



# Recommendations from American Indian and Alaska Native Adolescent Girls for a Community-Based Gestational Diabetes Risk Reduction and Reproductive Health Education Program

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## Abstract

**Background:** American Indian/Alaska Native (AIAN) women have twice the risk compared to the general US population of adolescent obesity, pregnancy, and gestational diabetes. The purpose of this study was to explore the perspectives of adolescent AIAN girls who are at risk for gestational diabetes (GDM) on their awareness and understanding of GDM and reproductive health; and on an existing validated diabetes and preconception counseling (PC) education program for non-AIAN teen girls with diabetes.

**Methods:** Five semi-structured focus group interviews with 13 AIAN females (age  $15.5 \pm 1.8$  years) were conducted. Questions related to their awareness, understanding, and perceptions of risk for GDM. The moderator also showed video clips and booklet excerpts from the existing program to elicit feedback. Interviews were recorded and transcribed verbatim. Analysis included inductive coding and the constant comparison method.

**Results:** Key themes were constructed: 1) Lack of awareness and knowledge of GDM; 2) Need for pregnancy planning and culturally responsive GDM and reproductive health resources; 3) Importance of using empowerment frameworks to promote positive reproductive health behaviors.

**Conclusions:** The participants' lack of awareness and knowledge of GDM and their risk for developing GDM reveals the need for new health programming to mitigate risk for unplanned pregnancies and GDM, and to promote healthy pregnancy and birth outcomes. These findings have been used in conjunction with findings of focus groups of other key stakeholders to inform the development of a culturally tailored GDM risk reduction program for AIAN adolescents.

**Keywords:** American Indian and Alaska Native, adolescents, gestational diabetes, reproductive health, preconception counseling

## Introduction

American Indian and Alaska Native (AIAN) women are disproportionately affected by adolescent obesity, adolescent pregnancy, and gestational diabetes mellitus (GDM); all with nearly twice

the U.S. prevalence, and even higher rates of type 2 diabetes [1-3]. In the general population the highest proportional increase in GDM is among the youngest age group (15-19 years old) with prevalence almost doubling from 1991-2000 [2]. GDM in

turn increases the risk of obesity and type 2 diabetes in the offspring, creating a vicious cycle [4]. Thus, the need for early interventions to prevent GDM in AIAN youth is compelling. Raising awareness, receiving preconception counseling, and adopting a healthy lifestyle *prior* to pregnancy could help to prevent both GDM and type 2 diabetes. However, significant gaps exist in the current body of knowledge about effective strategies to reduce the risk for GDM, and knowledge on effective strategies is scant for AIANs and for adolescents.

The existing curriculum that serves as a basis for the AIAN tailored GDM risk reduction curriculum is entitled READY-Girls (**R**eproductive-health **E**ducation and **A**wareness of **D**iabetes in **Y**outh for **G**irls) [5]. READY-Girls is a validated theory-based preconception counseling (PC) program for teens with diabetes to raise awareness about diabetes and pregnancy and prevent unplanned pregnancies and pregnancy complications. READY-Girls is based on the Expanded Health Belief Model (EHBM), which posits beliefs lead to an intention to take action, linking decision making to actual behavioural outcomes [6,7].

The purpose of the qualitative needs assessment and formative evaluation phase of this multi-phase, multi-institution project is to gain insight from the perspectives of AIAN adolescent girls and other key stakeholders and experts on an AIAN-specific GDM risk reduction program. Other key stakeholders queried were health care professionals with expertise in AIAN health and diabetes, AIAN women with a history of GDM, and elected tribal leaders and tribal and urban Indian health care organization administrators. Findings from these interviews and focus groups are reported elsewhere [8]. All key stakeholder perspectives and recommendations have been used to inform the cultural tailoring of the existing READY-Girls preconception counseling program for adolescent AIAN females who are at increased risk of GDM. This paper reports the findings from AIAN adolescent girls who are at risk for GDM, our priority audience.

## Methods

### Research design

The focus group method of interviewing was intentionally chosen as a means to offset the power dynamic between interviewer and participant, by 'outnumbering' the researchers with more than one participant. This practice is especially important when discussing sensitive topics, or when interviewing children/adolescents [9,10]. This study was approved by the University of Colorado Multiple Institution Review Board and University of Pittsburgh Institutional Review Board.

### Sample/Setting

Girls who participated in this project were recruited with their mothers, and each mother and daughter participated in separate focus groups, whenever feasible. Recruitment methods included passive flyers, eNewsletter announcements, and word-of-mouth. Focus groups were conducted at American Indian community centers in Denver, CO, and Portland, OR,

which serve urban AIAN people and families from multiple tribal affiliations. Participants were all currently urban living, though some reported they had lived on reservations in the past. Using convenience sampling [11], each girl (12-18 years old) was required to be accompanied by an AIAN female adult caregiver (mother, grandmother, aunt, older sister). Inclusion criteria required girls to be overweight or obese by self-reported weight and height with body mass index (BMI)  $\geq 85^{\text{th}}$  percentile for age. Girls could not have a diagnosis of type 2 diabetes and needed to be fluent in English. Participants included 13 AIAN adolescent females (age  $15.5 \pm 1.8$  years). Three of the five focus groups included only adolescent females and two included a mother/daughter dyad. Rationale for this structure included challenges with recruitment and transportation issues with two participants.

### Data Collection Procedures

A researcher with qualitative methods training, and assisted by a note-taker, conducted semi-structured focus groups. To facilitate these focus groups (N=13), a moderator guide with both primary questions and follow-up probes was used [9]. The two principal investigators and two qualitative methods experts developed the moderator guide. Experts in the fields of diabetes, both pediatric and GDM, reproductive health, the health care of AIAN women and girls, mother/daughter communication, and adolescent health reviewed the guide. The moderator guide questions can be found in **Table 1**. Moderator guide questions focused between questions and on two primary areas: overall awareness and understanding of gestational diabetes, including its risk factors and prevention, and reproductive health and their impressions and suggestions for modifying the existing READY-Girls video and educational booklet.

Participants viewed video clips and excerpts from the READY-Girls booklet and were encouraged to mark up and write additional comments on selected excerpts from the existing READY-Girls booklet. During the last portion of the focus group interview, the moderator asked participants to share their written comments or their impressions of the booklet.

### Data analysis

A professional transcription service transcribed verbatim the digitally recorded focus group interviews. Data were analyzed using a note-based constant comparison method [12] including field notes, note-taker notes, and verbatim transcriptions [13]. Two trained qualitative methods researchers coded independently and then discussed the codes, combined the codes in the case of redundancy, and achieved consensus to increase reliability [14] of the coding scheme. A combination of inductive and deductive coding approaches guided coding. Qualitative data analysis and data organization was digitalized using Atlas.ti (Mac version 8.0). Researchers used Atlas.ti to assist in organizing, sorting, coding, and storing data and to facilitate a transparent analytical process [15].

**Table 1. Semi-Structured Focus Group Moderator Guide.**

|                     |  |
|---------------------|--|
| <i>Introduction</i> | How can a woman stay healthy during her pregnancy?<br>How does weight affect a pregnancy?<br>What do you call it when people get diabetes while they are pregnant?<br>What do you know about gestational diabetes?<br>What do you know about preconception counseling?<br>What do you know about your tribal culture that would help us as we modify this intervention to make it more culturally appropriate for/acceptable to you and girls like you? How should it be included?<br>If you had questions about gestational diabetes, pregnancy, puberty, birth control, who in your community would you ask? Where would you go to get this information? |
| <i>Video</i>        | What narrator and setting would you pick for your community?<br>Tell me about the things you like and those that you don't like in this video<br><br>Tell us about what we need to know about teens from your community so that we can be sure this video works for them.<br>What do you think of these scenarios? (asked after each video clip was viewed)  |
| <i>Booklet</i>      | Tell me about the things you like about this booklet.<br>Tell me the things you don't like about this booklet.   |

Three researchers also analyzed the marked-up booklets using content analysis technique [16]. These codes were discussed among the researchers and the principal investigators, collapsed for redundancy, and used to construct categories and themes, which paralleled and augmented those from the focus group data.

## Results

Overall, participants lacked awareness and understanding of GDM and their risk for developing GDM. Three primary themes were constructed from the focus group open-ended questions and marked up booklet data and are explained in detail in this section. These themes include: lack of awareness and knowledge of GDM; the need for pregnancy planning and culturally relevant GDM and reproductive health resources; and, the importance of using empowerment frameworks to promote positive reproductive health behaviors.

### Lack of Awareness and Knowledge of GDM

Participants understood basic principles of a healthy pregnancy, such as, eating more fruits and vegetables, consuming water, managing stress, getting plenty of sleep, seeking social support, and eating less 'junk food'. However, they knew very little about GDM, preconception counseling, or the relationship between pre-pregnancy weight and GDM. One participant shared, in responding to "how can a woman stay healthy during her pregnancy":

*By eating lots of fruits and vegetables, and cutting out bad things from your diet, like junk food and coffee, and not smoking, using drugs, alcohol, and [getting] lots of exercise, and sleep.*

Another participant shared her limited understanding of GDM:  
*I know it's a specific kind of diabetes that you get when you're pregnant, and I haven't honestly learned too much about it.*

*I know – I think eating a lot of sugar and cutting back really quickly has an effect, too.*

Another participant described her experience with her older sister who was pregnant and had GDM (this participant called it 'temporary diabetes'):

*I was eight years old when she had it – but since she had temporary diabetes while she was pregnant, there was a chance that her daughter could get it, because she had it while she was pregnant. So she had to eat salads and stuff like that. And she was really overweight and she loved to eat junk and fast food and stuff like that, but she started eating salads and all that stuff. And then after she was pregnant, the diabetes left, after she had her baby.*

Collectively, these quotations exemplify some baseline understanding of healthy pregnancy principles, but limited understanding of GDM. Participants shared their general understanding of diabetes typically in context of an older adult in their family with type 2 diabetes, as suggested here:

*But I really only know more about regular diabetes, because my grandmother had it for so long and I helped her with that. I helped her with her insulin shot, and – because I never really learned about it in school or anything like that, so during my health classes, I used to try to look up stuff - because she wanted to get off her insulin. So trying to regulate her – I forget what it's called.*

Any discussion about their own risk perceptions of developing GDM, or modifiable risk factors for GDM - such as pre-pregnancy body weight, pregnancy weight gain, and physical activity as a means to manage weight both pre and during pregnancy - was starkly missing from these responses.

### Need for Pregnancy Planning and Culturally Relevant GDM and Reproductive Health Resources

The lack of structured reproductive health and GDM education emerged as the second primary theme from these interviews.

Participants' discussion about diabetes was primarily anecdotal from stories about their grandparents who had diabetes, and girls explained they tend to learn about sex and reproductive health from the Internet and "all of my friends". Participants suggested the Internet is their preferred source of information, and that school-based 'sex-ed' primarily focuses on basic biology and/or sexually transmitted diseases (STD). They thought more effective reproductive health education should contain these topics but also include other consequences of sex and unplanned pregnancy, such as GDM. One participant shared:

*And I also think it's a lack of education kind of thing. I kind of started with the sex ed. in middle school, but it only taught me, this is the vagina, .... and it didn't really teach me, okay, if you have sex, here's all these things that could happen. You could get pregnant, you could get STDs, you could [get].... all these other things"; and I think that needs to be taught, also, with the biology part. So I think that's super important and I think when you are planning to have a pregnancy and have a baby, emotionally you're ready.*

Participants lacked information about preconception counseling. However, one participant worked through the term in the focus group, when asked "what does the term preconception counseling mean to you?" by clearly articulating:

*So pre means before, and conception obviously means getting pregnant, right? So before getting pregnant, and counseling – to me – means kind of like a guide, almost. And people usually go to counseling because they want a better mindset, and they want to fix their problems. So probably fixing your problems before – or trying to go down the right path before you're pregnant, or just being more aware. It's kind of – you want to get pregnant, I feel like, but you want to make sure you're doing things the right way, and setting yourself up for a good pregnancy.*

Participants in this particular focus group suggested the "preconception counseling" concept was novel, and reiterated the need to be physically, emotionally, mentally, and spiritually aware of implications of pregnancy, as supported by the traditional holistic mind, body, spirit wellness paradigm of many AIAN populations. Participants did not think most girls their age plan for pregnancy and suggested:

*Especially with our generation, it's really cool to have sex and it's really cool to be sexual and stuff like that. So I think people are having sex out of peer pressure through media and through everything else. So much is how you fit in, so I think like more people are getting pregnant because they don't really know what safe sex is, or they're not really using protection. A lot of my friends are pregnant or have had babies, and they're all under 17. From what I see in my community, more people are having babies not prepared.*

Lack of access to resources specific to GDM, pregnancy, and diabetes was discussed as a formidable barrier for girls and their mothers. Participants felt that more education to support better preparation to care for themselves during pregnancy could prevent pregnancy-related complications such as GDM:

*If they had a website, I'd be more likely to go to the website than actually read that [booklet]. And I think access is one of the key things for people, is when you can't find access to something, you usually go without it.*

Participants also discussed how best to provide these types of resources and who might be a role model or influential figure to provide such information for AIAN adolescent females. Participants said they wanted "real stories" from "people I can relate to". They also suggested highlighting statistics on the relevancy of GDM for AIAN adolescents may heighten perceived susceptibility of the condition. Participants suggested preference for AIAN females or elders (e.g., mothers, aunts, cousins, and grandmothers) who understand the culture and offer AIAN values and perspectives to reproductive health and diabetes education:

*And something for me, like I have to spiritually be connected to them, and culturally. I'm not trying to be racist, but if [I'm] a Native teen, I don't want a White woman to be the advocate and teach me white things. I want someone who will teach me my traditions and teach me how to sing and dance and drum and bead. I want someone who I have common interests with and someone I can relate to.*

This concept of cultural tailoring and incorporation of traditional AIAN values is identified and elaborated in the third primary theme from these findings - empowerment and safety.

### **Importance of Using Empowerment Frameworks to Promote Positive Reproductive Health Behaviors**

Participants discussed the need for health education to emphasize empowering adolescent females to make healthy choices which prioritize their mental, emotional, physical, and spiritual well-being. They indicated adolescent females need to have healthy role models and to be aware of their right to determine when and if they want to have sex. They also believed in the importance of integrating AIAN traditional teachings of respect towards females for their role in the cycle of life. Participants shared that adolescent females need education on how a healthy intimate relationship should prioritize their own safety:

*But I think that they should learn how your partner should treat you and respect you. Because I think a lot of people are like, "Oh, well he yells at me because he loves me," or, "He calls me a bitch because he's frustrated because he just cares about me so much." I think women are taught that – I'm sorry – but when girls are so young, like kindergarten, and a boy hits them, we are taught that it means they like us. And girls growing up, it's abusive – They're still in that mindset.*

Peer pressure to have sexual relations was raised as a reproductive health safety concern. Participants noted that reproductive health and GDM education should focus on the facts, but also emphasize building self-esteem and provide resources and outlets for support when issues such as domestic violence or peer pressure impact a female's sense of safety and well-being. One participant shared how she'd

like self-esteem building skills incorporated into reproductive health classes at her alternative high school:

*I think if you have good self-esteem – I feel everything kind of starts in your mind. And I feel like if you have a very solid foundation of who you are and how to deal with things, I feel like there's [there should be] a class on that. And definitely having good examples of who strong women are and who you could be... so like a sex ed. and a health class, and in the health class, they teach good coping skills, like self-empowerment – And I think that's really important.*

Together, findings from these focus groups suggest unique additions to increase relevance and applicability for adolescent AIAN females who are at risk for GDM.

## Discussion

The participants lacked awareness or understanding of GDM and its risk factors, placing them at risk for unplanned pregnancies and for developing GDM. Gestational diabetes risk reduction centers on a woman achieving a healthy body weight prior to pregnancy, as well as management of weight gain during pregnancy. The former requires women to recognize the relationship between risk for GDM and their pre-pregnancy weight, and to receive education, resources, and support to plan and achieve a healthy weight prior to pregnancy. This means GDM risk reduction education must occur well *before* a woman plans to get pregnant as weight loss of any kind once a woman is pregnant is not recommended. This poses a challenge for adolescents, as the majority of teenage pregnancies are unplanned [17]. Moreover, risk for GDM is higher for AIAN females than non-AIAN females [18], and the prevalence of unplanned adolescent pregnancy is also higher [17,19,20]. Therefore, raising awareness through preconception counseling should begin in early adolescence, ideally prior to her first sexual encounter. The original PC program, READY-Girls is based on the EHBM and this health behavior change theory supports engaging increased self-susceptibility and severity (risk perception) as a step towards healthy behavior change [7].

The participants also emphasized the importance of empowering adolescent girls to make healthy choices regarding their reproductive health through education to enhance self-confidence, and that an effective GDM risk reduction program should include tools and resources focused on adolescent girls' self-confidence. The EHBM construct "self-efficacy" supports this theme, as does published literature related to AIAN adolescent health and pregnancy prevention [17,21].

While this study was limited by including convenience sampling at two locations, as is typical of qualitative research, this is not intended to offer generalizability or transferability to wider audiences. However, in the context of this overall study, these data informed tailoring of the education program in conjunction with focus group and individual data from a much larger sample size as mentioned earlier in this paper. Additionally, the focus group moderators and note-takers were

not AIAN. A non-AIAN moderator may have influenced the extent to which participants shared the need for AIAN tailored materials, however, it may have enhanced this discourse as participants did not assume the moderator understood their perspective and thereby perhaps explained in more detail than they would have with an AIAN focus group moderator. To mitigate the 'outsider' researcher concern, each focus group was hosted at a site already comfortable and familiar to the participants (i.e., an AIAN community center) and each focus group was hosted by an AIAN adult woman who introduced the research project, the researcher, and remained available for questions outside of the room during the focus group.

## Conclusions

The participants' lack of awareness and understanding of GDM could increase their risk of developing GDM and possible subsequent pregnancy-outcome complications. They emphasized the need for culturally-responsive resources and educational materials. They provided invaluable insight into culturally tailoring a curriculum intended to support efforts to reduce risk for diabetes, unplanned pregnancy and GDM. These findings contribute new understanding to address gaps in current knowledge about such health risks among at-risk AIAN youth. In particular, these findings that the participants' lack of awareness and knowledge of GDM suggests that new health programming is needed to mitigate risk for developing GDM, and to promote healthy pregnancy and birth outcomes in this vulnerable population. Moreover, introducing PC education early to AIAN adolescents, prior to sexual activity, can also potentially prevent unplanned pregnancies. This information may also help to address inadequacies in other current reproductive health curricula that may be lacking in their cultural relevance and relatability for AIAN youth. More culturally relevant health programming is urgently needed to address the disparity in pregnancy and birth outcomes and improve the health of AIAN women, their children and future generations.

In the final dissemination phase of this project, the newly developed AIAN GDM risk reduction program will be available to all clinicians who provide care to AIAN adolescent girls. Given the lack of resources specific to GDM risk reduction for AIAN females, this culturally tailored curriculum will be an invaluable tool for diabetes educators upon its completion. We recommend delivery of the program in collaboration with tribal and urban Native communities and health care professionals who have expertise in AIAN patient care. Respecting cultural nuances may help make the educational material more relatable to this priority audience.

## Competing interests

The authors declare that they have no competing interests.

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### Authors' contributions

| Authors' contributions             | KM | SS | KJN | MAT | YGR | KG | DCP |
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| Research concept and design        | ✓  | -- | --  | ✓   | --  | -- | ✓   |
| Collection and/or assembly of data | ✓  | ✓  | --  | --  | ✓   | -- | ✓   |
| Data analysis and interpretation   | -- | ✓  | --  | ✓   | --  | -- | --  |
| Writing the article                | ✓  | ✓  | ✓   | ✓   | ✓   | ✓  | ✓   |
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