

Reducing Risk for Gestational Diabetes Mellitus (GDM) Through a Preconception Counseling Program for American Indian/ Alaska Native Girls

Perceptions From Women With Type 2 Diabetes or a History of GDM

Purpose

American Indian and Alaska Native (AIAN) women are disproportionately affected by gestational diabetes mellitus (GDM). GDM is a risk factor for subsequent diagnosis of type 2 diabetes (T2D) in both mother and offspring, yet there is minimal research being conducted in this population. The purpose of this portion of a larger 5-year study is to examine AIAN women's experiences of having GDM or T2D during pregnancy, inform the development of a GDM risk reduction and preconception counseling (PC) program tailored to AIAN girls, and enhance mother-daughter communication and support within the program.

Methods

AIAN women with TD2 or a history of GDM (N=5) were interviewed to understand their unique perspectives on diabetes and pregnancy, behaviors to reduce risk, and content for a PC education program for AIAN girls. Interviews were digitally recorded, transcribed verbatim, and analyzed using the constant comparison method to construct themes across the interviews.

Results

Four primary themes were constructed: lack of knowledge on GDM and GDM risk factors, importance of

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AIAN culture for health and wellness, suggestions for communication with AIAN girls to reduce risk of GDM, and the emotional impact of GDM diagnosis.

Conclusions

Participants wished they had known about risk factors for GDM and how to reduce their own risk of developing GDM. Findings from this study have been used to adapt an existing PC program, originally developed for non-AIAN girls with diabetes, for AIAN girls who do not have diabetes but have risk factors for developing GDM in future pregnancies.

estational diabetes mellitus (GDM) is the most common medical complication of pregnancy and has a prevalence rate ranging from 7% to 18% in all US pregnancies. The incidence of GDM has doubled in the past decade, paralleling the obesity epidemic. Defined as glucose intolerance with onset during pregnancy, GDM can cause severe complications and is a significant risk factor for developing type 2 diabetes (T2D) for both the mother and the baby. These adverse health outcomes include large babies (with increased risk of birth injury or cesarean delivery), maternal high blood pressure, preeclampsia, and neonatal hypoglycemia.

Women with GDM have a 35% to 60% chance of developing T2D within 10 to 20 years. Compared to the national average, American Indian and Alaska Native (AIAN) women have approximately twice the rates of GDM and of subsequently developing T2D.^{3,4} The increased frequency of GDM among AIAN women places them at a disproportionate risk for developing T2D and adds risk to future generations of developing diabetes.⁵⁻⁷ These risks are exacerbated by inequities within the social determinants of health, including poverty, differential access to health care as a result of issues related to geographic isolation, limited access to health resources, and lack of culturally responsive and grounded reproductive health programming available to AIAN women.8 Unless these needs are addressed, AIAN women will continue to have a significantly increased risk for developing GDM and T2D. 9-14

Because GDM is a strong indicator for poor pregnancy and birth outcomes and for both mother and child developing T2D,^{5-7,15} preventing GDM in a woman's first pregnancy is imperative. Studies in diverse populations

have documented that preconception counseling (PC) has helped women to plan their pregnancies and significantly reduced perinatal complications in women with diabetes. 16 Preconception counseling is special care and advice from health care professionals to raise awareness about the risks associated with diabetes, help women plan their pregnancies when it is safe and wanted, and prevent complications.¹⁷ Currently, the only validated PC program that targets teens with diabetes is READY-Girls (Reproductive-Health Education and Awareness of Diabetes in Youth for Girls), as developed by Charron-Prochownik and her team. Findings from the randomized controlled trial testing READY-Girls suggest those women who received PC at an early age were more vigilant with family planning. 21 Soliciting support from mothers to assist in delivering accurate information regarding reproductive health to their daughters was also identified as being beneficial.²² Researchers Charron-Prochownik and Moore have assembled a new team to develop and test a culturally appropriate PC theory-based intervention entitled Stopping GDM, by adapting the original READY-Girls program, to be completed during a 5-year period. Stopping GDM will focus on helping AIAN adolescent girls and young adult women optimize their metabolic health and attain a healthy weight by adopting a healthy lifestyle prior to pregnancy to reduce their risk of GDM, specifically by reducing risk factors associated with GDM while garnering support from their mothers.

Over the course of this 5-year project, researchers will engage in 3 phases, including (1) information gathering and program development/alteration, (2) program implementation and evaluation, and (3) program dissemination. This article presents a component of the qualitative findings from the first phase and focuses on findings from interviews with adult AIAN women who had personal experience with GDM (1 participant had T2D during pregnancy) during their pregnancies.

Methods

Design

Researchers employed a qualitative grounded theory methodology as it is well suited to aid health education researchers to study complex phenomena within their contexts and develop interventions and education programs.²³ The qualitative nature of this project was used to explore AIAN women's lived experiences with GDM and the way they perceive connections between culture, health,

Table 1

Moderator Guide for Individual Interviews and Focus Groups

	Interview Questions
Introduction	 What do American Indian/Alaska Native teenage girls who are at risk for diabetes need to know so they can prevent unplanned pregnancies and have healthy pregnancies when they are ready? Did you get this information when you were growing up? IF YES, tell me about that experience. Tell me what you know about "preconception counseling." How do you think American Indian/Alaska Native teen girls go about getting this kind of information? What else do you think I should know about GDM and AIAN women?
Video reaction	 In the video, who should the presenter be? What settings would you pick for your community? Tell me what you like about the video clips; what you don't like.
Booklet reaction	 Tell me what you like about the booklet; what you don't like. Thinking about the materials you've seen, how could they be changed so they would be good for young women/teen girls in your community who are at risk for diabetes? Please share with me anything else we should know about your tribe or community that can help us make the video and booklet a better fit for girls from your tribe/community.

and prevention within the context of reproductive health and GDM prevention. Researchers used a combination of semistructured individual interviews and 1 focus group primarily for the convenience of the participants.

Sample/Recruitment

Recruitment was through word of mouth and flyers posted at local AIAN community centers. Maximum variation sampling was employed to ensure that this convenience sample included women with a previous diagnosis of GDM and/or a diagnosis of T2D during pregnancy and that all participants were AIAN mothers. Although not part of the original inclusion criteria, all of the participants had daughters between the ages of 6 months and 20 years. This is noteworthy as the Stopping GDM program is intended for AIAN girls (ages 12-24 years) and their mothers. The data set includes 1 focus group (n = 2) and individual interviews (n = 3). A combination of individual interviews and 1 small focus group served as data collection methods, due to participant's challenges with transportation and scheduling.

Data Collection

Data were collected in both Portland, Oregon, and Denver, Colorado. These sites were selected as they are not part of the second phase of this 5-year project (the randomized controlled trial) and because the researchers have community and academic partners in both of these sites. Data collection took place at the aforementioned AIAN community centers and, in 1 case, a coffee shop as requested by the participant. Data collection was facilitated by using a semistructured moderator guide developed by the principal investigators and qualitative methods experts. Moderator guide questions can be found in Table 1. Participants viewed several video clips and read booklet excerpts from the original PC program, READY-Girls, to generate feedback ideas for cultural tailoring of this material. All interviews and focus groups were moderated by the first author, accompanied by a note taker, digitally recorded, and transcribed verbatim. The University of Colorado Multiple Institution Review Board approval was obtained prior to all human subjects research.

Data Analysis

Two qualitative researchers (first and third authors) coded the data using the constant comparison method, as supported by the grounded theory approach.²⁵ A combination of inductive and deductive coding approaches was employed. The constant comparison coding approach included coding data, categorizing the codes, and reorganization of the categories into thematic representation through a series of assertions and interpretations. Atlas.ti

(Mac Version 8.0) was used to digitalize and support the process of data coding and transcription organization, to construct categories using network maps, and to eventually identify themes across the transcriptions. ^{26,27}

Results

Using both inductive and deductive coding techniques, 4 predominant themes were identified in these interviews. They include (1) lack of knowledge about GDM and opportunities for health information, (2) traditional Native culture and how to incorporate this into a GDM risk reduction education program, (3) reproductive health communication with AIAN girls, and (4) the emotional impact of having diabetes during pregnancy as an AIAN woman. Direct participant quotations supporting each of these themes can be found in Table 2.

Lack of Knowledge About GDM and Opportunities for Health Information

Interviewees reported a general lack of knowledge and awareness about GDM, ways to reduce one's risk for getting GDM, and the link between body weight and GDM or subsequent diagnosis of T2D. Interviewees shared that they did not know what GDM was before their diagnosis or that they could reduce their risk of getting GDM. Participants indicated their understanding of diabetes was typically in relation to an older adult, such as a grandparent who had diabetes. The majority of the interviewees indicated that they did not know the purpose of the "sugar test" that was performed while they were pregnant. In addition, 1 woman described surprise at being diagnosed with GDM when she was pregnant the second time, as she did not have GDM during her first pregnancy. This confusion suggests that she was unfamiliar that GDM could be present in one of her pregnancies but not necessarily in all of her pregnancies. Although participants discussed the importance of postpartum weight loss, they did not know this weight loss was related to reduction in risk for a subsequent diagnosis of T2D. Although interviewees did state "nutrition" and "healthy diets" as important aspects of a healthy pregnancy, they did not specifically know the relationship between healthy eating habits and weight gain management during pregnancy and that healthy eating habits reduce risk of GDM. Interviewees speculated that most AIAN women who have never been diagnosed with GDM also do not know what GDM is and therefore strongly suggested including the whole family in GDM education, especially female family members, as a family-centered approach for diabetes education. In addition, participants preferred weight management education that focused on physical activity, balance, and healthy eating, rather than weight loss, when educating girls on healthy weight management practices.

Traditional Native American Culture and Pregnancy Health and How to Incorporate This Into a GDM Risk Reduction Education Program

Another significant theme that was identified from these interviews included the importance of cultural practice in healthy pregnancies and birth outcomes. Participants noted that Native American communities are family centered, often including extended family, and therefore inclusion of the entire family, or even a whole community, in health education programs is important. From this perspective, the women indicated that an educational program that centers on family and community connection would encourage the girls to engage in a GDM risk reduction program. Participants emphasized the importance of creating a GDM risk reduction and PC education program that draws on community strengths and values, and they explained that given cultural variations across tribes in terms of language and traditions, such a program would need to be somewhat generalized across tribal groups or flexible to meet the needs of the community for which it is being implemented. However, they also cautioned consideration of the many traditions among different tribes and that the AIAN population is not homogeneous in nature. They also suggested the importance of producing education materials that are reflective of AIAN culture by featuring AIAN faces in the graphics/images in the education materials and including AIAN actors in the videos, so those seen on these materials "look like girls in our community." Moreover, they indicated the importance of developing education materials that reflect Native American values of health, wellness, and healing and the concept of "balance" within the mental, physical, spiritual, and emotional domains of life as represented on the medicine wheel. Participants suggested including Native American stories that promote teachings about the importance of achieving balance in mind, body, and spirit and to recast fertility and "moon time" as sacred rather than something about which to feel shame or embarrassment. And finally, the participants suggested that reproductive health programming be created to celebrate the strength of

Table 2
Participant Quotations Supporting Each Major Theme

Theme	Quotation
Lack of knowledge about GDM and opportunities	No, I didn't know anything about it. I didn't have any teachings on it or anything. All I know is seeing my grandma when I was younger. She used to take shots, and I knew she had diabetes.
for health information	I didn't know anything about it. I had no idea what it was. I knew that my grandma was diabetic and my mom was diabetic, but that was all I knew. I didn't know that you could be diabetic during pregnancy, or that it could come on with a pregnancy. I had no idea.
	I heard of it, but I didn't know what it was or when the onset took place. I just knew at 30 weeks, you'd drink that drink and that's how they're able to tell. But with my first daughter, I didn't pass the first test. So I went back for the second test and I passed that one. So I didn't have it. But with my son, it came up positive right away, which was really surprising.
Traditional Native American culture and pregnancy health and how to incorporate this into a GDM risk reduction	Because we really, in the Native culture, we put a lot of value on life. Everything has a life, everything has a spirit, [for example] the trees are alive. And if they realize that there are these other little potential life forms that exist inside of them that they are responsible for, that might be a huge thing for them to hear. Because I know that for my daughters it was, and for my sons. I was like, "You have little baby sperms floating around in there, and they're alive, man. They're waiting."
education program	But like I said, there's always the generations, the family, the traditional stuff, the cultural—we're different. It could be a grandma and a teenager and a newborn baby, all right there. And just make it family focused. And the girl would look at it and be like, "Wow, there's three generations of our people, like we're alive. How do we stay alive?" And I think that would be effective, too, maybe. You know, if you had grandma, and a teenager, and a baby. It would capture their attention and make a huge statement, like about womanhood. And make it about womanhood and motherhood. Because the girls that are taught really value that a lot, about being a female. Girls who are taught that when they're young, kept in ceremony, raised on the red road and stuff like that. And talking about their moons, and what that medicine is and what that medicine means. They become creators of life.
	And I think kids will listen to that. They'll listen to that, if you mix it up—because you asked about culture. I think that if you mix it up with a creation story somehow—because we listen to stories And our kids, they listen to what we say, so we teach them with words. And I just think that if you were able to share with them some kind of creation story, and just intermingle it with the information about how their eggs are already there and need to stay healthy, then that's part of creation. They're making their own creation story. I think that you might ring some bells.
	My Lakota grandma on my dad's side—because I got my period when I was with her. And so I was like, "Grandma, I got my" (we call it our moon). And after that, she said that she was going to prepare preparations for me. Even before that, she taught us a lot about our own culture. She taught us traditions. She was a medicine woman, but she never told anybody. And her being a medicine woman, I remember her doing a lot of ceremonies and us being brought up in that and that also brings balance, that spiritual balance. And I think that that also helps with everything: your life, the way that you eat, the way that—like she taught me the type of, how you should act when you become a woman. Because you're learning and you're becoming a woman.
Reproductive health communication with AIAN girls	Well, I think now—there's more now than there was when I was younger. Nobody wanted to talk about it. They didn't talk to us about anything when we were young. So yeah, me and my cousins—we didn't know much about it. What I learned, I learned at school or from friends. And I went to school with a lot of other Native girls, but they were kind of in the same boat as me. We kind of all winged it. But now, oh, I think it's completely different. I talked to them. I'm really open with them. They're open with me. My daughter was 12—my youngest daughter—was 12 when she started menstruating. And she came to me, and we went over tampons, pads, and she's tried both.
	(continued)

Table 2 (continued)

Theme Ouotation I talk to her a lot about what I had to go through, as being young and pregnant, and do you want that kind of life? And school should always be first. I never really had anybody talk to me like that. Well, I have a stepdaughter. She's 12, she's going to be 13. And they went through that in sixth grade. And I think her questions were more along the line of her period and—and being embarrassed. And I've told her, straight up, I'm just like, "You can have sex one time and get pregnant." I was like, "You can do it one time, your very first time, and get pregnant," And she was like—"I've known one girl who, that happened to her." But that was a different conversation, only because they brought that up. Emotional impact of having I think for me, I just shared that it was embarrassing for me to tell people that I had gestational diabetes, because I felt that they were already blaming me, like, "How did you do-what did you eat? What were GDM or type 2 diabetes you doing? How were you taking care of yourself, how did you get that?" And then my family members, while pregnant as an of course, were like, "You don't look like you have it," or, "You don't look unhealthy, you don't look AIAN woman overweight." And it's just like, but it's not that, It's deeper, Yeah, there is a stigma to it, just like everything else. Like everything else with being Native American. But I would say, put in here that it's not your fault, you didn't do anything wrong, it's something that happens, it's out of your control—because that was the one thing I—that was the issue I had where it was, I couldn't control that. It was something that I could not control, but I could keep it under control. So I would say to reiterate that, especially to a young mom. I just felt shamed. I think it was just more like, when people would offer me food, like desserts and stuff, and I'd be like, "No, sorry, I can't eat it." "Why not?" "Because I have gestational diabetes, that's why." They're like, "Oh okay, sorry. How did you get that?" And I think I felt it more from my ex-husband—my now soon-to-be ex-husband's side of the family, where they were just like, "Oh, she has diabetes, oh, she's going to get diabetes now after she has diabetes," or, "Her baby's going to be born big." It was just different. It was a different embarrassing experience. When they put me on insulin. I was so upset that day. I couldn't even—I left the doctor's office and I got around the corner to where a gas station was, and I pulled over and called my mom. I was so upset. And she was so upset. She was like, "Oh my God, you're too young." My daughters-well, all my kids saw how upset I was about doing the shots. It's not the same, I guess, as when my grandma had to do the shots. It's not as—it's way easier than it was back then. But it's still a shot you gotta do twice a day. And they know, I talked to them about it. I was like, "I could lose"—and I was having neuropathy on my feet. So they knew it was a big deal. No, I was just—like I said—really disappointed that they told me—because I cried when I found out I had it. I was like, "No!" because I thought back to my grandma and watching her take her medicines and get really sick. Abbreviations: AIAN, American Indian and Alaska Native; GDM, gestational diabetes mellitus.

Native American women as sacred life givers, as such framing promotes healing to value and honor female fertility and the role of women in traditional Native American society. Participants suggested that Western medicine and the biomedical framework of health and prevention often do not resonate with elders in their community or with the participants themselves (as evidenced above), and sensitive issues such as pregnancy planning and weight management should focus on how best to link traditional AIAN health practices into the education program. One

participant recommended inclusion of Native American colors and designs as a "good place to start" but to remember "putting a dream catcher on something does not make it Native-friendly," suggesting that a deeper understanding of what educational materials would resonate with the population is critical.

Participants also lamented the loss of aspects of their traditional culture with more AIAN families moving to urban areas, losing Native languages and some traditions, and especially the loss of traditional foods in their

diets, which includes the loss of many traditional foodgathering practices. Participants believed this change in diet is a significant reason for the increase in diet-related chronic disease, such as diabetes, among AIAN people.

Reproductive Health Communication With AIAN Girls

Each of the women interviewed had a daughter, and all but one had a daughter between the ages of 12 and 24 years, which is the priority audience for this GDM risk reduction and PC education program. Regarding recommendations for communicating between mother (or adult female caregiver) and daughter, participants shared they are far more open in discussing reproductive health topics such as puberty, birth control, menstruation, and sex with their daughters than they were with their own mothers and grandmothers. Participants shared this with pride and indicated they were intentionally more open and communicative with their daughters because their personal experience was lacking in support, communication, and reliable information about sensitive issues such as these. Participants indicated that AIAN elders tend to be shy and reserved about discussing such issues, and although "respecting one's body" is part of traditional Native culture, the details and intricacies of transitioning from a girl to a woman are often not openly discussed. Participants observed that communicating with their daughters about sensitive topics such as sex, pregnancy, and weight management requires frequent conversations, without judgment. Sharing their own stories is beneficial as it helps their daughters understand what their experience may have been—especially with regard to unplanned teenage pregnancies.

Participants suggested that health care professionals or even teachers of "sex ed" classes at school may attempt to connect with girls about these topics but that giving the "facts" typically is not enough as most teens have an "it's not going to happen to me" attitude. They reiterated it is important for AIAN teens to hear stories and to connect PC counseling or GDM risk reduction education to traditional AIAN teachings—such as the cycle of life and concept of balance between mind, body, and spirit.

Emotional Impact of Having GDM or Type 2 Diabetes While Pregnant as an AIAN Woman

The fourth theme from these interviews was the emotional impact or stigma of the diagnosis of GDM on the participants' lives. Although not explicitly asked, each participant enthusiastically shared her diagnosis (GDM or T2D) story, and for most interviews, this was the time when participants were most loquacious with their responses. Beginning with symptoms prior to diagnosis, the diagnosis itself, and the way their lives changed after the diagnosis (with regard to self-diabetes care), participants described the emotional and mental impact with terms such as fear, shame, and powerlessness. The best way to mitigate these feelings for girls who are at risk for GDM would be through education prior to diagnosis, including emphasis on controllable risk reduction factors such as managing their weight and staying physically active. Education prior to pregnancy would alleviate much of the fear, and understanding the innate high risk that AIAN women have of being diagnosed with GDM would assuage some of the shame associated with GDM. Participants discussed powerlessness as a fatalistic negative emotion, suggesting that "everyone in my family eventually gets diabetes, so I will too." This disempowered perspective led participants to fear future diabetes complications, such as referring to a grandparent who was taking insulin, had amputations, or died of diabetes complications, and participants shared that this bleak perspective on the trajectory of diabetes was especially stressful during pregnancy. Education focusing on controllable risk reduction factors such as managing body weight was recommended to better prepare AIAN women to prevent a diagnosis of GDM.

Discussion

The American Association of Diabetes Educators position statement on cultural sensitivity and diabetes education states that diabetes education should be tailored to meet the needs of minority groups, including American Indians and Alaska Natives who are disproportionately affected by diabetes. ⁴ The perspectives of AIAN women who have personal experience with GDM or T2D are essential for developing an educational program aimed to reduce the risk of GDM among AIAN women. To the authors' best knowledge, there is no published research on AIAN women's knowledge and awareness of GDM, despite their high risk for developing this disease. 3,28 Researchers in Samoa, another indigenous culture with accelerating risks of diabetes, determined that GDM awareness was low among Samoan women, and increasing awareness and education on GDM risk factors may decrease the prevalence of both GDM and T2D among Samoan women.²⁹ Awareness of one's risk for developing diabetes and given information and strategies to decrease that risk is embedded within the expanded health belief model³⁰ (EHBM), used to frame READY-Girls. The EHBM supports READY-Girls' inclusion of the concepts of perceived susceptibility and perceived severity (together these concepts are the "risk") as means to enhance a person's likelihood to make health-related behavior change. It also identifies strategies to decrease barriers and increase benefits to performing healthy lifestyle behaviors, as well as emphasizes the importance of increasing self-efficacy to engaging in health-related behavior. Women in this study wished they had known about GDM prior to their own diagnosis and shared that this simple step of increasing awareness would greatly benefit their communities. The EHBM will also be employed as the guiding theory for Stopping GDM, and the concepts of perceived susceptibility and perceived severity will ground the program's first messages by increasing community-wide awareness of AIAN girls' risk of developing GDM.

Participants shared that incorporating Native culture such as storytelling and inclusion of Native elders in education would be important in tailoring a GDM risk reduction education program for AIAN girls and their families. This approach is also likely to align well with traditional Native American values on the importance of extended family, group needs over individual needs, and respect for elders.³¹ In addition, participants shared the importance of communicating with their daughters and how they would have benefited from having conversations with their mothers and elders as children.

Participants also shared their personal experience with GDM diagnosis and indicated their lack of awareness and knowledge, feeling unprepared, feelings of shame and embarrassment, fear of stigma, and shock about their diagnosis. These authors know of no published literature specific to AIAN women, but these findings replicate those in similar qualitative studies on women's experiences with GDM. ^{32,33} Educational resources for AIAN people can help decrease the stigma and shame associated with GDM by offering AIAN communities tools to better understand the risk factors of GDM and how extended families and entire communities can support women who are at risk of GDM or have been diagnosed with GDM.

Implications and Recommendations for Diabetes Educators

This is an important opportunity to address these gaps in health education on the lack of knowledge and understanding of GDM among AIAN women. Although the sample size in this qualitative study is small, the perspectives from this unique group of women are crucially important contributions to the larger pool of needs assessment qualitative data collected as the first phase of this multiphased project. It appears the women included in this project were not provided education or resources on GDM prior to their diagnosis. If these AIAN women did receive information on how to reduce their risk of GDM, they may have not received it in a way that makes sense to them or that connects with them, or they do not perceive themselves at high risk. They may not understand the high-risk implications of GDM for the mother, baby, and future generations.

Diabetes educators can play a pivotal role in providing preconception counseling to patients at high risk for developing diabetes, including adolescents and young adult women at risk for GDM. While diabetes educators in the clinical setting often do not see patients until after a diagnosis of diabetes, community-based and public health diabetes educators have the unique opportunity to raise awareness of GDM, especially in high-risk communities. Since many diabetes educators do not have expertise in working with AIAN populations, it is strongly advised the diabetes educator use culturally responsive and tailored information and seek to deliver the program collaboratively with health care professionals who have specific expertise in working with AIAN populations.

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