan**

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Disparities in overweight and obesity prevalence exist in many segments of the population based on race and ethnicity, gender, age and socioeconomic status. In general, the prevalence of overweight and obesity is higher among Native Americans.<sup>1</sup> Moreover, obesity is a risk factor for type 2 diabetes, which is a growing concern for Native American adults and youth who exhibit diabetes prevalence rates at more than twice that of the total population .<sup>2-3</sup>

To address health disparities among Native Americans in Oklahoma, our research team conducted formative research with 43 Native American women aged 20-78 years who were eligible to receive Supplemental Nutrition Assistance Program (SNAP) benefits, formerly known as the food stamp program, or Food Distribution Program on Indian Reservations (FDPIR) benefits, commonly referred to as commodity food benefits. The intent of the formative research was to utilize social marketing principles to identify local understanding as it pertains to health product, promotion, price (including benefits and barriers of health promotion behaviors) and place factors for the development of a social marketing campaign.<sup>4</sup> Participants in our previous research identified diabetes as the major health concern for Native American families. Although overweight and obesity were mentioned as health concerns, the connection to diabetes was pervasive throughout the research. Results from preliminary research also indicated that Native American women prefer intergenerational health programs. Further, participants identified Elders as important change agents for health improvement. Similarly, Orians et al. (2004) identified that “successful outreach messages emphasize the importance of elder women in the social fabric of the community.”

The Social-Ecological Model can be used to provide a conceptual framework for understanding health behaviors of Native Americans and can assist in development of planning and evaluation of multiple component nutrition and health programs.<sup>6-8</sup>

Findings from our preliminary research with Native American women living within the Chickasaw Nation boundaries support the use of an ecological perspective as nutrition and health behaviors were described as being affected by multiple levels of influence, including individual, interpersonal and environmental factors.<sup>4</sup> Lessons learned from the Native American Pathways study further support our use of an ecological perspective in that interventions in this study addressed environmental change, individual and cognitive behavioral change as well as family level changes for obesity prevention among Native American children.<sup>9</sup>

Formative research has been used “to make intervention programs both culturally and geographically appropriate”.<sup>10</sup> Health interventions which involve community members and build upon culturally bound knowledge are necessary to improve the health status of Native American families by ensuring “delivery of health care that is culturally appropriate and relevant to families and communities”.<sup>11</sup> Collaborative efforts are necessary among community members and community programs, such as the Chickasaw Nation: Get Fresh! Program which provides nutrition education opportunities for limited resource Native American families by means of the Supplemental Nutrition Assistance Education Program (SNAP-Ed) funding.

The results of our preliminary research in coordination with the findings of others, presented cogent reasons for the utilization of formative assessment approaches to investigate the role of Elders as possible change agents for improved health. The objective of this research was to identify individual, interpersonal and environmental factors which influence health from the perspective of Native American Elders. The proposed research specifically addressed the following priority areas in the RIDGE request for proposals:

- Proposals identifying innovative and successful ways to cope with special challenges to American Indians/Alaska Natives, including transportation, multiple locations to apply for benefits, delivery models, etc.
- Proposals which investigate model policies and successful educational delivery models addressing obesity, diabetes and other diet-related health conditions for American Indian/Alaska Native populations.

## **RESEARCH GOALS AND OBJECTIVES**

The long-term goal of this research is to prevent diabetes among Native Americans living in the Chickasaw Nation boundaries through a better understanding of individual, interpersonal and environmental aspects of Native American Elders' views of diabetes prevention. The objectives of this proposal for attainment of the long-term goal were to:

1. Frame diabetes from the perspectives of Elders who live in the Chickasaw Nation and
2. Begin development of a diabetes prevention plan based on the role of Elders as agents of health change. The rationale underlying this investigation was that indigenous involvement is necessary to gain insight into the complex reasons for the

disparate occurrence of diseases such as diabetes among Native Americans.<sup>12</sup> Key objectives of the research were to frame the prevention of diabetes from the perspective of Elders who live in the Chickasaw Nation boundaries and to develop a diabetes prevention plan jointly with Elders based on the information shared.

## **RESEARCH METHODS**

The research design was qualitative and included group discussions and storytelling interviews. Group discussions and storytelling interviews were lead by a moderator (Dwana (Dee) Robertson or Stephany Parker). An assistant moderator (Teresa Jackson or Stephany Parker) was present for group discussions, but not for storytelling interviews. The assistant moderators and moderators had training and prior experience conducting qualitative research with Native American populations. To honor tradition and culture, as well as facilitate an open environment for sharing, the moderator and/or assistant moderator were of Native American heritage for all phases of the research.

Group discussions were audio-recorded while storytelling interviews were both audio- and video-recorded. All audio-recordings were subsequently transcribed verbatim. Transcripts were analyzed using thematic content analysis.<sup>13</sup> Initial coding was conducted at a line by line level to identify relevant themes. The researchers then used in vivo codes to describe themes in order to preserve the symbolic markers of participants' speech and meanings when applicable.<sup>13</sup> Focused coding followed and consisted of categorizing data at the theoretical level.<sup>13</sup>

The current research was iterative and designed in four phases to build upon that which was learned in each phase of the research to inform the subsequent phases. Elders who participated received a \$50.00 cash incentive for their participation in each phase. The Oklahoma State University Institutional Review Board and the Chickasaw Nation Institutional Review Board (CNIRB) approved the final research protocol and study procedures.

**Recruitment procedures.** The researchers originally proposed to randomly select Elders 60 years of age and older, from a list of individuals receiving Chickasaw Nation Food Distribution Program on Indian Reservations (FDPIR) benefits and who lived in the Ada, Oklahoma area. However, after review of the research proposal by the CNIRB, recruitment procedures were revised. The CNIRB required that Elders voluntarily sign up at the FDPIR sites to protect and respect the anonymity of Elders on the FDPIR lists. As such, sampling procedures were revised to convenience and purposive sampling as opposed to the original random selection process.

**Phase 1.** The aim of the first phase of the research was to determine individual spheres of influence related to diabetes prevention. The semi-structured script was developed by the researchers to explore Elders' views of perceived severity, perceived susceptibility and cues to action in relation to type 2 diabetes. Elders who signed up to participate at the FDPIR store were called by telephone and asked to participate in a group discussion about their views of diabetes prevention. For this phase of the research, Elders who agreed to participate were assigned to groups according to diabetes status. A total of seven group discussions were conducted in this phase

consisting of four to ten individuals per group discussion. A total of five groups were conducted with individuals diagnosed with type 2 diabetes and two groups were conducted with individuals without diabetes.

**Phase 2.** The aim of the second phase of research was to explore personal and family experiences with diabetes. Individuals were purposefully recruited for this phase of research because they were perceived by the researchers to have especially meaningful insight related to the diabetes experience in the Native American community. Individuals who participated in this phase were video-taped individually and asked by a moderator to share stories about their diabetes experiences. Eight individuals were recruited to participate in this phase consisting of four individuals with diabetes and four individual without diabetes.

**Phase 3.** The aim of the third phase of the research was to further explore environmental spheres of influence related to diabetes prevention. The semi-structured script was developed based on the findings from the previous phases and was intended to delineate Elders' views of promotion of diabetes prevention, including ideas for how Elders might facilitate the implementation of change. Elders were recruited to Phase 3 of the research from those who agreed to participate in Phase 1. A total of five group discussions were conducted in this phase. Each group discussion was composed of six to nine individuals. For Phase 3, participants were not grouped according to diabetes status because researchers surmised that responses did not differ according to diabetes status in the previous phases of the research.

**Phase 4.** The aim of the fourth phase of the research was to facilitate the development of a diabetes prevention plan using a round table format. A total of six round table

discussion groups were conducted. Each discussion group consisted of 7-13 individuals. For the first three round table discussion groups, Elders were presented with seven programmatic ideas based on the findings from the previous phases. The ideas were presented in random order to minimize order effect and the semi-structured script was developed to determine Elders' views of the benefits, barriers and feasibility of each programmatic idea. The discussion ended with Elders rank ordering their programmatic preferences. Three additional round table discussions were conducted with Elders following analysis of programmatic preference. The intent of the last three groups was to further delineate procedural aspects of program implementation.

## **FINDINGS**

**Sample.** Participants provided demographic information for Phase 1 of the research only. A total of 47 Elders participated in the study with a mean age of 67 years. Approximately 60% (n=28) of Elders in the study indicated being diagnosed with diabetes and 72% (n=34) of the Elders were female.

### **The Diabetes Experience from the perspective of Native American Elders**

The research was designed as an iterative process with each phase building upon that which was learned in the previous phase. As such, the qualitative findings presented in this section are a summary of findings from Phases 1-4 of the research.

**Perceived susceptibility and severity.** Overall, Elders viewed diabetes as being a very serious disease impacting their family, friends and Native American community. An Elder who participated in Phase 1 of the research revealed the magnitude of the disease when she shared that “it [diabetes] *really runs rampant*. Like my husband’s

family, his mom, his three brothers, they're not considered overweight. Now granted their diets may not be that good. So I'm wondering if it's hereditary, and it kind of looks to me like *you eventually get it [diabetes] anyways.*" In general, Elders also shared a sentiment that diabetes is unavoidable. The impending nature of diabetes was shared by an Elder who stated "Thankfully I'm not diabetic *yet*, but I'm always thinking about it. Thinking, you know *is the next doctor's appointment going to be the one that they tell me?* It's just one of those things that you live with as a Native American."

Not only was diabetes often considered impending, but it was also considered a stigma with sometimes devastating and deadly consequences. Elders used words such as *brand, label* and *convicted* to describe the experience of diabetes. An Elder articulated the stigmatization of diabetes when she shared that "This diabetic sounds like ah, what do you call it whenever somebody's got a, *a brand, a brand, uh . . . the label, sounds like she's got a label* that diabetic and *it's hanging over her all the time.*" The consequences of having diabetes were also considered devastating to the physical body as shared by another Elder who commented " my brother had all of the ear marks, the *terrible things that you get from diabetes . . . one thing was he lost his sight at a young age, he, his heart enlarged, and then he had a charcoal foot, and that's where the bone starts to dissolve* and he would not let them *cut his leg off . . . He got MRSA in it, it's the infection that you don't get rid of.*"

As Elders reflected on why diabetes has impacted Native Americans, they shared *historic and generational trauma*<sup>14</sup> associated with the onset of the disease. A sense of

European and Western contamination of blood and ways of living were cited as negatively impacting the overall state of health and quality of life among Native Americans as expressed in the following comments:

“ . . . Native Americans didn’t have diabetes at that time and then all of the sudden here comes *this influx of mixing blood.*”

“ . . . I always considered that our tribe was, well the Indian races were prone towards diabetes because several hundred years ago *we had a rather drastic change in our society and our diet. As European influence came in we changed our diet, we changed the way we lived* and the truth is it takes years, generations for the human body to adapt.”

“No cause, it was like I said back during that day in time you didn’t hear about all this cancers and diabetes and grow they own food, you know their own gardens so I just think um, you know they say *money is the root of all evil*, so these companies and stuff where they supposed to put two tastes and something, they go and ask you know, *they’re trying to help themselves and killing us*, I think.”

European contamination was referred to as causing a shift in ways of living as well as value systems among Native American families. The following comments illustrate the generational trauma experienced by changes in ways of living and value systems:

“*The values have changed tremendously.*”

“... they[younger generations] *picked up on bad habits as far as drinking and doing drugs and smoking and all that*, I’m not saying that all that was bad, but *it was abused*, tobacco and everything, it was abused and the older crowd when they were raised up, *they[older crowd] were raised up different than the younger crowd now . . .*”

**Cues to action.** In general, Elders conveyed that physical complications associated with diabetes were the primary reasons individuals choose to undertake health promoting behavior changes. Physical complications were commonplace and often resulted in hospitalization and insulin treatment to manage diabetes.

“. . . he went to the *hospital for a week* and *they put him on two kinds of insulin* and he passed away at 59 . . .”

“*they rushed me to the [hospital]* and I *stayed there for 5 days* and then they said that um, they brought it down and they checked my deal and *kept checking and run test . . .*”

A sense of futility in prevention efforts was pervasive in many conversations with Elders.

Elders grieved the loss of friends and family members to diabetes and conveyed

feelings of despair as evidenced in the following comments:

“Well, *I’m upset with him that he didn’t take better care of himself*, I tried to talk him into it but you know he, he’s like most adults, he had his own mind about him and the truth is, it was his life not mine, it’s not my place to tell him how to live I just *had hoped that he would look at it different; had hoped that he’d get real serious* about trying to get it under control and he did not.”

“There’s really *nothing else you can do.*”

“. . . *I’m just depressed and I just don’t care* and you don’t suppose to be like that.”

Although Elders sometimes shared feelings of hopelessness and futility related to diabetes prevention, they also conveyed a strong sense of spirituality. Prayer was shared as a means to cope with the complications of diabetes as well as a means to bestow a more hopeful outlook on diabetes for future generations.

“I tell you what you can do, *the best thing to get out, that is prayer.*”

“. . . even though I’m taking medication for my nerve, they call it diabetic nerve pains, it’s very painful sometimes, I can’t think at night, I get depressed sometimes I have to get up, and like she said, *I pray about it, yeah, and I just deal with it.*”

“. . . just like they said they pray and that’s what I do, *I pray all the time and I go to church all the time, I just take it one day at a time . . .*”

“...I’m the kind of person that, *I will pray with you, I will talk to you about things...*”

**Behavioral capability and self-efficacy.** Elders demonstrated a feeling of *internalized blame*<sup>14</sup> associated with diabetes that impacted behavioral capability and self efficacy. Elders sometimes faulted genes or current ways of living. As such, behavioral capability related to diabetes prevention among younger generations was often bleak.

“... [Diabetes] *may be hereditary... susceptible genetically... we came from a background that had different diets* than what people in Europe [had] ...”

“Well, it’s just the way they [younger generation] eat, *they were brought up eating that way* and they just can’t seem to change the way they eat, and it’s hard for them, it’s hard for anybody [to know] what to eat and *they know it’s bad for them, but they, that’s just the way they eat all their lives, you know.*”

“I believe there’s enough information out there, but *people are just not listening to it.*”

In general, Elders recommended that education begin at a young age to foster the development of healthful eating behaviors throughout life because “them youngsters, by the time they get out of high school, they feel like they’re much smarter than them old folks, they’re not going to pay attention anyway.” Furthermore, they suggested that nutrition and health education in general should be less complicated and family oriented.

“...just *make it simple enough...sometimes there is too much information.*”

“I’m talking about *simple exercises*, like yard work...it’s a number of things. exercise...eating...spiritual ceremonies...”

“...we need to be educated about our diets *from the time that we’re small children...*”

“Um, it would be something if they could ah, with the people that has diabetes, they had someone to participate to send out a *letter to a family* and ask if, you know *could have a session with your family*, you know that would be a good start.”

Self efficacy was identified in the tradition of responsibility and honor ascribed to Elders as well as in the custom of intergenerational knowledge translation to youth.

Sentiments were such that youth are the future and are worth the time and investments necessary to improve their overall health. Elders shared fond remembrances and stories about how they learned from their parents and grandparents and conveyed a desire to re-engage youth of the current generation in such traditions.

“ ... from this experience [my aunt’s diabetes], I began to try to tell [my grandkids], let’s go in this direction, let’s eat right...*they’re now passing it on to their children.* And so this thing going to go and they’re going to be really healthy...and health wise.”

“...I learned ...*from my mom, well, my grandmother, too.* Because...she was always telling me stuff and *I always listened to Grandma. She was my hero.*”

“We’ve got to be able to let our young people know that they are important enough to invest some caring and thought into them, into their lives, to guide them in the ways that are appropriate for good health management...*Kids are precious, they’re our legacy...*educate others about their worth. *Educate people about their worth.*”

“...*Cause we’re responsible for those children too,* when we’re in a crowd, *that was tradition with the Chickasaws.* With all Natives, they were all like that, we’re responsible for all those babies. It didn’t matter whose baby it was, if you’re an adult, you take care of that baby like it was yours.”

**Partnerships and support.** Overall, Elders felt that prevention of diabetes among youth should start at home. At the same time, Elders acknowledged the challenges of implementing and maintaining healthful behaviors in the household. Elders felt that parents would need an encouraging environment and a support system to help parents instill healthful behaviors in their children as illustrated in the following comments:

“Everybody, we all *need attention,* we all *need someone to encourage us,* we all need someone to you know just um, like you’re talking about maybe, possibly the single mother. *Encourage her, promote her,* when you promote someone you’re building them up, you’re giving, you’re *helping them to feel so much better about*

*themselves, when you're, when a person feels good about themselves they pass it on. You pass it on."*

*"We all have to pull together, I mean it would have to be a family thing, everybody agree on it and, and try to do their part in it, I don't know what kind of things to do but you know."*

Although Elders generally felt that improved health should "start at home", partnerships at the community and systems levels were often referred to as more likely solutions than individual and interpersonal ones. Many Elders communicated a feeling that their traditional roles have been disenfranchised as a result of changing traditions and imposed shifts in ways of living. Expectations for modern conveniences and fast food consumption on the part of younger generations were viewed as being a barrier to changing behaviors as well as promulgating a disconnect between the values of Elders, their children and grandchildren.

*"You're going to try to help your kids and teach them what to eat what not to eat and do everything that you can do and then get in the car or something and you see fastfoodX pass and fastfoodY so how can you, *how can you help somebody that doesn't want to help themselves? Even though you know how bad it is.*"*

*"I got my grand kids that about wear momma out, every day they come home from school *they want 2 dollars here, 2 dollars there* either that, *they want a salary*, they already figured the salary they get they going to use it on food at, they ain't going to lunch they're going to stores."*

*"I'm just sitting up here and listening to, but I think ah, I think what they learned to eat like vegetables, I got 3 grandkids, they won't eat nothing, they want to go to fastfoodX you know or this, this quick food stuff and *you could put the food out for them and they won't eat it*, they'll just sit up there, ya'll get through, let's go to the store, let's go to you know, but ah I don't know what to do with something like that, their 14, 15 years old, *don't want to eat the cooking stuff you put on the table you know.*"*

*"my great granddaughter, she's 12 years old, when she comes home from school what does she do? She goes to the kitchen, sees what she can find in there to eat and *if it's not anything sweet, well she starts hollering.* We'll tell her there some apples, there some oranges and you know just different things that we try to keep on them, but you can't do it all the time."*

Moreover, imposed and unwelcome intervention into household affairs was viewed as negatively impacting the roles and responsibilities of parents and grandparents.

*“The state would be after you. That’s what’s the matter today I think.”*

*“Well you’re going to have to start the parents at it, even in school, got to stopping it, ever see you mistreating one of them kids ah, for not feeding them they going to get you.”*

Duly, although Elders indicated that compulsory and punitive intrusion into household affairs such as parenting, childrearing and feeding practices were unwelcome, support from agencies and institutions into medical matters, food policies and educational expertise was viewed as essential to diabetes prevention.

*“Well when they go to these camps don’t have no pop machine sitting out there, you know it’s just water only that we drink here.”*

*“I think we’re going to have to start kind of like with the WIC program and them start teaching these new mothers about diabetes and about feeding the babies when they start feeding them food to feed them the right foods, cause if you start out feeding them the right thing then they’re going to continue to eat them as they get older.”*

*“Perhaps there could be more enhancement of health values in the classes in school because a number of children aren’t going to get the support they need at home, however much it might be desired.”*

*“I tend to agree with what she said about the educational facilities, that the truth is I’ve spoken to my children about it but I can only touch so many people by myself and the look in an organization that has a wide spread contact with young people, you’re just about going to have to go to either the educational establishment or the tribal establishment in some form to get a group that has contact with enough people to really get the word out on them on a big basis.”*

*“Like the nutritionist at the commodities. They’re professionals so they should know you know things that we don’t know. Like I said have a session and say well the 3<sup>rd</sup> month of, I mean the 2<sup>nd</sup> or 3<sup>rd</sup> week of every month you know we would have this meeting at whatever, whatever from whatever time to whatever time so if you want to learn how to do this and this and know this is really up to you if you want to go to learn how to protect your whoever.”*

**Strategies to prevent diabetes.** Elders indicated that a variety of educational strategies were necessary to prevent diabetes. The most preferred strategy was community gardening where families could have access to fresh foods that were not contaminated by processing procedures. Community gardens would also serve as a place for families to learn more about traditional food ways. Reality based programming sessions were next preferred where families could attend a session where they would learn about diabetes from those who have had the disease. Elders placed a great deal of value on personal experience with diabetes from negative to positive experiences. Elders recommended that individuals who had severe complications be invited to share the complications and what will happen if future generations do not tend to their health. They also recommended that individuals who have successfully managed diabetes come to share the positive aspects of diet and physical activity changes. The third most preferred strategy to prevent diabetes was diabetes talking circles. In this strategy, families would come together to talk about how to prevent diabetes and this strategy would also serve a means for people to express their feelings about diabetes using traditional talking circles and group support. Additional strategies with which Elders were in favor included church wellness groups, healthy living retreats and traditional storytelling related to healthy ways of the past. Elders conveyed a need to make traditional foods more healthful and indicated an interest in developing a traditional cookbook that might also include traditional stories about foods to be passed on to younger generations. Elders also implied that many aspects of the programmatic strategies presented could be combined which would allow for a more holistic and multi-faceted approach to diabetes prevention.

## **DISCUSSION**

Throughout the course of the current research, Elders conveyed a genuine concern about the future health of Native American children. At the same time, Elders shared a general sense of being at a loss in terms of what to do to prevent diabetes in younger generations perhaps because of the repeated loss, internalized blame and historical trauma associated with the disease. Brave Heart and DeBruyn (1998) suggest “healing strategies that include modern and traditional approaches at all levels-individual, family and community.” The current research supports identification and use of healing strategies that address multiple levels of influence. Elders were insistent that not one program, strategy, agency or institution was sufficient to address the prevention of diabetes in youth. Partnerships and support were indicated as important interpersonal and environmental factors for the prevention of diabetes in younger generations. Tribal specific support was also mentioned as central to prevention and included locations for programming, incentives for participation and funding for diabetes prevention efforts. In addition to tribal support, family, religious, school and community support were also cited as necessary for prevention. Overall, Elders indicated most favor for diabetes prevention plans that were family, spiritual and tribal based.

## **POLICY RECOMMENDATIONS**

Chino and DeBruyn (2004) report that for “many tribal communities, the conceptualization and implementation of capacity-building strategies are themselves disparate in that they are based on imported Western frameworks” and they further contend that “mainstream models, programs, and funding agencies too often assume

that tribal community members and practitioners can immediately begin to resolve an issue; they pay little attention to the social, cultural, historical, and political environment and to the time needed to build effective working relationships.”

Based on the current research, the researchers recommend that consistent and continuous federal support is necessary to address diabetes disparities experienced by Native American populations. Specific recommendations include: increase funding for tribal SNAP-Ed programming and Food Distribution Program on Indian Reservations Nutrition Education; alter SNAP-Ed guidance to make the funding source more conducive to tribal governments; address SNAP-Ed gardening allowances to facilitate and respect Native American ways of fruit and vegetable production and consumption; increase non-competitive funding opportunities for tribes to assess current dietary guidance and develop culturally relevant diabetes prevention programs; extend funding duration to allow for the time needed to build collaborations with tribal Nations as well as accommodate tribal and university institutional review board processes.

In addition to sustained federal funding and support, it is also necessary for agencies and institutions to define, or perhaps, redefine principles of practice related to diabetes prevention when working with tribal partners, similar to the principles of practice developed by the Centers for Disease Control and Prevention, Native Diabetes Wellness Program.<sup>16</sup> Furthermore, development of collaborative solution based diabetes prevention strategies in coordination with tribal partners that *acknowledge and*

address historical and generational trauma<sup>14</sup> and share a vision of hope<sup>16</sup> that diabetes can be prevented are necessary.

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