American Indian Diabetes Beliefs and Practices: Anxiety, Fear, and Dread in Pregnant Women With Diabetes

L.D. Carson,* J. Neil Henderson, Kama King, Keith Kleszynski, David M. Thompson, and Patricia Mayer

■ **ABSTRACT**

Diabetes among American Indian (AI) people is a health disparities condition that creates excessive morbidity and mortality. This research delineated culturally constructed models of type 2 diabetes among 97 pregnant women in two large AI nations in Oklahoma. The data analysis of explanatory models of type 2 diabetes revealed the participants' intense anxiety, fear, and dread related to the condition. The sample was further stratified by combinations of diabetes status: *1*) absence of type 2 diabetes (*n* = 66), *2*) type 2 diabetes prior to pregnancy (*n* = 4), and *3*) gestational diabetes (*n* = 27). Patients were interviewed regarding perceptions of the etiology, course, and treatment of diabetes. The research incorporated an integrated phenomenologic and ethnographic approach using structured and semi-structured interviews to yield both quantitative and qualitative data.

General findings comprised three main categories of patients' concerns regarding type 2 diabetes as an illness: *1*) mechanical acts (i.e., injections), *2*) medical complications, and *3*) the conceptual sense of diabetes as a "severe" condition. Specific findings included significant fear and anxiety surrounding *1*) the health and well-being of the unborn child, *2*) the use of insulin injections, *3*) blindness, *4*) amputation, and *5*) death. Paradoxically, although there was only a slight sense of disease severity overall, responses were punctuated with dread of specific outcomes. The latter finding is considered consistent with the presence of chronic diseases that can usually be managed but present risk of severe complications if not well controlled.

University of Oklahoma Health Sciences Center, College of Public Health, American Indian Diabetes Prevention Center, Oklahoma City, OK

*Also known as L. Carson Henderson

Corresponding author: L.D. Carson, Carson-Henderson@ouhsc.edu

According to the Indian Health Service, 16.3% of American Indians/Alaska Natives (AIs/ANs) have diagnosed type 2 diabetes, and 30% of AIs/ANs have prediabetes (1). These data indicate that AIs/ANs are 2.2 times more likely to have type 2 diabetes than non-Hispanic whites (1). AIs/ANs with diabetes are four times more likely than their white counterparts to experience an amputation as a complication of diabetes. They are six times more likely to experience kidney failure. In Oklahoma's 37 federally recognized tribes, 24% of AIs with type 2 diabetes experience diabetic retinopathy as a complication of their condition (2,3).

Regarding diabetes during pregnancy, the prevalence rate of gestational diabetes mellitus (GDM) is ~7% (4). The rate has increased in recent years among both AI and white pregnant women. Although the rate of GDM in AI women exceeds that in the white population (5), it varies greatly across tribes. In some AI/AN and Canada First Nations tribes, the rate may be as high as 15% (6). Findings from Acton et al. (7) regarding an analysis of data from 105 Indian Health Service units

identified a 46% increase in the type 2 diabetes prevalence rate in women of child-bearing age for the period 1990–1996. This represents a notable public health concern with diverse cultural, genetic, and political-economic variables.

Among all populations, GDM is a major cause of congenital anomalies, malformations, shoulder dystocia, neonatal hypoglycemia, and perinatal death (7,8). It places pregnant women at risk for hypertension, pre-eclampsia, premature birth, macrosomia, and an increased incidence of cesarean section (8–10). Unfortunately, research has also indicated that offspring of mothers with GDM are at an increased risk for obesity, abnormal glucose tolerance, and type 2 diabetes later in life (5,7,9). This increased risk has become an important variable in the perpetuation of high diabetes prevalence in AI/AN tribes.

When women are identified as having GDM, the first line of treatment is medical nutrition therapy (MNT) with dietary control, physical activity, and regular glucose monitoring. If glucose goals are not met, pharmacotherapy is implemented. Insulin is the pharmacotherapy utilized by the majority of caregivers. According to the American Diabetes Association's Standards of Medical Care in Diabetes—2015 (2), the potential risks and benefits must be considered because data are insufficient to establish the safe use of oral diabetes medications during pregnancy. In addition, an article by Rowan et al. (11) indicated that more research is needed regarding the long-term effects on children of the use of metformin during pregnancy. This statement was made in the context of the Metformin in Gestational Diabetes Offspring Follow-up study. Health care providers of the Choctaw Nation of Oklahoma and the Chickasaw Nation prescribe insulin and not oral agents because of the as-yet-unknown effects of oral agents on fetal outcomes (2,9).

Preliminary research suggests that one possible source for persistent and increasing type 2 diabetes prevalence is the presence of non-obvious psychocultural factors that impede the productive application of pharmacological, health education, and prevention tools. In our research, we conducted a further examination of contributing psychocultural variables.

Background

Beliefs and Practices: The Impact of Explanatory Models

One category of psychocultural factors operating to impede effective diabetes prevention and case management may be found in the divergent models of the condition held by practitioners and patients. Specifically, professional and lay explanations for disease, treatment, and prevention can vary radically. Kleinman et al. (12) labeled explanations for the etiology, treatment, course, and preventive measures for sickness "explanatory models" (EMs). For example, patients have their own multifaceted EMs and are influenced by members of their social networks. Likewise, providers have their own multifaceted, evidence- and practice-based EMs that are further influenced by their professional peer networks. Similar EMs facilitate communication and are associated with increased adherence to treatment recommendations and patient/provider satisfaction. However, EMs that are discordant between practitioners and patients may reduce effective communications and adherence to treatment recommendations, and negatively affect health outcomes.

Anxiety, Fear, and Dread: The Impact of Emotion

As a chronic illness, diabetes often arouses intense feelings of anxiety and fear among those diagnosed, those who have family or friends with the condition, and those who are at risk for developing it. Anxiety, fear, and dread are intense emotions that may influence whether people with symptoms of type 2 diabetes

seek treatment or resort to denial as a coping mechanism. Fears may be related to variables such as the self-care and pharmacological requirements and misconceptions relevant to these variables. This was apparent in two studies by L. Henderson (13,14) involving AI elders with type 2 diabetes, in which there were large components of denial, avoidance, and nonadherence among the elders' peer group.

Methods

Recruitment and Inclusion Criteria

In this study, 97 pregnant participants from two Oklahoma AI tribes were interviewed to gather information about variables that may negatively affect the prevention or control of GDM. The participants were AIs as evidenced by a Certificate of Degree of Indian Blood (CDIB) card, pregnant, and receiving care from the tribal health care systems. Subjects recruited could 1) be without diabetes, 2) have GDM, or 3) have type 2 diabetes prior to pregnancy (PGDM). All aspects of the study protocol were reviewed by the institutional review boards of the University of Oklahoma Health Sciences Center, the Chickasaw Nation, and the Choctaw Nation of Oklahoma.

Data Collection

This study used qualitative research methods involving semi-structured interviews for data collection. Patients were interviewed using the Diabetes in Pregnancy Questionnaire, and all interviews were digitally recorded. Interviews were transcribed using professional transcription services.

Diabetes in Pregnancy Questionnaire

The questionnaire was derived from prior research of the principal investigator and co-principal investigator (L.D.C. and J.N.H., respectively) with Oklahoma AIs and from literature on explanatory model elicitation (12,14–17). The questionnaire was utilized in two prior studies and successfully elicited research-valid,

culturally based responses. The questionnaire consisted of the following sections: 1) Demographic and Social Characteristics, 2) Medical History (self-report), 3) Explanatory Model Elicitation, 4) Provider/Patient Interactions, and 5) Degree of Cultural Identification Questionnaire (DCIQ).

Individuals' degree of cultural identification (DCI) must be considered for many reasons. Within contemporary AI society, some people adhere largely to cultural systems existing in the distant past, whereas others remain proud of their tribal identity but adhere mainly to mainstream American culture. The result is that cultural heterogeneity is wide-ranging and varies by situation and context, including the context of the health care setting. The DCIQ was created using variables that correspond to traditional AI cultural identity, based on prior research. Developed by one of the authors (L.D.C.) it was utilized by the research team and others in multiple studies (13,14,17).

Data Analysis

Specific variables of interest were initially identified by conducting an extensive review of the literature regarding AI populations, type 2 diabetes, PGDM, GDM, and patient/provider communication across cultures. Coding was aided by computer software Atlas.ti (Atlas.ti Scientific Software Development, Berlin, Germany). Coded qualitative interview data were analyzed for responses regarding fears of self-injection of insulin, amputation, dialysis, blindness, and death and concern about the child as a result of type 2 diabetes complications. Responses regarding these fears were coded as "present" or "absent."

In addition to the qualitative data, questionnaire items yielded a number of discrete variable categories that were categorized and ranked. Quantitative data included diabetes status, family members with diabetes, age, tribal affiliation, degree of

TABLE 1. Two-Tailed Spearman's Rho Correlations for Age, DCI, and CDIB

Variables	n	r	P
Age			
Diabetes status	96	0.280	0.006*
DCI score	96	0.185	0.072
CDIB	93	0.098	0.349
DCI Score			
Diabetes status	97	0.140	0.170
CDIB	93	0.298	0.004*
CDIB			
Diabetes status	93	0.268	0.022**

*Correlations are significant at 0.01 level. **Correlation is significant at 0.05 level.*

Indian blood (per CDIB percentage), expressed fears, and a DCI score that ranged from "acculturated" (0) to "traditional" (6).

Nonparametric statistical analyses, conducted using SPSS software (IBM Corp., Armonk, N.Y.), used ranked scores to determine correlations and relationships between CDIB percentage; DCI; age; diabetes status; fears of self-injection, amputation, blindness, dialysis, and death; and concern about risks to the child. Spearman's rho rank correlation coefficients were used to test for correlations among the variables DCI, CDIB, age, and diabetes status. Wilcoxon tests were used to determine differences in age, CDIB, and DCI among respondents who cited fears compared to those who did not.

Results

Characteristics of the Sample

The sample included subjects with GDM (*n* = 27), subjects with PGDM (*n* = 4), and pregnant subjects without any form of diabetes (*n* = 66). The designated sample size in each subject category was predicated on the prevalence of each within this population: pregnant women without diabetes having the highest prevalence, women with GDM the next highest

prevalence, and those with PGDM the lowest prevalence. Age and parity were followed as covariates. Thirty percent of the sample were pregnant with their first child. The average age of participants was 25.03 years (SD 6.1330).

Statistical Correlations

Several statistically significant positive correlations between certain variables were identified. Age and diabetes status were positively correlated. Diabetes status was also positively correlated with CDIB, with those having a higher degree of AI genetic loading also having an increased incidence of diabetes. CDIB and DCI scores were also positively correlated, with those identifying as more traditional having a higher percentage of genetic loading. There was no significant relationship between age and either DCI or CDIB, nor was there a relationship between DCI and diabetes status (Table 1).

Fear of Neonatal Complications

In the research presented here, fear of neonatal complications was the number one fear cited by our respondents, as shown in this example:

> **Interviewer:** "Are you worried about your baby for any reason?"
> **Participant:** "I was scared to
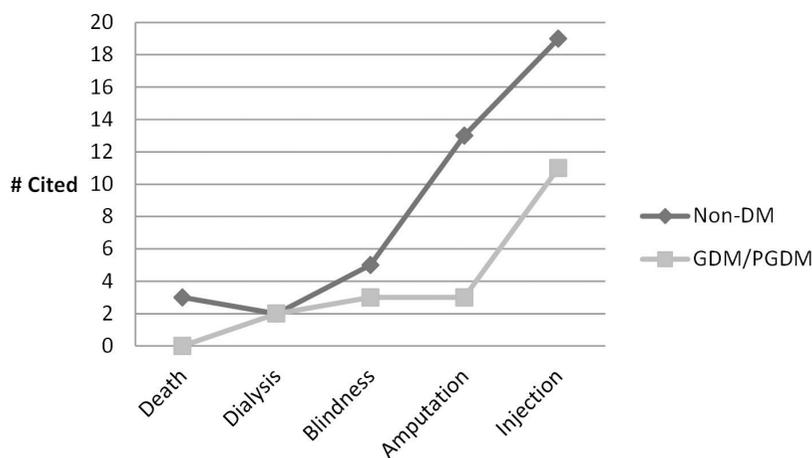
FIGURE 1. Fears by diabetes status. DM, diabetes mellitus.

death honestly."
Interviewer: "What of?"
Participant: "That she was gonna die."
Interviewer: "Do you think that your baby might grow up to have diabetes?"
Participant: "I think it's a good possibility."
Participant: "Well yeah, because my aunt, she knew a lot, she said that whatever I eat goes straight to the baby, and sometimes it's twice as bad on the baby when I do that."
Participant: "I was afraid because they kept telling me my baby could end up dying. Basically, I could really end up hurting my baby, I think that's why."

Of the respondents with diabetes, 44% of those with GDM and 75% of those with PDGM expressed fears with regard to damage to the child or the future risk of the child developing diabetes during the lifespan.

Intra-population comparisons between respondents with and without type 2 diabetes showed that there was a significant difference in the number of women who expressed fear of neonatal complications. Findings indicated that there was an increased sense of awareness among respondents with diabetes. A

χ^2 test comparing the frequency of anxiety between respondents with and without diabetes showed a statistically significant deviation from the hypothesized values (χ^2 [1] = 0.032, $P < 0.01$) (Figure 1).

Fear of Injections

Second to fear concerning damage to the child was fear regarding insulin injections. In this study, the prevalence and intensity of the fear of insulin injections indicated its significance among AIs/ANs who have or are at risk of developing type 2 diabetes. Thus, medical professionals treating AIs/ANs with diabetes should be aware of the "fear factor" among their patients. Furthermore, this fear factor should be understood as an important variable related to patients' decisions to seek and adhere to treatment or suffer deleterious outcomes, as illustrated in the following example:

> **Interviewer:** "What do you fear most about diabetes?"
> **Participant:** "Taking insulin."
> **Participant:** "Having to check it (blood glucose) every day, and insulin shots."

Participants often saw insulin as a treatment of last resort that predicted horrible complications and death. Insulin dependency may mean to them that they are beyond hope, when in fact that is not truly the case. The decision to use insulin

is dependent on the success of MNT and physical activity to normalize glucose levels. The fear of insulin injections may compound anxieties and lead to delayed care-seeking and poor self-management (18).

The prevalence and intensity of this fear among pregnant respondents was striking. Of the 97 people interviewed, >30% cited a fear of self-injecting as an extremely significant factor in their discourse on diabetes (Figure 2). As DCI scores approached more traditional identification levels, fear of injection increased. Additionally, there were a few respondents who expressed a fear of the insulin itself:

> **Participant:** "I am worried about having the GDM and how that is going to affect my child. I know that they wouldn't have you take insulin if it wasn't going to be safe. You know, but you still have to worry if you are taking mass amounts of insulin, you have to be worried about what kind of effects that is going to have."

Previous studies have provided similar accounts. The studies by L. Henderson with elder AIs (13,14) found that the use of insulin was perceived as making one "sicker." Accounts were given of family members who were placed on insulin, only to die or worsen after starting the medication. In actuality, the family member was placed on insulin only after other efforts failed. The insulin was an attempt to halt the cascade of severe complications.

Fear of Amputation and Blindness

In this study, participants expressed fears of both blindness and amputation:

> **Interviewer:** "I know you had gestational diabetes. What did do you fear most about diabetes?"
> **Participant:** "My eyesight, or losing my legs, or my feet."
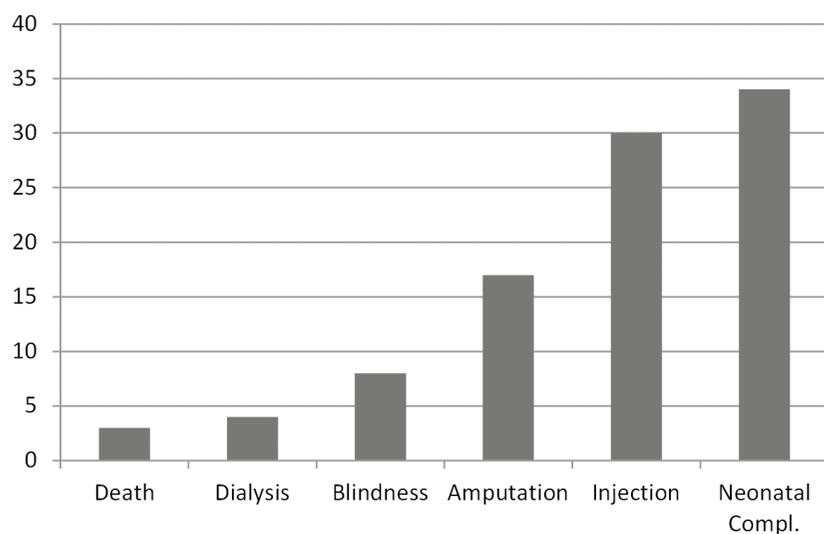
FIGURE 2. Fears about diabetes. Compl., complications.

Sixteen participants cited a fear of amputation in conjunction with diabetes. Interestingly, respondents without diabetes cited fear of amputation with greater frequency than those with diabetes (20 vs. 10%) (Figure 1). Amputation causes a perceived degradation of the body and can be perceived as leaving a person "useless" (19). What was not revealed in this research with AIs is the question of whether there is a cultural belief driving this fear. J. Henderson et al. (17) found in research conducted with elder AIs regarding autopsy, amputation, and other end-of-life issues that there was concern about postmortem preservation and that all body parts are required for full spiritual coherence, peace, and function in the after-life. This concern was found in those elders who strongly identified with traditional AI culture.

The fear of blindness follows close behind fear of amputation in frequency, with respondents with and without diabetes citing fear of blindness in relatively the same frequencies. Using the Wilcoxon test, there was a slight statistically significant difference in the DCI of respondents citing fear of blindness compared to those who did not, with DCI tending to be higher among those citing fear ($z = 2.003$, $P < 0.05$) (Figure 1).

Fear of Death
Death, the direst of complications, was cited the least by research participants (Figure 2). However, some participants stated that premature death would hurt family members and hinder the respondent's ability to be a part of the child's future.

Adherence to Diabetes Self-Care
Despite the prevalence of fear of pharmacological treatment and diabetes complications, there was a lack of knowledge regarding the importance of early care-seeking for these complications and the importance of optimal diabetes self-care. Most respondents stated that they would only seek treatment for diabetes symptoms when there was a change in severity of the symptoms. No one indicated that they would seek blood glucose testing or any other testing even though they understood the possible consequences and their higher level of risk. In this group of pregnant women, few attended diabetes education classes on a regular basis.

Fears expressed by the respondents followed similar trajectories, despite diabetes status (Figure 1). Intuitively, individuals with all forms of diabetes

would become more familiar with the consequences of nonadherence and complications as they become more exposed to the prospect of insulin injections or complications. However, although fear and anxiety of complications was expressed by our sample, these emotions did not improve care-seeking or adherence. This may be a product of the "normalization" of diabetes in the population, lack of attendance at diabetes education and prenatal classes, inadequate provider communication (including regarding treatment approaches), misinformation, or a variety of other factors that require future investigation.

Conclusions
The findings presented here suggest that there is a significant lack of knowledge regarding the biological mechanisms of diabetes, translating into an inability to connect complications to nonadherence. The pregnant women in this study were not regularly attending prenatal classes, nor were they regularly attending diabetes education classes. Particular attention should be paid to the creation of strategies that would either *1*) encourage attendance or *2*) provide other means for patient education. These two goals might be accomplished by providing incentives for attendance or having the classes become social events, reducing the perception that it is a "class" with attendance requirements. To increase attendance at prenatal classes, community interventions may be conducted that stress the importance of the classes to a healthy outcome for both pregnant women and their babies. Health educators may be advised to design programs with EM constructs and emotional affect in mind.

Patient misconceptions may not be obvious. For example, providers might address the perceptions surrounding the cause and prevention of amputation. One respondent believed that amputation was caused by hypertension, leading to fear of having or developing hypertension

during pregnancy. Understanding lay belief systems surrounding diabetes and tailoring messages to patients to address beliefs and possible misconceptions could help to increase adherence.

These findings provide practitioners with new information that delineates patients' culturally based EMs regarding diabetes. The findings underscore the important role emotions such as fear and anxiety play with regard to insulin injections. The findings additionally underscore the importance of addressing these fears repeatedly during prenatal visits in the context of poor attendance at prenatal and diabetes education classes.

Social, behavioral, and medical professionals working with patients who have GDM or type 2 diabetes need to understand and utilize the social component of the diagnosis, which includes family and friend networks. Health professionals may want to consider options such as including family members in prenatal and diabetes education classes and in any discussions of treatment, self-management, or complications from nonadherence.

The findings from our study contribute to a more complete understanding of health beliefs and behavioral dynamics in terms of how illness is culturally constructed. Knowledge gained from this research may facilitate health care delivery in that diabetes education before and during pregnancy can effectively be aligned with preexisting biomedical and cultural patient models, making diabetes education and treatment more relevant and meaningful.

Acknowledgments

Duality of Interest

References

1. Indian Health Service Division of Diabetes Treatment and Prevention. Diabetes in American Indians and Alaska Natives: Facts At-a-Glance, 2015. Available from www.ihs.gov/newsroom/factsheets/diabetes. Accessed 26 August 2015

2. American Diabetes Association. Executive summary. In *Standards of Medical Care in Diabetes—2015*. Diabetes Care 2015;38(Suppl.1):S1–S93

3. Roubideaux Y, Acton K. Diabetes in American Indians. In *Promises to Keep: Public Health Policy for American Indians & Alaska Natives in the 21st Century*. Dixon M, Roubideaux Y, Eds. Washington D.C., American Public Health Association, 2001, p. 193–208

4. Evert A, Hei K. Gestational diabetes education and diabetes prevention strategies. Diabetes Spectrum 2006;19:135–139

5. Moum K, Holzman G, Harwell T, et al. Increasing rate of diabetes in pregnancy among American Indian and white mothers in Montana & North Dakota, 1989–2000. Matern Child Health J 2004;8:71–76

6. Raymer T. Diabetes as metaphor: symbol, symptom, or both? In *Indigenous Peoples and Diabetes*. Ferreira M, Lang G, Eds. Durham, N.C., Carolina Academic Press, 2006, p. 313–334

7. Acton K, Burrows N, Moore K, Querec L, Geiss L, Engelgau M. Trends in diabetes prevalence among American Indian and Alaska Native children, adolescents, and young adults. Am J Public Health 2002;92:1485–1490

8. Setji T, Brown A, Feinglos M. Gestational diabetes mellitus. Clinical Diabetes 2005;23:17–24

9. Kim C. Gestational diabetes: risks, management, and treatment options. Int J Women's Health 2010;2:339–351

10. American Diabetes Association. Statistics about diabetes. Available from http://diabetes.org/diabetes-basics/statistics. Accessed 26 August 2015

11. Rowan J, Rush E, Obolonkin V, Battin M, Wouldes T, Hague W. Metformin in gestational diabetes: The offspring follow-up (MiG TOFU). Diabetes Care 2011;34:2279–2284

12. Kleinman A, Eisenberg L, Good B. Culture, illness, and care: clinical lessons from anthropologic cross-cultural research. Ann Intern Med 1978;1:9–23

13. Henderson L. The cultural construction of diabetes mellitus among Oklahoma Choctaw elders and health care providers: discordance between models. Association for Anthropology and Gerontology Newsletter 2002;23:4–6

14. Henderson L. The cultural construction of diabetes mellitus among Oklahoma Choctaw elders and Choctaw Nation tribal health care providers: an examination of concordance between models and implications for care-seeking and compliance [Doctoral Dissertation]. Ann Arbor, Mich., UMI Dissertation Services, ProQuest Co., 2002

15. Pfifferling J. A cultural prescription for medicocentrism. In *The Relevance of Social Science for Medicine*. Eisenberg L, Kleinman A, Eds. Boston, Reidel, 1981, p. 197–222

16. Henderson J, Henderson L. Cultural construction of disease: a "supernormal" construct of dementia in an American Indian tribe. J Cross Cult Gerontol 2002;17:197–212

17. Henderson J, Henderson L, Blanton R, Gomez S. Autopsy, diabetic amputations, and end-of-life issues among elderly American Indian people. Presented at the American Anthropological Association Annual Meeting, New Orleans, La., 2010

18. Peyrot M, Rubin R, Lauritzen T, et al. Resistance to insulin therapy among patients and providers: results of the cross-national Diabetes Attitudes, Wishes, and Needs (DAWN) study. Diabetes Care 2005;28:2673–2679

19. Wong M, Haswell-Elkins M, Tamwoy E, McDermott R, d'Abbs P. Perspectives on clinic attendance, medication and foot-care among people with diabetes in the Torres Strait Islands and Northern Peninsula. Aust J Rural Health 2005;13:172–177