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Perceptions and Concerns Regarding Diabetes Mellitus During Pregnancy Among American Indian Women

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Abstract

Diabetes among American Indian (AI) people is a condition that creates excessive morbidity and mortality and is a significant health disparity. This research delineated culturally constructed models of diabetes mellitus (DM) among 97 pregnant women in 2 large AI Nations to Oklahoma. Analysis of data revealed intense anxiety, fear, and dread related to DM during pregnancy. The sample was stratified by DM status: (a) absence of DM ($n = 66$), (b) DM prior to pregnancy ($n = 4$), and (c) gestational ($n = 27$). Structured and semistructured interviews elicited patient culturally based explanatory models (EMs) of etiology, course, and treatment. The research incorporated an integrated phenomenologic and ethnographic approach and yielded both quantitative and qualitative data. General findings comprised the following main categories of patients' concerns regarding DM as an illness: (a) care-seeking behaviors, (b) medical management, (c) adherence and self-management, (d) complications, and (e) the conceptual sense of DM as a "severe" and feared condition. Many findings varied according to acculturation status, but all included significant fear and anxiety surrounding (a) the health and well-being of the unborn child, (b) the

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use of insulin injections, (c) blindness, (d) amputation, and (e) death, but with (f) a paradoxically lowered anxiety level about diabetes severity *overall*, while at the same time expressing extreme dread of specific outcomes. The latter finding is considered consistent with the presence of chronic conditions that can usually be managed, yet still having risk if severe.

Keywords

diabetes; American Indian women; disease anxiety; pregnancy

According to the Indian Health Service, 16.3% of American Indians/Alaska Natives (AI/AN) have been diagnosed with diabetes mellitus (DM), and 30.0% of AI/AN have pre-DM. These data indicate that AI/AN are 2.2 times more likely to have DM than non-Hispanic Whites (Indian Health Service Division of Diabetes Treatment and Prevention, 2008). AI/AN with DM are four times more likely than their White counterparts to experience an amputation as a consequence of DM. They are six times more likely to experience kidney failure. In Oklahoma's 37 federally recognized tribes, 24% of AI peoples with DM experience diabetic retinopathy as a complication of their condition (American Diabetes Association, 2013; Roubideaux & Acton, 2001).

Regarding DM during pregnancy, the prevalence rate of gestational DM (GDM) is approximately 7% (Evert & Hei, 2006). Unfortunately, this rate has increased in recent years among both AI and White mothers. However, the prevalence of GDM in AI women continues to exceed that of the White population (Moum et al., 2004) but varies greatly across tribes. In some AI/AN and Canada First Nations tribes, the prevalence rate may be as high as 15% (Raymer, 2006). Findings from Acton et al. (2002) regarding an analysis of data from 105 Indian Health Service Units identified a 46% increase in the DM prevalence rate in women of childbearing age for the period 1990–1996. This represents a notable public health concern. It also represents a significant health disparity which may have political/economic underpinnings.

Among all populations, DM during pregnancy is a major cause of congenital anomalies, malformations, shoulder dystocia, neonatal hypoglycemia, and perinatal death (Acton et al., 2002; Setji, Brown, & Feinglos, 2005). It places pregnant women at risk for hypertension, preeclampsia, premature birth, macrosomia, and an increased incidence of cesarean section (Kim, 2010; Setji et al., 2005). Research has also shown that offspring of mothers with DM are at an increased risk for obesity, abnormal glucose tolerance, and type 2 DM later in life (Acton et al., 2002; Kim, 2010; Moum et al., 2004). This increased risk is an important variable to be considered when examining the perpetuation of high DM 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. The pharmacotherapy used by most health care providers is insulin. Although oral medications may be used, this is not a common practice. According to the Standards of Medical Care in Diabetes (American Diabetes Association, 2013), the potential risks and benefits of oral medications must be

fully considered because current data are insufficient to establish the safe use of oral diabetes medications during pregnancy. An article by Rowan et al. (2011) indicated that additional research is needed regarding the long-term effects of the use of oral agents on children whose mothers received oral medications during pregnancy. This statement was made in the context of the Metformin in Gestational Diabetes: The Offspring Follow-Up (MiG TOFU) study. The tribal physicians that participated in our research prescribed insulin and not oral agents because of the as yet unknown impact on fetal outcomes (American Diabetes Association, 2013; Kim, 2010).

Preliminary research suggests that one possible source for the persistent and increasing DM prevalence is the presence of deeply embedded psychocultural factors that may impede effective prevention and treatment. From the cultural perspective, disease is revealed, both to patients and providers alike, only through a set of complex interpretive activities. The construction of clinical realities is made up of intricate interactions between social practices, biology, and cultural frames of meaning.

BACKGROUND

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 DM held by practitioners and patients. Specifically, professional and lay explanations for disease, treatment, and prevention can vary radically. Explanations for the etiology, treatment, course, and preventive measures for sickness have been labeled *explanatory models* by Kleinman, Eisenberg, and Good (1978). The permutations of the content of explanatory models (EMs) in even a simple patient and provider dyad is complex. For example, patients have specific EMs which are likely congruent with those held by members of their culture and social networks. The words used to describe the symptoms are culturally determined. Another source of miscommunication is the use of biomedical terminology that means something other to the patient than it means to the provider. For example, sugar and diabetes become linked in communication so that the disease becomes the “sugar illness disease” (Evaneshko, 1994; Henderson, 2002a).

Likewise, providers have their own multifaceted, evidence-based, and practice-based EMs and are influenced by their professional peer networks. Patients’ health behaviors and providers’ practices can be considered a synthetic outcome of these multiple factors. Similar EMs facilitate effective patient/provider communication and are associated with increased adherence to treatment recommendations as well as patient/provider satisfaction. However, EMs that are not congruent may reduce effective communication and adversely affect patient adherence, negatively impacting health outcomes. Effective treatment for chronic conditions requires that health care providers understand patient EMs in expanded cultural and contextual terms.

The Impact of Emotion

As a illness, diabetes often arouses intense feelings of anxiety and fear among those who have it, those with acquaintances, those who have family members, and those who are at

risk. These feelings are often associated with the treatment regimens, diabetes self-care requirements, and the possible complications that can arise from having diabetes. Parker (1994) conducted a study within an AI population in rural Oklahoma in which nonstructured interviews and clinical observations were used to elicit reactions to being diagnosed with diabetes. Multiple emotions were expressed including fear, attainment of peace, and grief related to diagnosis. Health care providers must understand these fears and emotions and the rationales behind them, especially in populations such as AI/AN in which individuals face a staggering level of diabetes prevalence.

Fear, anxiety, and dread may affect a person's relationship to his or her sense of safety, whether in term of diabetes or in relation to other chronic conditions. These emotions are causal factors that influence whether or not people with symptoms seek treatment in a timely manner. Some of the most informative responses in the research presented here involve avoidance of health care visits because of the fear of being told they have developed diabetes. This was apparent in the L. C. Henderson study with AI elders with type 2 diabetes in which there were definitive components of denial and avoidance (Henderson, 2002a). For the subjects in that study, having a health care provider state that one has developed DM elicited a range of responses, mediated somewhat by the endemic nature of the condition among AI/AN. Responses ranged from fear to a lack of alarm concurrent with a "normalization" of the condition because of the high prevalence rate within the population.

Affective states are reflected in the illness narrative elicited by the DM in Pregnancy Questionnaire used in this study. The questionnaire is partly composed of Kleinman, Eisenberg, and Good (1978) and Kleinman's (1980) EM questions as well as Pfifferling's (1981) "Patient's Cultural Exam" questionnaire. The illness narrative is the voiced "cognitive map" (Wallace, 1970) or "cultural model" (Shore, 1996) that indicates the informal and internal interpretive schema that is connected to motivations to take action based on available information. An analysis of the textual data that describes subjects' cognitive maps of DM for affective references has shown the primacy of such data for understanding diabetes self-management behavior.

METHODS

In this study, 97 pregnant participants from two Oklahoma AI tribes were interviewed to gather information about barriers which may impact the prevention or control of GDM. 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.

Inclusion Criteria

The participant had to be AI/AN as evidenced by a Certificate of Degree of Indian Blood (CDIB) card, pregnant, and receiving care from the tribal health care systems. The CDIB card has a numeric designation that indicates, by reference to the Dawes Commission rolls, the amount of AI genes present. Subjects recruited could (a) be DM-free, (b) have DM diagnosed during pregnancy (GDM), or (c) have DM prior to pregnancy (PGDM).

Subject Recruitment

Recruitment strategies were developed in collaboration with the tribes and were accomplished by a former community health representative, a member of one of the participating tribes, who was assigned to the prenatal clinic sites. Prior research has shown that recruiting subjects with the assistance of tribal members is very effective and inspires trust in both the research process and the members of the research team.

Data Collection

Both qualitative and quantitative research methods were used. The questionnaire contained both structured and semistructured questions for data collection. Patients were interviewed using the DM in Pregnancy Questionnaire and all interviews were recorded using digital audio recorders. Interviews were transcribed using professional transcription services.

DM in Pregnancy Questionnaire

The questionnaire was derived from prior research of the PI and Co-PI with Oklahoma AIs and literature on explanatory model elicitation (Henderson, 2002a; Henderson & Henderson, 2002; Henderson & Henderson, 2004; Kleinman et al., 1978; Pfifferling, 1981). The questionnaire was used in two prior studies and successfully elicited research-relevant, culturally based responses. Consultation with tribal health care representatives was done regarding the content of the questionnaire. The questionnaire was then altered to make it more culturally specific.

The questionnaire consisted of the following sections:

1. Demographic and social characteristics: age, tribal membership, place of interview, occupation, household composition, degree of AI blood as shown on a CDIB card, place of residence, family structure, kinship dynamics, support group information, and access to care variables.
2. Medical history: Medical history was self-reported by the subject and included questions about parity; problems with past pregnancies; date and context of diabetes diagnosis; severity of the condition at diagnosis; severity of complications at the time of the interview; treatment (present and past); degree of blood glucose control; care-seeking pattern; and adherence to recommendations regarding diet, medications, and follow-ups.
3. Explanatory model elicitation: This was designed to elicit information concerning (a) DM before and/or during pregnancy, (b) DM-related pregnancy complications, and (c) fetal or neonatal DM-related health, problems. There was also an interrogatory technique used to alleviate subjects' possible discomfort in answering questions that might indicate a lack of optimal diabetes self-management. The technique uses questions regarding "projected others" in which the subject is asked how others would respond to the requirements of self-management. This proved to be quite productive for data collection and increased the comfort level of the participant.

4. Provider/patient interactions: This section elicited perceptions of effective/noneffective methods of communication and disease management used by the subjects' health care providers. The questions were designed to identify barriers and facilitators to effective patient/provider communication.
5. Degree of cultural identification questionnaire (DCIQ): degree of cultural identification (DCI) must be considered for many reasons. First, it is important to examine any illness or disease in the context of culture for accurate interpretation of disease constructs. Second, within the AI society today, some people highly identify with cultural systems extant in the distant past, whereas others remain proud of their tribal identity but identify with primarily mainstream American culture. For many elders, their DCI is more strongly traditional compared to the younger generation. The result is that cultural heterogeneity is very wide ranging. The DCI score is based on variables corresponding to cultural identity, including knowledge of current tribal community issues, ability to speak tribal language(s), attendance at tribal events, traditional food preparation and consumption, attendance at tribal churches, ownership of traditional regalia, and seeking traditional tribal healers for medical or spiritual care. The DCI score represents a scale from "mainstream" to "traditional." Obviously, there can also be situational and contextual variance regarding the expression of tribal culture versus mainstream American culture. The DCIQ was developed by author L. C. Henderson and has been used by the research team and others in multiple studies.

DATA ANALYSIS

Coding

Specific topics of interest were initially identified by conducting an extensive review of the literature regarding AI populations, DM, PGDM, GDM, and patient/provider cross-cultural communication regarding health care. This was additive to topics of interest identified during three previous studies in the Choctaw Nation of Oklahoma (Henderson, 2002a; Henderson, 2009). After all topics were identified, coding proceeded aided by computer software. Major groups of similar codes were identified. From these major groups, codes were more specifically refined. Arithmetic interrater reliability checks were conducted using the Miles and Huberman (1994) formula until a minimum 80% convergence was achieved.

Statistical Analysis

Qualitative interview data were analyzed for responses regarding fear of self-injection of insulin, amputation, dialysis, blindness, death, and worry about their unborn child as a result of DM complications. Responses were coded as "present" or "absent."

In addition to the qualitative data, questionnaire items yielded a number of discrete variable categories which, were categorized and ranked. Quantitative data included DM status, family members with DM, age, tribal affiliation, CDIB percentage, expressed fears, and a DCI score that ranged from 0 to 6.

Nonparametric statistical analyses, conducted using SPSS software, used ranked scores to determine correlations and relationships between CDIB percentage, DCI, age, DM status and fears of self-injection, amputation, blindness, dialysis, death, and worry about risk to the unborn child. Spearman's rho rank correlation coefficients were used to test for correlations among the variables DCI, CDIB, age, and DM 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

Subject Characteristics

The sample included subjects with GDM ($n = 27$), subjects with PGDM ($n = 4$), and pregnant subjects without any form of DM ($n = 66$). Designated sample size in each subject category was predicated on the prevalence of each within this population: pregnant women without DM having the highest prevalence, GDM the next highest prevalence, and PGDM the lowest prevalence. Equal numbers of subjects were accessed in each clinic site. Age and parity were followed as covariates. Thirty percent were pregnant with their first child. For DCI and CDIB distributions, see Figures 1 and 2.

The average age of the total participants was 25.03 years ($SD = 6.133$). The average age for those without DM was slightly younger at 23.8 years ($n = 66$), whereas the average age for those with DM was slightly older at 27.7 years ($n = 31$). Ninety-two out of 97 participants had family members with DM (95%). Only five participants did not have family with DM but used the phrase "not yet," indicating an expectation that someone in the family would develop DM eventually. Of the women with DM, 97% indicated that at least one family member also had diabetes. Only one participant with DM had no family with the condition.

Several statistically significant positive correlations between certain variables were identified (Table 1). Age and DM status were statistically, significantly, and positively correlated. As age increased, the incidence of DM increased. DM status was also positively correlated with CDIB, with those having a higher degree of AI genetic loading having an increased incidence of DM. CDIB and DCI scores were also positively correlated, where those identifying as more traditional had a higher percentage of genetic loading.

The fear most often cited was neonatal damage to the unborn child. Forty-four percent of those with GDM and 75% of those with PDGM expressed fears regarding damage to the child or future risk of developing DM later in life (Figure 3).

Intrapopulation comparisons between respondents without DM and those with some form of DM show that there is a significant difference in the number of women from the two categories who express fear of neonatal complications (see Figure 3). This may indicate that the degree of worry expressed by respondents is not just simply a product of normal maternal worry but an increased sense of endangerment to the fetus among respondents with diabetes. A chi-square test comparing the frequency of anxiety between DM and non-DM respondents showed a statistically significant deviation from the hypothesized values ($\chi^2[1] = 0.032, p < .01$).

Second to the fear concerning damage to the unborn child was the fear of insulin injections. Certainly, not many people would wish to inject insulin, but the prevalence and intensity of this fear among the respondents in our study was quite striking. Of the 97 persons interviewed, more than 30% cited a fear of self-injecting as extremely significant, and this fear increased anxiety regarding diabetes during pregnancy (Figure 4). Because DCI scores approached more traditional identification levels, the fear of injection increased. In addition, there were a few respondents that 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.”

Besides strong fears of self-administering insulin injections, other complications that are feared by research participants included (a) amputation, (b) blindness, and (c) death.

Sixteen participants cited a fear of amputation (see Figure 4). Amputation instills fear and dread in persons with DM for obvious reasons. Paradoxically, women without DM cited fear of amputation with greater frequency (20%) than those with DM (10%; Table 2).

The fear of blindness was next in frequency, with respondents with and without DM citing this in relatively the same frequencies as earlier (Figure 5, see Table 2). Even though this population of subjects was quite young, there are still indications that with age, fear of blindness increases. It is impossible to determine, however, if this fear is the result of the older subjects having an increased knowledge of diabetes complications or an unidentified variable. Using the Wilcoxon test, there was a slight statistically significant difference in the DCI of respondents citing fear of blindness and those who did not, with DCI tending to be higher among those citing fear ($z = 2.003, p = .045, p < .05$).

The direst of complications from DM, death, was surprisingly cited the least by research participants (see Figure 4). However, some participants were worried about dying because it would hurt family members:

Participant: “Well, afraid of dying, leaving your family behind,” “Basically, I could really end up hurting my baby...”, “That I couldn’t take care of my kids.”

It is notable that fears expressed by the respondents follow similar trajectories despite DM status (see Figure 5). Intuitively, individuals with all forms of diabetes would become more familiar with the consequences of nonadherence and resultant complications as they became more exposed to diabetes education. However, this was not the case in this sample. Those who had attended diabetes education classes were few. This may be a product of the normalization of diabetes in the population (classes being perceived as unnecessary), misinformation about the importance of diabetes education, or other factors which require further investigation.

DISCUSSION

Fear of Neonatal Complications

Research regarding GDM has historically focused on medical management and fetal risk. By comparison, fewer studies have explicitly addressed maternal emotions and Fears (Lawrence, 2011). In those studies, most women expressed concern for the infant during the pregnancy. In the research presented here, fear of neonatal complications was the number one fear cited by our respondents:

Interviewer: “Are you worried about your baby for any reason?”

Participant: “I was scared to death honestly.”

Interviewer: “What of?”

Participant: “That she was gonna die.”

Interviewed: “Do you think that your baby might grow up to have DM?”

Participant: “I think it’s a good possibility.”

Interviewer: ‘Are you worried about your baby for any reason?’

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.”

Fear of Injections

In this study, it was evident that the prevalence and intensity of the fear of insulin injections carried considerable weight among pregnant AI/AN who may be at risk of developing diabetes. Thus, medical professionals treating AI/AN with DM should be aware of the “fear factor” among their patients. Furthermore, the fear factor should be understood as an important variable related to patients’ decisions to initially seek and subsequently adhere to treatment:

Interviewer: “What do you fear most about DM?”

Participant: “Taking insulin.”

Participant: “Having to check it (blood glucose) every day, and insulin shots.”

Participant often saw insulin as a last resort medically that would be predictive of extreme complications and death. The initiation of insulin may have numerous emotionally based meanings and as such result in a sense of hopelessness. It is emphatically not the case that the initiation of insulin predicts poor outcomes when used during pregnancy. The emotional tags and/or misinformation regarding insulin should ideally be addressed by the health care provider in the initial clinic appointment, with diabetes education classes to follow. As stated previously, oral DM medications are not often used during pregnancy, and the tribal health care providers in this research used insulin to treat those with GDM. The decision to

use insulin is dependent on the success of MNT and physical activity to normalize glucose levels. The fear of insulin coupled with a possible reluctance on the part of the health care provider to start insulin treatment early in pregnancy compounds the problem and may contribute to nonadherence (Peyrot et al., 2005).

Previous studies by the author as well as others have provided similar accounts. Author L. C. Henderson conducted a study among AI elders with diabetes and found that the fear of taking insulin was extraordinarily intense as examined within the context of the elders' EMs (Henderson, 2002a). The initiation of insulin was perceived as a predictor of death, as something that made one "sicker." Stories were related of family members who began to take insulin injections and then died or worsened after starting the injections. In actuality, the family member was placed on insulin only after other efforts failed. The insulin was an attempt to halt the cascade of complications but was sometimes unsuccessful. Therefore insulin was perceived as being extremely harmful:

Participant: "I didn't know how serious it was. Then there weren't too many people who had diabetes. At first, I didn't take it serious. They wanted to put me on insulin, but I wouldn't do it. I quit taking insulin for over two years because my sugar wasn't over 200 (Henderson, 2002b)."

Fear of Amputation and Blindness

In this study, both blindness and amputation were expressed fears:

Interviewer: "I know you had gestational diabetes, what did [*sic*] do you fear most about diabetes?"

Participant: "My eyesight, or losing my legs, or my feet."

Participant: "Well, they say the worst thing that could happen is it affects your heart and your eyes and I don't want to be blind. (Pause) I think that would be the worst thing is to get, turn blind."

Amputation precipitates perception of one's body as marginalized and degraded (Wong, Haswell-Elkins, Tamwoy, McDermott, & d'Abbs, 2005). What was not revealed in this research was the existence of a cultural belief driving this fear. Coauthors Henderson, Henderson, Blanton, and Gomez (2010) found in research conducted with elder AIs regarding autopsy, amputation, and other end-of-life issues that there was concern about postmortem preservation. Within the traditional life-view, all body parts are required for full spiritual peace and function in the afterlife. This construct was most often identified in those elders who strongly identified with traditional AI culture.

Adherence to DM Self-Management

In spite of the considerable fear of complications, there was a paradoxical lack of concern about both early care seeking and adherence. Most respondents stated that they would seek treatment for diabetic symptoms only when there was a change in severity of the symptoms. The endemic nature of diabetes within AI/AN populations may result in a normalization of the condition until it becomes related to severe morbidity at which point a threshold phenomenon occurs, which would precipitate health-seeking behavior. In addition, in AI

elders with diabetes, author L. C. Henderson found that nonadherence was perceived as a normal and socially acceptable behavior within the culture, adherence placing oneself outside of the peer group (Henderson, 2002b).

No one in the study presented here indicated that they would willingly seek blood glucose testing even though they understood the consequences of DM during pregnancy and their higher level of risk. In this group of pregnant women, it was unfortunate that few attended diabetes education classes on a regular basis. A similar finding was cited in a study by Smith-Morris in the Arizona Pima (Smith-Morris, 2006). Possibly the women were not reached early enough in pregnancy because of a delay in seeking prenatal care, and even if subsequently enrolled in diabetes education classes, attendance was irregular. In the Pima study, it was hypothesized that transportation issues may have been a factor. Transportation did not seem to be a factor in our research.

A study by Loewe, Schwartzman, Freeman, Quinn, and Zuckerman (1998) examined physicians' narrative constructions of chronic disease as they effect patient education and adherence. It was stated that "education does not simply involve presenting education to poorly educated diabetics, or even of reminding patients of things they repeatedly forget, such as diet, but returning to the things that patients know best." Fear was not considered to be the best motivating factor. It was said that: "It can initiate actions, but I don't know if it maintains actions, and so I'm not convinced that that's the way to go ... I think she's going to need some other support and backup to keep her going."

The physicians in the study wanted the patients to realize the long-term consequences of their disease without becoming fatalistic and to realize that they can be sick, without feeling ill. The "unenviable task, the key to good storytelling, was to instill these perspectives without, at the same time, conveying one's sense of melancholy or pessimism" (Loewe et al., 1998).

CONCLUSIONS

The findings presented here suggest that there is a significant lack of knowledge regarding the biological mechanisms of DM, which intuitively translates into a difficulty connecting poor self-management of diabetes to complications, whether maternal or fetal. The pregnant women in this study neither were regularly attending prenatal classes nor were they regularly attending diabetes education classes. Only 13 women in this sample had attended diabetes education classes. The cultural and societal system may not value a classroom environment, and this may constitute a disincentive to attend. But the outcome of little or no prenatal/diabetes education classes may profoundly affect care-seeking behavior and adherence to the self-management necessary for the adequate control of PGDM and GDM.

Considerable attention should be paid to the creation of a strategic plan that would either (a) encourage attendance at the classes or (b) provide other means for patient teaching. These two goals might be accomplished through incentivizing attendance or having the classes become culturally acceptable social events. To increase attendance at prenatal classes, community interventions may also be conducted, which stress the importance of the classes

to a healthy outcome for both mother and baby. Health professionals ideally would design prevention programs and diabetes education programs with EM constructs and emotional affect in mind.

Providers of medical care to AI women with GDM must make efforts to talk with their patients about the important role MNT and physical activity play in the control of DM and emphasize that insulin injections might be avoided if self-management is successful. The findings also underscore the important role emotions such as fear and anxiety play regarding the insulin injections. Providers should reassure their patients that the use of insulin does not predict a dire outcome.

Providers also should examine the perceptions surrounding the cause and prevention of amputation. One respondent believed that amputation was caused by hypertension, leading to a fear that high blood pressure during pregnancy might lead to amputation.

These findings provide practitioners with new information about patients' culturally based EMs regarding diabetes. These findings underscore the concept that social, behavioral, and medical professionals working with patients who have GDM or DM optimally must understand the emotions the condition arouses in AI/AN people and, indeed, in most individuals. The social component of this diagnosis includes family and friend networks, which is very important in this culture group and in other communities and populations as well. Health professionals may want to consider options such as including family members in any discussions of treatment (especially regarding insulin), optimal self-management, and possible maternal/fetal complications.

The findings from our study contribute to a more complete understanding of societal beliefs and behavioral dynamics in terms of how illness is culturally constructed, with particular emphasis on the potential impacts of suboptimal maternal self-management of diabetes on infant mortality in the context of GDM. Knowledge gained from the 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 more relevant and meaningful.

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References

- 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. *American Journal of Public Health*. 2002; 92:1485–1490. <http://dx.doi.org/10.2105/AJPH.92.9.1485>. [PubMed: 12197981]
- American Diabetes Association. Executive summary: Standards of medical care in diabetes—2013. *Diabetes Care: Clinical Practice Recommendations*. 2013; 36(Suppl, 1):511–566.

- Evaneshko, V. Presenting complaints in a Navajo Indian diabetic population. In: Joe, J.; Young, R., editors. *Diabetes as a disease of civilization: The impact of culture change on indigenous peoples*. New York, NY: Mouton de Gruyter; 1994. p. 357-377.
- Evert A, Hei K. Gestational diabetes education and diabetes prevention strategies. *Diabetes Spectrum*. 2006; 19:135–139. <http://dx.doi.org/10.2337/diaspect.19.3.135>.
- Henderson, LC. 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. Ann Arbor, MI: University Microfilms International; 2002a.
- Henderson LC. The cultural construction of diabetes mellitus among Oklahoma Choctaw elders and health care providers: Discordance between models. *Association for Anthropology and Gerontology Newsletter*. 2002b; 23:4–6.
- Henderson, LC. Battling a new epidemic: American Indian elders and diabetes. In: Sokolovsky, J., editor. *The cultural context of aging: Worldwide perspective*. 3. Westport, CT: Praeger; 2009.
- Henderson J, Henderson LC. Cultural construction of disease: A “supernormal” construct of dementia in an American Indian tribe. *Journal of Cross-Cultural Gerontology*. 2002; 17:197–212. [PubMed: 14617965]
- Henderson, J.; Henderson, LC. Oklahoma Choctaw Indians. In: Ember, C.; Ember, M., editors. *Encyclopedia of medical anthropology: Health and illness in the world’s cultures*. The Netherlands: Kluwer-Plenum; 2004.
- Henderson, JN.; Henderson, LC.; Blanton, R.; Gomez, S. Perspective on brain autopsy, diabetic amputations, and end-of-life issues among elderly American Indian people. Paper presented at the American Anthropological Association Annual Meetings; New Orleans, LA. 2010.
- Indian Health Service Division of Diabetes Treatment and Prevention. *Diabetes in American Indians and Alaska Natives: Facts at-a-glance*. 2008. Retrieved from http://www.ihs.gov/MedicalPrograms/Diabetes/HomeDocs/Resources/FactSheets/2012/Fact_sheet_AIAN_508c.pdf
- Kim C. Gestational diabetes: Risks, management, and treatment options. *International Journal of Women’s Health*. 2010; 2:339–351. <http://dx.doi.org/10.2147/IJWHS13333>.
- Kleinman, A. *Patients and healers in the context of culture*. 1. Vol. 3. Berkeley, CA: University of California Press; 1980.
- Kleinman A, Eisenberg L, Good B. Culture, illness, and care: Clinical lessons from anthropologic cross-cultural research. *Annals of Internal Medicine*. 1978; 88(2):251–258. [PubMed: 626456]
- Lawrence J. Women with diabetes in pregnancy: Different perception* and expectations. *Best Practice & Research Clinical Obstetrics & Gynecology*. 2011; 25:15–24. <http://dx.doi.org/10.1016/j.bpobgyn.2010.10.003>.
- Loewe R, Schwartzman J, Freeman J, Quinn L, Zuckerman S. Doctor talk and diabetes: Towards an analysis of the clinical construction of chronic illness. *Social Science & Medicine*. 1998; 47(9): 1267–1276. [PubMed: 9783869]
- Miles, M.; Huberman, A. *Qualitative data analysis: An expanded sourcebook*. 2. Thousand Oaks, CA: Sage; 1994.
- Moum K, Holzman G, Harwell T, Parsons S, Adams S, Oser C, Gohdes D. Increasing rare of diabetes in pregnancy among American Indian and White mothers in Montana & North Dakota, 1989–2000. *Maternal and child Health Journal*. 2004; 8:71–76. <http://dx.doi.org/10.1023/B:MACI.0000025729.65328.73>. [PubMed: 15198174]
- Parker JG. The lived experience of Native Americans with diabetes within a transcultural nursing perspective. *The Journal of Transcultural Nursing*. 1994; 6(1):5–11. [PubMed: 7826547]
- Peyrot M, Rubin R, Lauritzen T, Skovlund S, Snoek F, Matthews D, Kleinbreil L. 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. <http://dx.doi.org/10.2337/diacare.28.11.2673>. [PubMed: 16249538]
- Pfifferling, J. A cultural prescription for medicocentrism. In: Eisenberg, L.; Kleinman, A., editors. *The relevance of social science for medicine*. Boston, MA: Reidel; 1981. p. 197-222.
- Raymer, T. Diabetes as metaphor: Symbol, symptom, or both?. In: Ferreira, M.; Lang, G., editors. *Indigenous people and diabetes*. Durham, NC: Carolina Academic Press; 2006. p. 322

- Roubideaux, Y.; Acton, K. Diabetes in American Indians. In: Dixon, M.; Roubideaux, Y., editors. Promises to keep: Public health policy for American Indians & Alaska Natives in the 21st century. Washington, DC: American Public Health Association; 2001. p. 193-208.
- Rowan J, Rush E, Obolonkin V, Battin M, Woudes T, Hague W. Metformin in gestational diabetes: The offspring follow-up (MiGTOFU). Diabetes Care. 2011; 34(10):2279–2284. [PubMed: 21949222]
- Setji T, Brown A, Feinglos M. Gestational diabetes mellitus. Clinical Diabetes. 2005; 23:17–24. <http://dx.doi.org/10.2337/diaclin.23.1.17>.
- Shore, B. Culture in mind: Cognition, culture, and the problem of meaning. New York, NY: Oxford University Press; 1996.
- Smith-Morris, C. Diabetes among the Pima. Tucson, Arizona: University of Arizona Press; 2006. p. 31-32.
- Wallace, A. Culture and personality. 2. New York, NY: Random House; 1970.
- 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 Area. Australian Journal of Rural Health. 2005; 13:172–177. [PubMed: 15932487]

Figure 1.
Degree of cultural identification from questionnaire. DCI = degree of cultural identification.

Figure 2.
Percentage of Indian blood per CDIB card. CDIB = Certificate of Degree of Indian Blood.

Figure 3.

Fear of neonatal complications by DM status. GDM = gestational diabetes mellitus; PGDM = diabetes mellitus prior to pregnancy; DM = diabetes mellitus.

Figure 4.
Fears about diabetes.

Figure 5.

Fears cited Non-DM versus DM. DM = diabetes mellitus; GDM = gestational diabetes mellitus; PGDM = diabetes mellitus prior to pregnancy.

TABLE 1

Statistical Correlation Among Demographic Variables (two-tailed Spearman's Rho)

Variables	<i>N</i>	<i>r</i>	<i>p</i>
Age			
DM status	96	0.280	.006**
DCI score	96	0.185	.072
CDIB	93	0.098	.349
DCI Score			
DM status	97	0.140	.170
CDIB	93	0.298	.004**
CDIB			
DM status	93	0.268	.022*

Note. DM = diabetes mellitus; DCI = degree of cultural identification; CDIB = Certificate of Degree of Indian Blood.

* Correlations are significant at .05 level.

** Correlations are significant at .01 level.

TABLE 2

Non-DM Versus DM Fears by Percentage

Fear	Non-DM	GDM/PGDM
Death	3 (5%)	0 (0%)
Dialysis	2 (3%)	2 (6%)
Blindness	5 (8%)	3 (10%)
Amputation	13 (20%)	3 (10%)
Injection	19 (29%)	11 (35%)
Neonatal complications	19 (29%)	15 (48%)

Note. DM = diabetes mellitus; GDM = gestational diabetes mellitus; PGDM = diabetes mellitus prior to pregnancy.