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Participant Experiences of Talking Circles on Type 2 Diabetes in Two Northern Plains American Indian Tribes

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Abstract

The Talking Circle, a culturally appropriate, 12-week educational intervention, was employed on two Northern Plains American Indian reservations to provide information on type 2 diabetes. In a phenomenological study, funded as a minority supplement to the Talking Circle intervention, the authors asked 8 American Indian participants of the Talking Circle to describe their experience of being an American Indian Talking Circle participant. Seven common themes describe the phenomenon of participating in a Talking Circle diabetic intervention. The Talking Circle technique was effective in providing information on type 2 diabetes through culturally appropriate community sharing. Type 2 diabetes is viewed by both outsiders and those involved as a chronic disease of the utmost concern in American Indian communities.

Keywords

American Indian; type 2 diabetes; Talking Circle; Talking Circle participants

Type 2 diabetes has attained epidemic status among the United States American Indian population (Bullock, 2001). Burrows, Engelgau, Geiss, and Acton (2000) have noted the prevalence of type 2 diabetes among American Indians in Arizona as the highest in the world. In the Northern Plains area, rates of type 2 diabetes among the American Indian tribes are also elevated. In North and South Dakota, Lee et al. (1995) found the true prevalence rate for type 2 diabetes to be 33% for men and 40% for women aged 45 to 74. The Indian Health Service reported the Northern Plains area rate to be 68.7 per 100,000 in 1994 to 1996 (a rate adjusted for miscoding of Indian race on death certificates). In comparison, the United States All Races rate was 13.3 per 100,000 in 1995 (Department of Health and Human Services [DHHS], 2000). These statistics are disconcerting and have prompted new approaches to address the prevalence of type 2 diabetes in American Indian communities.

Type 2 diabetes is a chronic disease that affects many facets of the individual, as well as his or her family and community. Traditional Western prescriptive models of diabetes care focus on adherence to a regimen (Cohen, Tripp-Reimer, Smith, Sorofman, & Lively, 1994). These models have not been successful and are inappropriate for indigenous clients (Hernandez, Antone, & Cornelius, 1999) and/or their communities. This being the case,

culturally appropriate interventions are required. One such intervention was designed and implemented, namely, Diabetes Wellness: American Indian Talking Circles. In it, researchers used focus group data collected from community members on four reservations to develop and implement a research intervention on two Northern Plains reservations, with the other two reservations serving as control sites. The double aim of the project was (a) to impart knowledge related to diabetic risk factors and (b) to improve self-management of type 2 diabetes. The Diabetes Wellness project used a 12-session educational curriculum that was designed for use among American Indian cultures and provided an integration of oral tradition, storytelling, and Western medical information in a Talking Circle format. The research project is being analyzed to determine its impact on type 2 diabetes knowledge, attitudes, and behaviors (Center for American Indian Research and Education [CAIRE], 1998), and research results will be published elsewhere. The findings presented here, in which the authors seek to describe the experience of Talking Circle participants, are a subset of the major research project. It is funded as a minority supplement by the National Institutes of Health (NIH), National Institute of Nursing Research (NINR), to the larger ROI grant: Diabetes Wellness: American Indian Talking Circles.

THE TALKING CIRCLE

The Talking Circle is an ancient resource still used by numerous American Indian tribes to construct collective decisions and carry out a group process. The Talking Circle was a customary cultural technique used by the Northern Plains tribes that participated in this research study. In this research intervention, the Talking Circle format created a culturally appropriate avenue to convey information to Talking Circle participants; oral tradition and storytelling provided the educational foundation. The Talking Circle format has been used to teach culture and traditions (Cesario, 2001), and for health education and promotion (Hodge, Fredericks, & Rodriguez, 1996; Hodge, Pasqua, Marquez, & Geishirt-Cantrell, 2002; Strickland, Chrisman, Yallup, & Squeoch, 1996). Noted past research has demonstrated congruence between the integration of health education and a cultural custom such as the Talking Circle.

During a diabetes wellness Talking Circle, the Talking Circle participants, who numbered between 5 and 20, sat in chairs placed in a circle. The Talking Circle facilitator led, guided, and maintained the group process by first creating a comfortable environment that emphasized safety and confidentiality. Next, the Talking Circle facilitator welcomed everyone and asked someone in the group to offer a prayer to the Creator (higher being). The facilitator then delivered information on a specific type 2 diabetes topic from the curriculum. The Talking Circle was opened to all; each participant was given the opportunity to speak, and many told traditional stories and/or a story about their experiences. A Talking Circle participant, when speaking, may hold a feather, rock, or other symbolic item. During this time, the speaker takes the lead in sharing experiences, stories, and information with the group. While one person speaks, the facilitator and the other Talking Circle members respect and support the speaker by honoring them, being present, and attending to their words (Struthers, 2002). After each person has had a chance to contribute, the facilitator summarizes the events, and the Talking Circle is closed.

WINNEBAGO AND PINE RIDGE RESERVATIONS

This research study was conducted on a Nebraska American Indian reservation and on a reservation in South Dakota. A brief description of each reservation follows.

Winnebago Reservation

The Winnebago Reservation encompasses 30,747 acres and is located in rural northeastern Nebraska, with a small portion crossing over into western Iowa. The Winnebago Reservation is a sovereign nation governed by an elected Tribal Council. The Winnebago people maintain a strong culture, and cultural activities and practices are customary. Languages spoken are Winnebago and English (Mni Sose Intertribal Water Rights Coalition, 2002b). The population of the reservation is 2,600 (Winnebago Tribe of Nebraska, 2002). According to the 2000 census, 37% of the population was not in the workforce, 23.1% of families lived below the poverty line, and the per capita income was U.S.\$10,091 (Census Bureau, 2002b).

Pine Ridge Reservation

The rural Oglala Lakota Pine Ridge Reservation, population 17,775, is located in southwestern South Dakota on 2 million acres. Languages spoken are Lakota (one third of the population speaks Lakota as its first language) and English. The tribe is a sovereign nation and is governed by an elected executive committee (Mni Sose Intertribal Water Rights Coalition, 2003a). The Lakota people possess a strong culture, Lakota life way is usual, and the Black Hills are the spiritual center of the Lakota people. Economically, the Pine Ridge Reservation has been deemed the poorest area in the United States (American Indian Relief Council, 2002). According to the 2000 census, 48.8% of the population was not in the workforce, 46.3% of families lived below the poverty line, and the per capita income was \$6,143 (Census Bureau, 2002a).

Both the Winnebago and Lakota tribes (a) were historically removed from their original homeland and forced into a reservation location, (b) are rural, geographically isolated sovereign nations, (c) have some level of acculturation and/or assimilation to the European culture of the United States (Leininger & McFarland, 2002), and (d) receive their health care and health education from the government-operated Indian Health Service (DHHS, 2000). It can be determined from the descriptions provided that these reservations are representative of rural U.S. reservations and thus have many similarities, even though slight differences are noted, as would be expected among different tribes.

METHOD

Research Design

A culturally appropriate model, Diabetes Wellness: American Indian Talking Circles, used the Talking Circle format in an intervention providing education and dialogue on type 2 diabetes. Four community member peer facilitators who had expertise in the culture were hired and trained by the Diabetes Wellness Talking Circle principal investigator on Talking Circle facilitation and in various aspects of type 2 diabetes as a disease. Two were Lakota (and fluent in the Lakota language), and two were Winnebago. The facilitators wore many hats. The functions they fulfilled included (a) coordinating Talking Circle times and meeting places, (b) ensuring that healthy food was served at each Talking Circle, (c) recruiting and retaining the Talking Circle participants, (d) delivering the educational curriculum, (e) leading and expertly guiding the ensuing Talking Circle discussion in the old oral tradition, and (f) collecting research data and measurements. During the course of the diabetes wellness project, the 4 Talking Circle facilitators led 16 Talking Circles, each consisting of 12 sessions. Nine of these took place on the Pine Ridge Reservation and 7 on the Winnebago Reservation.

The Talking Circle participants consisted of 147 American Indian community members living in the Porcupine District of the Pine Ridge Reservation and on the Winnebago

Reservation. They participated in a 12-session Diabetes Wellness-Talking Circle. Of the 147 participants, 75 were Lakota community members and 72 were Winnebago people. Two neighboring reservations served as the control group, receiving usual diabetes care and health education. During the 12 sessions, the Talking Circle participants received educational information on many aspects of type 2 diabetes. These included general information regarding type 2 diabetes, facts on nutrition, and discussion of healthy lifestyles as they relate to the physical, mental, and emotional sides of the human being. Family and community features were covered as well. See Table 1 for an overview of the Talking Circle curriculum guide (CAIRE, 1998). Flip charts were used during each session to guide the educational process and ensure that the same information was presented to each group.

The research team collected data on the 12 Talking Circle sessions during a written, self-administered pretest and posttest after obtaining written informed consent. During the first or introductory session, the pretest was completed and individual anthropometrics were taken. At the conclusion, in the 12th Talking Circle session, a posttest and anthropometrics were obtained again. Later, with participant knowledge and written informed consent, research staff reviewed clinic health charts of Talking Circle participants for specific data.

Research Design of the Minority Supplement, “What the Participants Experienced”

We used descriptive phenomenology, a qualitative research approach, to answer the research question What are the experiences of American Indian Talking Circle participants? During open-ended, taped interviews, 8 American Indian Talking Circle participants (4 from the Pine Ridge Reservation and 4 from the Winnebago Reservation) shared their Talking Circle experience. During the interviews, the Talking Circle participants were prompted with additional questions if necessary, to elucidate a full explanation of the experience. See Table 2 for a list of the interview questions.

A qualitative research approach like phenomenology is a preferred method because it is compatible with traditional ways of knowing, as it examines the relationships and the whole (Crazy Bull, 1997). Phenomenologists examine the lived experience, or the meaning of a phenomenon, its essence (Oiler, 1982). They ask, What is this or that kind of experience like? (van Manen, 1990, p. 9). Using phenomenology, researchers attempt to capture what people and their lives are actually about, without setting up preconceived categories into which this information might or might not fit. Phenomenology is a research methodology used when nothing, or only little, is known about the nature of a selected phenomenon (Munhall, 1989). Thus, phenomenologists ask, without any schematic framework or prior expectations, What is it like when such-and-such happens to you? How did you feel in this particular situation? What, in other words, is the human nature, the existential experience, of a given phenomenon? What, then, is the phenomenon in the case at hand, and in this article? It is the experience of participating in a Talking Circle, where this Talking Circle is used as an intervention to supply education about type 2 diabetes to American Indians living on specific reservations.

Participant Recruitment

The purposive research sample consisted of 8 American Indian people residing on the Pine Ridge or Winnebago reservations who participated in 12 sessions of the Talking Circle intervention. The research study participants were chosen by Talking Circle facilitators using the following criteria: (a) participation in all 12 sessions of the Diabetes Wellness: American Indian Talking Circles research project, (b) good knowledge of the working of the Talking Circle, and (c) the ability to reflect on the experience and communicate the results to the researcher. The Talking Circle facilitators contacted the potential research participants and asked if they would like to be interviewed about their experience in the Talking Circle.

If they agreed, their phone numbers were given to the researcher, who then called and explained the research study. The participants were told they would be asked to describe their experience of being a participant in the Talking Circles and would be interviewed in person once or twice by the researcher at a site of their choice. Some Talking Circle participants might find it unethical or inappropriate to discuss what occurred in a Talking Circle. If this was the case, the participants had the option to decline research study participation. They were told that partaking in the study was in no way mandatory and that they could withdraw at any time without adverse effects from the University of Minnesota or from their tribe. The study acquired approval from University of Minnesota and from the Indian Health Service Institutional Review Boards.

Data Collection

The researcher collected the data during one or two open-ended and free-flowing interviews that lasted from 30 minutes to 1½ hours. She interviewed 2 research participants twice and 6 a single time. She obtained from the Talking Circle participants written informed consent and permission to tape the interviews. She then asked participants to describe their experience as a participant in a Talking Circle that gave information on type 2 diabetes, to say “what it was like.” The interview ended when the research participants had nothing more to say or describe. The interviews occurred in settings chosen by the participants and included various tribal reservation offices, homes and a Tribal Health Care clinic. Although the data reached saturation and became redundant after 4 interviews, the researcher continued until all 8 individuals had been interviewed. With the permission of the facilitators and participants, the researcher also observed two Talking Circles; this observation helped her understand the operation and mechanisms of the Talking Circle before the interviews took place.

Data Analysis

The first author, who is American Indian, used an emic, or insider (Leininger & McFarland, 2002), approach during data collection, data analysis, and validation of study results. Constant comparative analysis and phenomenological data analysis techniques taken from Colaizzi (1978), van Manen (1990), and Rose (1988) were used during the study. The steps of the process were as follows: (a) the first author conducted interviews to ascertain the phenomenon of participating in a Talking Circle diabetic educational intervention, (b) the audiotapes were transcribed, (c) the researcher listened to each audiotape while reading the transcripts to verify transcript accuracy, (d) she listened to the audiotapes a second time to get a good grasp of each participant’s tone and meaning, (e) she reflected on each of the audiotapes and transcripts separately to get a good intuitive grasp of the phenomenon, (f) she reread the first transcript and extracted themes with supporting significant statements, (g) the process was repeated for the remaining seven transcripts to compare and contrast descriptions of all research participants, (h) redundancies were eliminated, (i) the research participants received a summary of the final themes by mail and were instructed to contact the researcher by phone, mail, or e-mail to comment on and validate the results, (j) comments were integrated into the account, which thus described the experience of the interviewed Talking Circle participants. The second author, who is American Indian, also used an emic approach for review and approval of the seven themes.

Often, reliability in qualitative research studies is unwarranted and can weaken validity (Sandelowski, 1993). In this study, validity granted by the participants, not reliability, was the goal. Oiler (1986) has stated that validity is achieved when research findings are recognized to be true by those living the experience. Thus, validity occurred when Talking Circle participants verified the research results after being provided with a written summary of the results.

RESEARCH RESULTS

Participant Characteristics

The research sample of 8 Talking Circle participants was purposive. The interviews occurred on their home reservation between December 2000 and August 2001. The research participants were Lakota and Winnebago American Indians ranging in age from 40 to 70 years; they resided and worked in the community where the Talking Circles were conducted. Five of the 8 were female, and 5 identified themselves as having diabetes. Data collection included place of employment. This datum, however, is not reported for reasons of confidentiality because research participants live in small community settings.

Findings

Data analysis revealed seven common themes. American Indians perceive life through a holistic worldview (Lowe, 2002); thus, they view their world as interconnected within a large context. Accordingly, when responding to the interview questions, the research participants did not talk solely about their Talking Circle experience. They went on to reflect on how diabetes affected their life as a whole. Thus, the interviews provided a picture of the participants' experience of type 2 diabetes in their self, family, and community, as well as describing the experience of the Talking Circle itself. The seven themes are (a) living with, and surrounded by, diabetes; (b) exchanging emotions and feelings about diabetes; (c) receiving up-to-date diabetes information; (d) sharing experiences and stories; (e) obtaining guidance from the facilitator; (f) harmonizing diabetes using traditional indigenous methods; and (g) taking action to stabilize diabetes. Theme descriptions follow, with frequent quotes from the participants.

Living With, and Surrounded by, Diabetes—All the research participants described diabetes as being all around: within self, family, and community. Diabetes was “everywhere you go, and affected everybody.” It was depicted as a “silent killer” and as a “sickness that is affecting our people,” particularly the older ones. One participant estimated that half of the elders in his community were afflicted. Diabetes was portrayed in term such as these: “rampant in this generation,” “running in families,” “genetic,” and as “something in our makeup that goes into action when certain factors come together.” Causal factors were identified as things like being overweight, lack of exercise, stress, poverty, and socioeconomic factors.

Despite its terrible prevalence, however, type 2 diabetes is relatively new in Indian communities; the research participants thus searched for recollection of when it started, how it began, and why it happened. In the process of acculturation, “we had a sudden change in our whole lifestyle [in diet and activity levels].” One hundred years is not very long, it was felt, when you consider generations and the great process of adapting to mainstream America. One female participant said, “I never heard of diabetes back when I was a kid.” Another stated that, growing up with 12 brothers and sisters, they ate the right kinds of foods all the time, using little sugar.

That's why I don't know why I ever became to be a diabetic...I never did really hear about diabetes when I was young. Now, how or when all this started, I just couldn't tell you.... Now, most of us [my brothers and sisters] are diabetic.

Each participant stated whether he or she had diabetes and if family members had diabetes. “I have diabetes,” one speaker said, “part of the family has it and the other don't.” Another had a sister and another relative diagnosed this year with diabetes. One participant explained,

Both my parents were diabetic. My mom was blind and on dialysis. She died when she was 44 from diabetes. So, my kids didn't know their grandma, so that's sad.... I have been diabetic since 1988. So far, I am the only one of my family in this generation who has diabetes.

In another account, it was said,

My oldest son had it, my oldest daughter. Now my third oldest daughter has it... there's just so many of us here in the tribe.... I just think about my family and how it has affected us.

Five of the participants had type 2 diabetes and could tell when their blood sugar was elevated. From living with diabetes and from trial and error, they knew what nutritional choices, exercise, and stress relief were needed to normalize their levels, or whether, beyond these, health care assistance was necessary. When the blood sugar is high, "I get a headache and just don't feel good," one participant said. Said another, "If my blood sugar goes up, I can feel it. My vision gets blurry and I get light headed." The responsibility to control diabetes was expressed. "I guess it could kill a person if you don't watch it. You can control it, but you have to work on controlling it."

Another participant described her prediagnosis symptoms. She urinated all the time, she had a dry mouth and unquenchable thirst, her eyes got bad although she had no vision problems, her hair split, she was constantly tired, and she lost 60 pounds. She told a nurse friend about this, and the nurse said, "Let me poke your finger." My blood sugar was almost 500." At first, the individual

never really took it seriously. I just kept eating the things I wasn't supposed to...I blamed and was mad at my parents.... Every time I went to my appointments, my doctor would say, "How come your sugar is still high? Your pills should be helping you."

Diabetes is an intimate and personal thing. It was described as incurable, as being hopeless once you have it, and as a struggle, devastating, and a burden that limited what one could do physically. It represented uncertainty as well, "something that you just can't figure out what it's going to do to you. But you know your body will never be the same." Concerns loom as to who will be diagnosed next, and many believe "that they might get it someday." "It's something that is always there." Diabetes could occur at anytime, in any of us, it was felt. One mother said, "I have a son that is really overweight, so I worry about him getting diabetes. Because so many of my children are diabetic, the others who don't have it now are probably scared they are going to get it too."

Observing the effects of diabetes is a daily and inescapable event.

[My kids] see me giving myself shots. They see me poking my finger. I poke their finger and they don't like it because it's painful. I told them, "I don't want you getting diabetes, I want you to live a long time."

The complications that result from diabetes are highly visible. "My husband was diabetic. I seen how he just slowly, just slowly, went blind...diabetes just took over on my husband and that's what I seen." Compassion from others is reaped when they have seen the loss or seen the amputation, or you "start talking to somebody who has literally been through that." It really "gets in our hearts and in our minds." There is a constant witnessing, watching, monitoring, sensing, and thinking. One participant summed it up in this way; "God, you know, I really feel very bad about this situation."

It was felt that many deaths in the community were diabetes related, and thoughts of impending death from diabetes were prominent among the participants. One participant

strikingly described diabetes as “a death sentence.” Another stated, “My mother lived 15 months from the time she went on dialysis.... I stayed with her, so I watched her suffer.... I was there when she died, too.” There was concern over losing elders to diabetes. If the elders die, they cannot pass on knowledge about the traditional culture or be role models for the younger generations. This has significant consequences for the indigenous Indian culture. Thus, it is thought that the culture will die out perhaps, or become less. One woman described her husband, who “never thought he would make 50, because he has lots of family members who died from diabetes. But, he doesn’t have diabetes, he’s going to celebrate his 50th birthday today.” Truly, such an occasion is one to celebrate! According to one participant, the average survival age for a Nebraskan Indian man is 51 years old. Another described movingly how the community buries people because of diabetes. Then, we “come together, cry together and grieve together.” However, there is mutual support when diabetes strikes, and “there’s some personal satisfaction in your life when you’ve done the best you can for your relative that’s passed from diabetes.” Over and over, the research participants said, “It’s sad to see so many people lost to diabetes,” and many die young. One participant lived across the street from a dialysis unit. There, people with diabetes who are in kidney failure came to have their blood dialyzed three times a week. It is tough “watching these people come [to dialysis] all the time, a lot of them in wheelchairs,” knowing they are steadily dying. “We watch this every day—me and my wife.”

Exchanging Emotions and Feelings About Diabetes—The research participants expressed an array of feelings and emotional thoughts related to diabetes. These included sadness, loss, grief, keeping diabetes to yourself, worry, personal stress, stress from the reservation living conditions, feelings of being punished, denial, notions of self-infliction, emotional pain, anger, hopelessness, and shame. Like British Columbia Haida aboriginal people (Grams et al., 1996), the research participants expressed fear about diabetes. One said, “Quite honestly, it [diabetes] scares the hell out of you.” Undoubtedly, the Talking Circle provided a place to express and share emotions about diabetes. It “allowed people to talk about their feelings.”

Many references were made throughout the interviews to “sadness” related to diabetes. Feelings of loss and grief were also well known. Family members who had passed on because of diabetes were missed, and this caused people to feel sad. It is traumatic to lose loved ones over and over to the same disease. Grieving might not be completed or resolved, and the process remains fresh while all around you, others with whom you live slowly slip away from diabetes.

People who have diabetes are not always inclined to let others know about their disease.

After going to the Talking Circle, you kind of pick up on things, and I realized a couple of people in my department have diabetes. And they don’t let other people know. Which to me, may be a problem because if something happens to them, you don’t know what’s wrong. Now I am more aware and kind of watch out for them to see if things are good.

Another participant stated that diabetics are not always open about their condition. “I was one of those people.” The Talking Circle helped because “I’m a very private person. I don’t talk with anybody ... it made me open up.... I learned to get involved with people.”

In general, the research participants said they and others have a lot of stress and worry. Many thought that stress is intimately connected with diabetes. “I know stress has a lot to do with it [diabetes].” “Even the doctor told me, ‘Stress has a lot to do with diabetes.’” One participant had been through a lot in life and kept it all inside.

I had no self-esteem. I did not love or care for myself. I had thoughts of suicide. I went to treatment [for chemical health], and I had to let it all go, all the stress I had been carrying. From this, I thought, I brought it [diabetes] upon myself, that I made my own death sentence, If I knew of a way to release it [stress] and had somebody to talk to so I wouldn't carry all of that, maybe I would have never been a diabetic.

Another participant took care of her mother, who lived to be 101. This, at times, was stressful. "They say all the stress I had was what caused me to get diabetes." Everyday reservation life can be difficult and stressful, and people "are constantly worrying about something, worry about themselves and about other people."

Diabetes moved people to some interesting and significant conjectures.

I know you're supposed to be open to everything that you have. But, it [diabetes] is like a punishment. And I think some people may get angry at the Great Spirit because of this thing they have, this burden.

It was seen as "a curse on the Indian people for some reason." In that sense, "diabetes may not be good for our spirituality and our culture."

Denial surrounding diabetes was extensive. "We deny that we have it [diabetes] really" One participant said,

I was in denial. One day I was sitting and thinking, gee, this [diabetes] is with me for life. It's going to be with me until I die. I never really thought of it that way. So, I started taking it seriously...when I was diagnosed, I thought I was going to be like my mom who died from diabetes at age 44. But then I thought, Nope, I'm not going to be there. I'm going to live to see my grandkids grow up.

Another participant emphasized the emotional part of diabetes.

I just want to say that diabetes is a real emotional issue. My dad was diabetic, his brother was, his sister was and she had an amputation. As a result, we carry a lot of pain. I carry that [pain] too.

Many elders do not bother to eat properly or manage their diabetes because they feel hopelessness.

It's just not diabetes, I think it's just our life here...the anger...I remember my dad telling us kids (there was nine of us) that he was a diabetic. And he didn't know what that meant...there was no way to explain in Lakota what it really meant.... After he quit drinking, he told us he didn't know what using alcohol meant with diabetes.... There was nobody to talk to...I think he was kind of ashamed to have diabetes. And if you're ashamed, you don't talk about these things.

In contrast, the Talking Circle did give people a chance to express and share their feelings and emotions about diabetes. As a result, multiple positive thoughts evolved. "Last night when I came home from the circle, I felt good. I felt energized. I felt like I had accomplished something." Another said, "Just sharing the feelings. We spent a lot of time crying together. When we left, we felt good."

Receiving Up-to-Date Diabetes Information—All 8 research participants stated they acquired straightforward and comprehensible information on diabetes by attending and participating in the Talking Circle. They described the information received in the Talking Circle on diabetes as new to them, culturally appropriate, understandable, well put together, insightful, impressive, and long overdue. Others talked about information related to diabetes as traveling outward in a ripple effect as they passed on their new knowledge to family

members and others. In the Talking Circle, they learned diabetes was preventable and then identified diabetes prevention as essential. Beyond this, the Talking Circle provided for some the opportunity for a personal confrontation with diabetes. Many altered their lifestyle as a result of the Talking Circle experience. One participant summed up and spoke of the Talking Circle as “one of the most beneficial things that I could have done for myself in terms of diabetes education.”

Some Indian people think they have an understanding of diabetes because many people they know have diabetes. One participant said, “I thought I knew diabetes but from the Talking Circle, I learned it was more involved than what I realized.” Another said,

You kind of know that they do certain things with insulin and they have to watch their diet...and if they get bad, they go for dialysis...you know, they start losing limbs.... But there is a lot more to it than what I thought.... Some of the things pointed out to us had to do with the physical breakdown of the body, of the organs, and such.... To me, that was informative because I didn't realize why people had problems with infections and eye trouble, losing teeth, and all the other things that went with it [diabetes].

Participants found the detailed information about diabetes extremely beneficial, and one person said the Talking Circle was “really good for me and part of my family that sat in the circle.” For a person who did not have diabetes, realizing diabetes was preventable “was like a revelation. Like, I don't have to have it. And I just assumed I was going to...no matter what you do.” A person diagnosed with diabetes a couple of years earlier noted, “There was a lot I didn't know about it because I just became diabetic a couple years ago and it was a big help to me. I would say I learned a lot, spiritual-wise and everything.” Thus, it was good to “sit down and actually talk this out.” A participant who had had diabetes for 7 years declared,

I am surprised at the things I've learned recently. I should have known. And sometimes, I think, well, did someone tell me this before and I just didn't want to listen, or was I in denial about it? Or did I really get this information?

A change of attitude is sometimes necessary for the diabetic person.

This came with me getting really sick one time and deciding that I wanted to live. I really wanted to live, and I wanted to live physically as well as I could. I started taking better care of myself with that attitude. The information learned in the Talking Circles will help me accomplish my new desire to live.

The diabetes Talking Circles were long overdue, many of the participants found. “Why didn't we have this type of program a long time ago?” it was asked. One participant stated,

When I first heard they were having Talking Circles for diabetes, I thought, Gees, this should have been happening a long time ago. When I first became diabetic, they never told me. They never gave me any information on what to eat, what not to eat, what to do. It was just a paper stating what my pills were for. That was it. If I knew more information, and knew more about it, I would have taken it more seriously like I do today, And maybe, who knows? I would have never ended up on insulin.

A program for diabetes prevention was lacking in the community. According to one participant,

The Indian Health Service [our reservation health care provider] does not provide enough prevention. It's like when you really get sick, you go and they amputate. Or they increase your medicines...so, there's not enough education out there.

Because prevention is deficient and because so many people have diabetes,

It's kind of like a downward spiral...because so many people don't understand diabetes and a lot of them are stuck. They have feeling like I used to. "Oh, this is the end. You know once you have diabetes, forget it, that's it [it's over]" ...a lot of factors have to come together to make prevention happen. Like: having enough resources available and having role models of people who are living healthy lifestyles in the community.

Some workers from Indian Health Service tell us, "All you have to do is exercise and eat right. Eat fresh fruits and vegetables." And I was thinking, "Where do they think they are?" You know, it's totally unrealistic because our reservation living conditions are sad, our families are pitiful...It makes me angry to know they can say that to us in English, and you try to tell that to the person that has 12 kids to take care of, probably no vehicle, limited income, and they say that's all you have to do [exercise and eat right] and it [diabetes] would be prevented. But yet, we have all these challenges that we face every day. So, I'm thinking, "Get real here."

Information acquired in the Talking Circle is used every day by the Talking Circle participants. Many appreciated the visual aids, which showed amounts of fat, sugar, and salt contained in certain common foods. They felt this was good nutritional information.

The circle had an effect on my family because we started to pay attention to what we were eating, how it was prepared, what we did about going out to restaurants and fast food places. It caused us to change our diet to some extent.

Another participant said the Talking Circle information helped him to develop a program of his own.

Part of it was my need to not be diabetic, because so many of my relatives are, and I have watched them. Now, I'm 20 pounds lighter than I was before, I have chosen to arm myself with the tools that were available at the Talking Circle... Then, as a leader myself, I try to apply this throughout our community here...to cut down some of the myths about how everyone is going to get it [diabetes] because ultimately, diabetes is preventable.

Sharing Experiences and Stories—Generally, the participants described the Talking Circle as an enjoyable experience that provided a safe and comfortable environment where sharing occurred, questions could be asked, and people related to each other in a real American Indian cultural context. As a result, Talking Circle participants described a sense of closeness, a feeling of community, trust, opening of self, support, and the chance to share everyday, similar experiences. Assisting others around you is viewed as important. Sometimes, participants brought other family member to the Talking Circle so that they could receive the information directly and perhaps avoid diabetes. Sharing is vital, many thought, because "maybe I can help others."

A feeling of satisfaction evolved in the course of the Talking Circle as participants shared stories about family members and common experiences with diabetes in a supportive environment with others. There was an understanding, it was felt, at a deep cultural level. Talking and sharing deeply personal things had this result: A bond of real trust developed among the participants. "You realize you are not alone; a lot of people have diabetes and there's people around to help you. The Talking Circle got everybody talking, everybody opened up and people started coming out of their shells."

The sharing of personal stories in the Talking Circle was an experience described, as "phenomenal," by several participants. Hearing others tell "how they found out they had it

[diabetes] and how they feel about having it” built community. Participants realized they were part of a larger piece, part of a beautiful culture.

What really sticks out in my mind are the stories other participants shared. Personal stories, And what emotions I felt at that time. You know, like there was a lot of anger that some people have to live the way they do and not get what they should, or they are treated in such a way. Or the happiness that somebody shared and me feeling happy for them...also about the other community members and what they are experiencing.

Obtaining Guidance Front the Facilitator—It should be stressed that the Talking Circle facilitators knew the Talking Circle participants personally. This played an important role in recruiting the participants, keeping them engaged, and guiding the Talking Circle process. The facilitators provided a supportive environment, one that emphasized the necessity of confidentiality. All 8 people interviewed in this research study said they had been invited personally to participate in the Talking Circle by the facilitator. If they did not join right away, the facilitators kept encouraging them to become involved. In a small community, word of mouth is an effective vehicle. The Talking Circle was said to be a good thing, and people joined. In addition, the Talking Circle was held at convenient times to accommodate busy schedules.

Some participants joined the Talking Circle to help the facilitators. One man joined because his wife was a facilitator. A woman joined because her cousin was a facilitator and had invited her. “I joined in the beginning to support her...then ended up learning a lot and enjoying it.” Another joined because her sister was involved in the project; One couple came because a facilitator visited their house and “started to talk to us about this and that, and then talked to us about diabetes. That is how myself, and my wife, got involved in the Talking Circles.”

Harmonizing Diabetes Using Traditional Indigenous Methods—The American Indian culture is holistic; spirituality is an essential part of every day life, and communities possess ancient methods, techniques, and sacred practices that can be used to improve the outcome of diabetes. Currently, mainstream society labels these systematic and venerable procedures “alternative means.” In their interviews, participants described traditional methods that can bring balance and harmony to themselves and others. These included (a) prayer, (b) the use of traditional interpreters (traditional medicine people), (c) dreams, (d) traditional rituals to commemorate significant life events, and (e) higher levels of thinking that occur when a person is released from the ordinary and material world and, therefore, able to examine things within a spiritual higher level of wisdom. The belief in the Creator (higher being) was strong. “Even with diabetes, we learn to accept it, because you believe in the Creator. We all realize we’re not going to live forever and there’s a time set for us to transition to the spirit world [die].”

“Through prayer, things can happen.” Prayer was the most frequently acknowledged alternative method used. You get your help “from our Creator.” The participants prayed at various times for their loved ones, for others in the community, and for themselves.

I ask God to help me when I pray...I cry when I pray at night. Especially when I bring up diabetes. It is like the flu toughing everybody.... So, I always pray and ask God “Touch these people’s hearts. Touch their minds. Please tell them. Let them know it is a serious disease.”

“I just pray about it [diabetes] all the time,” said one participant. Another said,

I pray all the time...I pray about my health. Every morning, I pray for my family. And different ones in the hospital...I know the good Lord is taking care of me. Not only do I pray, I believe in my prayers.

American Indian people sometimes go to traditional medicine people (traditional interpreters). A research participant referred to medicine people as traditional interpreters because, she said,

I've been told they interpret because they are not the actual person's who's doing the healing. You know, it comes from someplace else. They help and I've been helped in that way. And I believe in that way. I've asked for medicine twice. I go to our traditional healer when I feel like I am out of balance and I believe it strengthens my sense of spirituality.

A participant told this story about traditional healing:

The medical doctors wanted to amputate my husband's foot from diabetes [an ulcer], but he wouldn't let them. He was in the Veterans Administration (VA) Hospital in Omaha and they wanted to amputate his foot on Monday morning. I went down there to see him on Sunday and he said to me, his wife, "Mom, you're going to check me out." He said, "I'm going to a medicine man in Wisconsin... because I'm not losing any of my limbs. I'm taking them with me when I go." So I checked him out of the hospital. I know the doctors came in, were talking to him, and were shaking their heads, saying "You know he shouldn't do it." The doctors called ahead to the VA in Toma, Wisconsin, to let them know that when we got to Wisconsin, that he would be in so much pain that they would amputate it [his foot] up there, in Wisconsin. I granted his request and we left the hospital and stopped at the Reservation along the way to pick up my brother. Then we left for Wisconsin. As soon as we got there, they took him into what they call the Long House. I couldn't go in because I was going through my change of life and I wasn't allowed in there, but my oldest son went in with him. Afterwards, we came home. Four days later, after we got home here, he took off the dressing they put on his foot and he called me from his bedroom. So, I went in and his foot was just completely healed. There was no sign of an ulcer or anything on his foot. He was healed. The healers gave us medication like a tea we were supposed to make and wash it [the ulcer]. So, he still had his foot when he died. He went blind after that and I asked him if he wanted to go to the medicine man and he didn't answer. It was just the idea he wouldn't have to lose a limb. But he didn't mind giving up his sight. And, I seen all this, so I experienced our traditional medicine and its remarkable ability to heal.

Dreams are important in the Native culture. According to a participant, her aunt was told in a dream that it was time for a transition.

My dad's sister was diabetic and had to have her leg amputated. When that happened she decided she did not want to live. Her father came to her in a dream and told her she would be joining him and so she decided that's when she would go. And that's when she went [died].

Another participant's son was paralyzed in a car accident that occurred while traveling to a rodeo as a passenger in a car driven by a drunk driver. All this was foretold in a dream.

Taking Action to Stabilize Diabetes—All the research participants discussed their role in alleviating diabetes and spoke of measures needed at various levels: culture, tribe, family, community, and individual. The participants saw their people and culture as threatened by

diabetes. It was felt most urgently that the time had come to start changing things, to “stand up and help ourselves.”

Culture is continuous, multidimensional, heterogeneous, and dynamic (Kagawa-Singer, 2002). Culture adapts, and is bound to modification, to ensure the survival of its members. However, even as it adapts and changes itself, it transmits its essential and inalienable worldview to future generations. The American Indian culture, like others, has adapted and changed to ensure its survival. Indian people “didn’t survive by staying in a mentality that wasn’t good for you, such as diabetes.” One participant stated the community as a whole needs to revisit and reexamine old traditions. For example, at memorials held for the deceased, much overeating is done. “We have all the things [food] we probably shouldn’t have at those things. Part of it is from our traditions.” The following questions, therefore, emerged during the interviews: How can we deal effectively with diabetes without altering the culture too deeply? How can we change traditional processes to more healthy ones? Who, finally, has the courage to do that?

Changes in daily habits were seen as necessary. Suggestions for healthy changes included preparing smaller portions of fatty food and serving healthier foods at frequent family get-togethers—birthday parties and so forth. Traditional foods from the old days were seen as good: corn grown in a garden, deer and buffalo rather than pork and beef. One participant discovered that if she ate a buffalo burger, her sugar stayed normal; when she ate a beef burger, it went up. Thus, having buffalo available in the store would be most helpful. Four of the research participants found it essential that important information reach the men, because most community programs are attended by women only. There are a number of single fathers, however, so a way to get information to them is essential. Along these lines, the Winnebago Head Start Program leadership decided to build on the Talking Circle’s work by setting up a college class on nutrition and diabetes. A certificate is given on class completion.

Young people are looked on in the Native communities as Tomorrow, the future itself. Their health now means a healthy community tomorrow. The younger generation, thus, was a source of major concern for many research participants, who thought that youth should be targeted and that diabetes education should be part of the school curriculum. More exercise for young people was felt to be necessary as well.

We now live in a society where things are readily available and accessible, such as Nintendos and VCRs. One time, I told my kids, “Oh man, you are so lucky. You just get up, go to the wall, turn the thermostat and you have heat. You can go to the bathroom and turn the knobs and have hot water.” Later on, I had to tell them they weren’t so lucky.

Turning a knob or clicking a gadget is not real physical effort. By way of contrast, 3 research participants spoke of the hard physical labor they did when young. They picked berries, hauled wood and water, gardened, and worked in the fields at a young age, earning money for the family. Children today do not do such things, it was observed.

A positive note is this: Schools at both research sites have begun to implement measures to counter diabetes. There is a screening program now for acanthosis nigricans, a dark thickening of skin in the neck or collar region, axillary (armpit), knuckle, or elbow area caused by hyperinsulemia. The presence and severity of the skin thickening indicates risk for type 2 diabetes (Stoddart, Blevins, Lee, Wang & Blackett, 2002; Stuart, 2000).

The outreach workers came to visit me because my kids had acanthosis nigricans. I thought, “Well, I’m diabetic, so I’ll teach them.” I don’t want my eight kids to be diabetic like me. I started talking to them, working with them. Now they’re aware.

Participants spoke of the personal changes they had made as a result of the Talking Circle education. “I changed my diet a little, and try to keep active.” A diabetic participant said,

I watch my diet, I exercise daily. I weighed 305 pounds, now I weigh 238. When I was 305 pounds, I had a hard time getting out of cars. I couldn’t run. I couldn’t walk. I walked 100 yards and I’m out of breath and stuff.... Right now, I feel pretty good.

Another person said, “I need to take that 30 minutes [to exercise]. I need to be concerned about that. I don’t want to have diabetes, because [to me] it means death.” Yet “knowing about it” and “doing something about it” are two different things. One participant, for example, admitted she was not where she should be in exercising to prevent diabetes;

The great and overarching question, finally, was this: “What are we going to do?” We need to think about the entire picture and how we can affect diabetes, it was felt. Many comments of a general nature were made. For example, measures of diabetes prevention have to become socially accepted. Certain ways of thinking might need to be modified. One participant stated that being overweight was sometimes viewed as a sign of success, as it signifies that a person has enough good food to eat, but was not helpful in the prevention of type 2 diabetes. Furthermore, a community leader who participated in the research noted that rigorous benchmarks and standards needed to be established that included visions of where the community is headed and a means of achieving outcomes, even if it takes 20, 30, or even 40 years. Diabetes is also an expensive proposition. Money is scarce, this leader noted, but the advantage this community has is

that it forces us, because we never have enough money, to be innovative. A lot of these innovatives don’t cost a lot of money ... but it’s getting the community to accept it. We need to arm ourselves with information and we need to access that information—collectively, as a community, as a people. The point blank question is “Do we want to live or do we want to die?”

One person wanted to find out why diabetes affects American Indians so much more than other people. Another said she yearned to “just go out there and take it away.”

One day, I heard these people talking, saying we need more dialysis centers. I said, “No we don’t need more dialysis centers. We need to start doing something about diabetes, we need to start talking.” I keep thinking, in a couple of generations, we won’t have such an outbreak like we do because we will change our lifestyle and our eating habits and become healthy people again.

Regaining balance and well-being was viewed as a necessity. One option to assist with this, according to many, was the Talking Circle.

DISCUSSION

In this qualitative research study, we have described the experience of participating in the Talking Circle intervention and related the perception of type 2 diabetes, through the eyes of American Indians living on two Northern Plain reservations. A phenomenological qualitative research approach is an appropriate method to use in Native communities (Crazy Bull, 1997), is a powerful tool for grasping community beliefs and thoughts (Meade, 2002), provides useful insights for developing appropriate diabetic care and education (Anderson, 2001), and identifies life priorities. When 8 American Indians were interviewed and asked to describe their experience of participating in the Talking Circle, the data clearly showed type 2 diabetes on American Indian reservations is a complex phenomenon that deeply affects human lives on a daily basis and extends to the cultural, spiritual, physical, mental, and emotional realms.

All the Talking Circle participants spoke of living with, and encircled by, type 2 diabetes. A similar description was given by urban Canadian aboriginal people with diabetes (Gregory et al., 1999), American Indians in Oklahoma (Parker, 1994), and Haida people residing in British Columbia (Grams et al., 1996). The Talking Circle curriculum provided essential up-to-date information on various aspects of diabetes and afforded an avenue for culturally appropriate, understandable facts on type 2 diabetes. This information might have been provided previously encased in a Western medical model or might not have been provided at all because of insufficient funding of the Indian Health Service. Certainly, it is essential to have up-to-date education about type 2 diabetes. Without this information, how can the client communicate effectively with health care providers? However, beyond this, the emotions and feelings surrounding diabetes must have an avenue for expression and release. Letting people tell their stories of illness, as well as their life, is therapeutic (Frank, 2000). For this to occur, a safe setting—and a culturally appropriate one—is needed. The Talking Circle provided a safe group environment where stories, experiences, sadness, grief, and hopes could be shared, along with other things that come in the wake of diabetes. Sharing with others is important for American Indians, who have a strong oral, as opposed to written, tradition (Hernandez et al., 1999). At the very heart of the Talking Circle project were the community facilitators, who recruited the participants, held them in the circle, and provided skillful guidance in a comfortable, supportive, and confidential setting. Among other things, the research participants described in their interviews ancient sacred cultural techniques that are still available today and that can help establish balance and harmony in the uncertain milieu of diabetes. Finally, the participants were convinced that everyone must take part in a great effort against type 2 diabetes and that it is necessary to search for culturally appropriate ways to prevent this epidemic, which is challenging communities, families, individuals, and, perhaps, the very existence of the culture itself. Community members are not living long enough to become elders. Soon, there might be no one left to impart traditional knowledge and maintain the American Indian worldview, with its very special spirituality.

IMPLICATIONS

As a chronic disease, type 2 diabetes is relatively new in American Indian communities (Garro, 1995). The Talking Circle participants in this research study talked about recent changes in lifestyle, diet, and physical activity. As well, Grams et al. (1996) found that food and eating, and loss of traditional ways were a concern among Haida people. Garro found that Manitoba Native people linked diabetes to environmental and social changes, and Hood et al. (1997) found Mohawk Indians were aware about lifestyle changes in their communities and their influence on diabetes. Still, how to provide effective ways to prevent and improve management of type 2 diabetes in a culturally appropriate manner is a question that looms large. American Indians communicate mainly through oral tradition, are community oriented, and perceive diabetes one way; Anglo-Americans, with a completely different background and ethos, perceive it another way (Parker, 1994). It comes as no surprise, therefore, that preventive measures that are effective in Anglo-American society might not be realistic in American Indian communities. Therefore, the solutions to the problems of diabetes for American Indians will be different from the customary ones of the mainstream society. Clearly, employment of new, comprehensive, and culturally based strategies is mandatory. Roubideaux et al. (2000) found that 95% of tribal leaders, Indian health professionals, and American Indian community members who participated in multiple focus groups expressed a strong preference for diabetes education materials to be relevant to their specific tribe or culture.

This particular research study demonstrates, from interviews with Talking Circle participants, that two tribes can effectively participate in a replicable yet culturally specific

intervention targeted to improve knowledge and management of type 2 diabetes. The model developed in the Talking Circles, which combines up-to-date Western medical knowledge with cultural stories and experiences presented by peers, was stated to be effective and accepted by the Talking Circle participants. It is a desirable cultural tool for encouraging people to really talk to each other, listen to each other, and support each other. Researchers and health professionals, however, should be aware of this: It might take years to structure and mobilize American Indian communities to successfully influence type 2 diabetes prevalence. As a consequence, the challenge continues.

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TABLE 1

Diabetes Wellness Curriculum Guide

Section	Title
1	Introduction
2	Diabetes, perceptions
3	Diabetes, facts and prevention
4	Diabetes, secondary prevention
5	Nutrition, basics
6	Nutrition, preparation
7	Nutrition, traditional foods
8	Healthy lifestyles, physical
9	Healthy lifestyles, emotional/spiritual
10	Healthy lifestyles, family
11	Healthy lifestyles, community
12	Closure

TABLE 2**Questions Asked During Interviews With the Talking Circle Participants**

-
1. Why did you go to the Talking Circles?
 2. Was anyone instrumental in assisting you to participate?
 3. When were you involved in the Talking Circles?
 4. For you personally, what does diabetes mean?
 5. What do you think causes diabetes?
 6. If you know your Native language, is there a word for diabetes?
 7. As you see it, how does diabetes affect your tribe and culture?
 8. Spirituality is an important part of Native culture. How does diabetes affect spirituality?
 9. Do you have diabetes?
 10. Where do you receive your health care?
 11. If you are at risk for diabetes, what do you do to prevent diabetes? OR If you have diabetes, how do you care for your diabetes?
 12. What do you most remember about the Talking Circles? In other words, what sticks out in your mind, what was powerful or awesome?
 13. Now that you have been involved in the Talking Circles, do you have any advice to offer others?
 14. Is there anything else you would like to say?
 15. Demographics: (a) age, (b) what is your tribe, and (c) place of employment—job title
- Probes like the following were used to clarify and deepen the interviews:
Please, tell me more. How does that thought relate to diabetes?
-