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American Indians' Family Health Concern on a Northern Plains Reservation: "Diabetes Runs Rampant Here"

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Abstract

Objectives—The objective was to identify significant family health concerns from the perspective of adult tribal members residing in a reservation setting on the Northern Plains of the United States. Findings were used to co-create culturally appropriate strategies to address the most significant family health concern.

Design and Sample—A focused ethnography within a participatory framework was employed. An advisory council, comprised of seven tribal members, guided the research team. A purposive sampling technique with a snowball process was used. Twenty-one adult tribal members volunteered to participate.

Measures—Face-to-face, audio-recorded, semi-structured interviews were conducted and transcribed verbatim. Other data sources included field notes of approximately 100 hours of field work, windshield surveys, and a focus group. Data were analyzed using Spradley's guidelines.

Results—The significant family health concern was "diabetes runs rampant here" with inter-related cognitive, emotional and behavioral responses. These responses were compounded by accumulated emotional trauma from witnessing premature deaths and severe comorbidities associated with diabetes. Contextual factors shaping "diabetes runs rampant here" were identified.

Conclusion—Holistic approaches are urgently needed in diabetes prevention and management programs. Implications for public health nurses are discussed and recommendations are provided for future research.

Keywords

Indians; North American; ethnography; culture; diabetes mellitus; family health; family nursing; public health

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Despite a clear connection between culture and personal health beliefs and practices, few studies have explored perceptions of health among American Indians (King, Smith & Gracey, 2009; Taylor, Keim, Fuqua, & Johnson, 2005). Health beliefs, values, and cultural practices are acquired within the lived family system (Barton, 2008a; McCubbin, 2007). In the American Indian (AI) population, “the concept of family is almost coextensive to that of the community. The community is formed of nuclear and extended families and one’s family is the core of a person’s identity...” (Tousignant & Sioui, 2009, p. 50). If family health issues are not accurately identified within the cultural context, service approaches may continue to be largely ineffective (Taylor et al., 2005). Thus, it was necessary to examine family health and family health concerns from the perspective of tribal members on a reservation located on the Northern Plains of the United States.

Background

Descendants of the original peoples of the United States are referred to as American Indians (AIs), Native Americans, Alaskan Natives, Hawaiian Natives, or Natives. In the United States, there are 562 federally recognized tribes (Stang, 2009). Approximately 1% of the American population is comprised of AIs with 43 tribes located on the Northern Plains (United States Census Bureau, 2010). In this region, AIs comprise up to 6.5% of the population (United States Census Bureau, 2010).

Health researchers identified that AIs fare worst in almost every health category as compared to other groups (Mendenhall, Berge, Harper, et al., 2010; Reid, Taylor-Moore, & Varona, 2014; Roh, Burnette, Lee et al., 2015; United States Census Bureau, 2010). Poorer health among AIs is associated with the history of colonization, poverty, malnutrition, poor hygiene, overcrowding, stress, and limited access to health care (Roberts, Jiles, Mokdad, Beckles, & Rios-Burrows, 2009). When examining social determinants of health, 98% of AIs served by Indian Health Service (IHS) met the federal poverty level guidelines (United States Senate Committee on Indian Affairs, 2009; Rodgers, 2009). Unemployment rates are 50 to 70% on many reservations. High school drop-out rates among AIs are almost double the national average (Chapman, Laird, & Kewal Ramani, 2010).

To gain a deeper understanding of health issues in tribal communities, health and illness experiences and beliefs must be examined within the family system and its contexts rather than solely from an epidemiological perspective (Barton, 2008a; McCubbin, 2007). Health disparities are concerning given the responsibilities delineated in treaty agreements between the United States government and the sovereign tribes (Roh et al., 2015; United States Commission on Civil Rights, 2004).

Research Objectives

Research objectives were: (a) define a healthy family, (b) identify significant family health concerns, and (c) determine strategies to address family health concerns from the perspective of adult tribal members residing on the reservation. The first objective was accomplished with a healthy family defined in terms of strong, social relations between its members (Martin & Yurkovich, 2014). In this paper, the second and third research objectives will be addressed.

Methods

Design and Sample

A focused ethnography within a participatory framework was the most appropriate research design to achieve the research objectives. While a focused ethnography provided core principles for conducting a valid study about the experiences of family health in this tribal culture, the participatory framework ensured that the project engaged tribal members (Varcoe, Brown, Calam, Harvey, & Tallio, 2013). While ethnography is used to describe a culture (Spradley, 1980), a focused ethnography, sometimes referred to as a mini-ethnography, is generally of a smaller scale and specific in its aim (Polit & Beck, 2012). A focused ethnography is organized around the premise that a culture is best described by the people within it (Polit & Beck, 2012).

The research team, comprised of the three authors, met with the Tribal Chair and Council and subsequently, a family health advisory council was established to guide the project. Seven tribal members volunteered to serve on the advisory council. The advisory council guided the formulation of research objectives, recruitment and sampling strategies, and identified initial, potential key informants (KIs). Collaboration was facilitated by monthly teleconferences, group emails, and three in-person meetings that occurred at the beginning, middle and end of the study.

Following ethical approval from the University of North Dakota and Indian Health Service and a signed resolution from the Tribal Chair and Council, recruitment began. A purposive sampling technique with a snowball process was used; KIs were selected on the basis of advisory council members' personal judgements about tribal members that would be most informative (Polit & Beck, 2012). Snowball sampling is an approach to locate information-rich KIs by asking well-situated people, "Who knows a lot about family health on this reservation?" (Patton, 2015, p. 298). Inclusion criteria were established; a KI must: (a) be over 18 years of age, (b) self-identify as a tribal member, (c) reside on the reservation on a full-time basis, (d) be able to understand, speak, and read the English language, and (e) be knowledgeable or experienced in family health. Recruitment of KIs ceased when data saturation was achieved as noted by no new codes and categories identified in the analysis of the transcript and corresponding field note (Polit & Beck, 2012).

Measures

Face-to-face, one-hour, audio-recorded, semi-structured interviews were conducted and used as the primary data source. Two researchers met with each KI at a mutually agreeable time and location on or near the reservation. Prior to the interview, the KI was provided with a consent form. Verbal consent was obtained; the consent form was not signed to eliminate a "paper trail." This procedure was employed to ensure that KIs' identities were protected with strict anonymity due to the nature of the small community. One researcher kept a list of KIs' names and mailing addresses, which was used to invite KIs to participate in focus group and then again to provide KIs with an executive summary of the study's findings.

Upon acquisition of a verbal consent, the interview began and a semi-structured interview guide was used. See Table 1 for the initial Discussion Guide.

Other data sources included windshield surveys and reflexive field notes. In community studies, researchers conduct a windshield survey (a tour of the community) to document observations about key structural features (Polit & Beck, 2012). Two windshield surveys were conducted to identify and document community assets and liabilities. The researchers spent approximately 100 hours on the reservation over a 12-month period to conduct interviews (25 hours), document their observations, thoughts, and feelings about family health (40 hours) and meet with advisory council members and the Tribal Chair and Council (35 hours). The research team met regularly to discuss the project. These discussions were audio-recorded and transcribed in the form of reflexive field notes that focused on the researchers' observations, thoughts, and feelings about family health on the reservation (Emerson, Fretz, & Shaw, 1995; Spradley, 1979, 1980).

Following analysis of the transcripts and field notes, the researchers provided feedback to several KIs about emerging interpretations and obtained their responses as a member check (Polit & Beck, 2012; Spradley, 1979, 1980). Five of the original 21 KIs volunteered to participate in a one-hour audio-recorded focus group. Prior to the focus group interview, a consent form was provided to each participant and verbal consent was acquired. A two-page document, summarizing preliminary findings, was circulated. The focus group was moderated by one researcher. The audio-recording was transcribed verbatim and analyzed to articulate penultimate findings.

The KIs, advisory council and Tribal Council received an executive summary of the findings. At the conclusion of the study, the researchers met with the advisory council, Tribal Council and local diabetes educators to co-create strategies to address the most significant family health concern.

Analytic Strategy

A qualitative data analysis software program was used to organize and manage data and support analytical comparisons. Researchers compared and contrasted identified domains in the first four transcripts and corresponding field notes and proceeded to independently analyze subsets of the data. Emerging domains were discussed at research team meetings and with advisory council members.

Field notes were documented throughout the study. The research team debriefed after every site visit to discuss and document their observations, thoughts, and feelings about family health. Field notes were analyzed in conjunction with the corresponding transcripts, using a process described by Spradley (1979, 1980). Ethnographic research requires constant feedback from one stage to another (Spradley, 1979). Data analysis proceeded through several levels including domain, taxonomic, componential, and theme analyses (Spradley, 1979, 1980).

The first step involved selection of a sample of verbatim notes about significant family health concerns. According to Spradley (1979), the "second step in the preliminary search is to look for *names of things*" (p. 104). "Diabetes is rampant here" was identified as the largest domain leading the researchers to revisit the data for characteristics associated with diabetes. To accomplish componential analysis, the researchers dialogued with advisory

council members to link personal responses to diabetes with the culture. Theme analysis included “a search for the relationships among domains and how they are linked to the culture as a whole” (Spradley, 1979, p. 84). Drawings were used to illustrate relationships among domains (Polit & Beck, 2012). The focus group and advisory council confirmed the domains.

Results

The sample consisted of 21 tribal members who volunteered to participate. Eighteen KIs were females and three were males, representing 14 extended families from an on-reserve population of approximately 16,500. Ages ranged from 21 to 62 years and KIs represented a variety of roles, including educators (K-12), retired or current health or social service providers, grandparents and parents.

Diabetes Runs Rampant Here

Diabetes mellitus was the most significant family health concern. Acquiring this chronic illness was synonymous with a “death sentence.” Cardiovascular disease, depression, vision problems, kidney failure, amputations, obesity, neuropathies, and chemical abuse were identified as comorbidities associated with diabetes. The severity of associated comorbidities was paramount. Witnessing family members’ experiences with diabetes compounded a complex interplay of cognitive, emotive, and behavioral responses as shown in Figure 1. By observing family members’ experiences of diabetes, this illness was known as painful, disfiguring, and deadly.

It [diabetes] affected everything...He had kidney transplants, one pancreas transplant and he had other complications too with the eyes with the treatment going blind, the neuropathies where the nerve endings are all just dying; the pain, always the pain in the extremities (KI 17).

A perceived origin of diabetes was also described by a KI within a historical context:

One of the ways that they thought ...the reason AIs are more prone to diabetes was because back in the days when they were hunters, they basically have only had access to rice and grains and meat and eat very lean meat like buffalo. And so we didn’t have all this processed food and that our bodies became accustomed to only making so much insulin... [We] never adjusted to the increases in sugar, in carbs (KI 2).

Genetic predisposition and lifestyle choices were acknowledged to affect intergenerational health.

If somebody had traced ... blood tests in 1908, 1910, you would find out that our kids were probably lean...and blood sugar is way down, cholesterol way down. All the... cardiovascular diseases were probably nonexistent. Over the course of 50 – 60 years, genetically, DNA and everything ... with us being sedentary now these diseases have just come up. I mean...our kids are being born with them (KI 4).

Several KIs identified that misperceptions were held by some tribal members regarding diabetes. See Table 2.

Acquiring or living with diabetes was associated with a need to alter one's lifestyle, which created a complex interplay of responses (Figure 1). Separation of the responses is artificial but necessary for succinctness.

Cognitive responses—Thoughts about the inevitability of being diagnosed with diabetes were shared: “We don’t care if we have diabetes - we are going to die anyway (KI1).” “I’m at risk for diabetes because my dad had it. Well, there is nothing I can do - I’m going to get it (KI 7).”

“Think it away” was a cognitive pathway that some tribal members followed when “pre-diabetes” or diabetes was diagnosed. “They pretend that they don’t have it [diabetes]. They try to ignore it and think that if they did that ...it’ll go away (KI 16).” Some tribal members believed that if they did not give credence to diabetes, then other family members would not “get it.” “Think it away” interplayed with emotive and behavioral responses.

Learning about diabetes after the diagnosis was another pathway described by some KIs. One KI shared that a relative was diagnosed with diabetes, and anger emerged because the individual diagnosed with diabetes then hears for the first time that diabetes may have been prevented by earlier lifestyle changes. Attitudes and beliefs about diabetes influenced emotional responses to diabetes.

Emotional responses—Fear, anger, denial, and feeling no control were identified as emotional responses to diabetes. Accumulated, emotional trauma compounded these responses. Family members’ deaths, known to be attributed to diabetes, shaped emotional responses. “All his grandmother’s brothers and sisters have died from diabetes (KI2).” By witnessing suffering, acting as caregivers, and experiencing numerous losses, emotional responses accumulated and compounded attitudes, beliefs, feelings and actions associated with diabetes.

To him, the biggest thing was changing fear. He was 28 years old when he found out he had diabetes...that made him angry. So it’s like, ‘well I don’t want to even acknowledge that I have it (KI5)’

In this instance, fear, anger, and denial were associated with resultant behaviors of “never checking his blood sugar,” and “he eats junk food...before he came here [workplace], we never had food here... [Now] we have cookies and donuts (KI5).”

“Feeling no control” over diabetes was equated with helplessness. Some KIs voiced that helplessness was also exhibited in family relationships. In some families, KIs identified that women controlled dietary intake and the men relied upon their spouses to provide them with adequate nutrition. Traditional gender roles enabled some men to relinquish responsibility and pass it onto their partner. Emotional responses were perceived to lead to adaptive or maladaptive behavioral responses.

Behavioral responses—Cognitively, it was understood that a diagnosis of diabetes would require a lifestyle change, which was sometimes synonymous with a loss of control.

Some tribal members were perceived to be resistant to change. A KI from the health care sector shared this observation:

‘Well we’re too busy. We work all day. And then we have to come home and wash clothes and clean house and do the dishes and whatever. We don’t have time to do it [change diet and exercise, manage their health].’ A lot of people just don’t want to put in that *extra effort* to do it. ...Like I said, change here ... to the people here in this town...change is bad (KI2).

Substance use and abuse was also identified as a response to diabetes. Some KIs spoke about denying diabetes by using alcohol or drugs.

Many KIs reflected upon their personal agency in taking action to address diabetes. “We are noting how strong the women are that were interviewed, how powerful they are. They know what is going on and their knowledge about the reservation and how power works on the reservation (Field note 24.7).” Role modeling a lifestyle that included nutritious food choices and fun activities in the schools were identified as effective strategies. Several KIs shared their perspectives that the youth would embody the changes and then teach the older generations.

Contextual factors shaping “diabetes runs rampant here”—These broad categories represented contextual factors that shaped “diabetes runs rampant here”: community assets and deficits. The most significant community asset was “our community is really a family-based community (KI19).” Family was identified as a support system to assist its members in various ways. Family members provided emotional, social, and spiritual support to individuals anticipating or living with diabetes (Martin & Yurkovich, 2014).

Additional assets were educational systems and resources to support religion and spirituality. Teachers provided learning activities related to proper nutrition and physical exercise. Grant-sponsored programs provided families with sports-focused and cultural events, facilitating knowledge translation about healthy lifestyles. Religious practices were discussed by the KIs and these practices were related to several belief systems. Spiritual practices based upon traditional AI beliefs were mentioned by those who had family members engaged in traditional ceremonies and rituals. KIs expressed that one’s spiritual practices did not always exclude a belief in the other. Community celebrations and ceremonies related to spiritual practices were perceived as venues to encourage tribal members to be caretakers of their physical and spiritual beings.

Poverty, unemployment, limited health and human resources, geographical isolation, policies, and politics were identified as community deficits. These factors intersected and shaped “diabetes runs rampant here.”

The majority of our families are low income families because we are an impoverished community. So when you think of them when they get food stamps around here because they have to ship everything and truck everything here – junk food is cheaper than the food that’s good for you...People who are not eligible for food stamps – they get commodities. Commodities are given by the government

and the reason that they get it is because ... in the Treaties it is listed that AI people will have medical, housing, food and shelter. It was all given to them in the Treaty. I know my parents were on commodities when I was young. And there was so much fat and sugar in all of that, that's why the kids start gaining weight (KI16).

Poverty and high unemployment interfered with accessing nutritious food and engaging in physical activities. Fast foods were readily accessible on the reservation with several restaurants and stores. Limited physical and human resources existed to support adequate housing, recreational activities and family health promotion. One KI shared that housing is an issue that is not readily recognized with limited tribal, financial resources to support new housing or recreation centers.

Health care was accessed mainly through IHS with a shortage of staff, especially in medical specialties. For example, tribal members who experienced vision problems were referred to agencies elsewhere in the state, with an additional financial burden to cover the cost of travel coupled with the issue that many tribal members lacked health insurance. Although diabetes education workshops were offered, KIs reported that they were poorly attended.

Geographical location was problematic in terms of a long winter season and distance from other communities and resources. "I think location and isolation is a big factor here." "[The Northern Plains] in general, seven months of winter can eat you alive if you don't know how to, you know, keep yourself healthy and especially your family (KI5)." Some KIs living on the periphery of the reservation spoke of having no transportation to connect with community resources and activities.

The local, political environment was described as needing leadership. Several KIs spoke about the politics of living in a small community. They shared that clusters of families dominate the decision-making processes, which was perceived as not benefitting the community as a whole. "I see the politics of a reservation as negative to our [youth]... You know there's so much politics that...anything you want to do on this reservation involves politics and not ability and that's not right (KI10)." The power of the federal and state government was acknowledged. "We have all these things in place for our tribe to get sovereign nation but the government still runs us (KI9)."

Discussion

The limitations of the study were embedded in the sampling technique. Utilizing a snowball process may have contributed to the recruitment of KIs with similar viewpoints. Transferability of these findings to other AI groups is therefore cautionary. However, the reliability and validity of the findings were strengthened by data triangulation, the participatory framework, the advisory council, and the third author's AI ancestry.

"Diabetes runs rampant here" fits with the escalating rates of diabetes in the AI population (Gracey & King, 2009; Jacobs, Kemppainen, Taylor & Hadsell, 2014; Stang, 2009). Loss of control associated with diabetes supported results from Jacobs et al.'s descriptive survey about AIs' beliefs of diabetes (2014). The resignation to acquiring diabetes was similar to other reports (Huttlinger, Krefting, Drevdahl, et al., 1992; Jacobs et al., 2014; Taylor et al.,

2005). When contemplating diabetes, some KIs described a coping mechanism of “think it away.” This finding was similar to a previous study among AIs, whereby avoidant strategies were passed on from generation to generation (Yurkovich, Hopkins & Rieke, 2012).

The KIs described a tribal culture with accumulated emotional trauma that compounded a complex interplay of cognitive, emotional, and behavioral responses to diabetes, which was an important contribution to the current evidence. Public health nurses are well positioned to facilitate identifying and managing accumulated emotional trauma. By conducting assessments that include a thorough family history along with an exploration of cognitive, emotional, and behavioral responses to diabetes, public health nurses can facilitate the healing process. Public health nurses could introduce the notion of a holistic approach and traditional healing by connecting interested tribal members with respected elders and healers (Bruyère, 2006; Ferreira & Lang, 2006; Roh et al., 2015; Yurkovich & Lattergrass, 2008).

Factors within the community context were recognized as inhibiting accessibility to, availability, and affordability of nutritious food, physical exercise, and health care. The “chaotic soup of politics” was described as consisting of jurisdictional conflicts and lack of communication between health care agencies and tribal leadership (Jorgensen, 2007; Yurkovich, Hopkins-Lattergrass & Rieke, 2011). In this study, KIs voiced similar concerns. Tribal members, public health nurses and other stakeholders must be involved in developing and implementing holistic approaches to prevent and manage diabetes. Multiple levels (individual, family, community, state, federal) must be invested and engaged (Gittelsohn & Rowan, 2011). Public health nurses can collaborate with tribal authorities to enhance inter-agency communication (Roh et al., 2015). Several scholars identified “nation building approaches” that include assertive decision-making, power backed by effective governing structures that match the traditional AI political culture, incorporation of strategic planning, and leaders acting as nation builders (Cornell & Kalt, 2007; Yurkovich, Hopkins-Lattergrass & Rieke, 2011). Establishing culturally relevant structures begins with a reintegration of spiritually-driven, holistic governing processes to promote a “healthier” tribal life (Yurkovich, Hopkins-Lattergrass & Rieke, 2011).

Findings were used as the basis for recommendations at the local level. These short-term strategies were identified to address diabetes: (a) consult local elders and healers to develop a holistic approach to diabetes prevention and management (Barton, 2008b; Mendenhall, Berge, Harper, et al., 2010; Taylor et al., 2005), (b) continue current diabetes prevention and screening programs that target youth, and (c) establish a local radio “talk show” about health to facilitate knowledge translation about healthy lifestyles among tribal members. “Diabetes education programs should be culturally and linguistically appropriate and designed in collaboration with the tribal community” (Tiedt & Sloan, 2015, p. 19). Long-term strategies are needed to facilitate sustainable economic development to address poverty, unemployment, food security, and housing.

Further research is urgently required. Explanatory models of diabetes in other AI groups must be explored (Everett, 2011; Ferreira & Lang, 2006; Huttlinger et al., 1992; Jacobs et al., 2014). A critical ethnography is warranted to explicate how health and social policies serve to disrupt or perpetuate health inequities among AIs (Roh et al., 2015). While a recent

systematic review identified that short-term health outcomes improve with culturally-based programs, longitudinal studies are needed to determine long-term effects (Attridge, Creamer, Ramsden, Cannings-John, & Hawthorne, 2014; Mendenhall, Berge, Harper, et al., 2010).

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Figure 1.
Person Anticipating/Living With Diabetes: Inter-related Cognitive, Emotional, and Behavioral Responses and Contextual Factors

TABLE 1

Initial discussion guide

Construct	Question
Family health	What are your family's most significant health concerns?
Public health	What is the most significant family health concern in this community?
Social determinants of health	What factors (e.g. historical, social, cultural, and political) shape/influence family health in this community today?
Social determinants of health	From your viewpoint, what are the barriers that prevent families from achieving their best health?
Personal agency and capacity building	What would help families be healthy?

TABLE 2

Beliefs about type 2 diabetes held by some tribal members

Question	Belief
Where does diabetes come from?	<ul style="list-style-type: none"> Everybody in our community is at risk for diabetes because everybody knows one person who has it (KI5). I know diabetes is pretty rapid here unfortunately (Focus Group).
How can diabetes be managed?	<ul style="list-style-type: none"> You can eat what you want – just have your insulin with you (KI1). I think that you, you have to have people who have done something about, about you know, because a lot of people think oh they have diabetes and they take shots so they can eat whatever they want (Focus Group).
What are the consequences?	<ul style="list-style-type: none"> Fear underlying the diabetes was an important issue that was coming forward all the time (Field Note, 23.07). They don't understand that it's building up...and in five years, there's going to be heart and kidney failure (KI2).