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Reducing risk for gestational diabetes among American Indian and Alaska Native teenagers: Tribal leaders' recommendations

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Abstract

Objective: To elicit feedback from tribal leaders and American Indian/Alaska Native (AI/AN) health system administrators as a national stakeholder perspective to inform the development of a gestational diabetes mellitus (GDM) risk reduction and preconception counseling intervention for AI/AN teenagers at high risk for GDM.

Methods: A semi-structured focus group interview guide was developed by both principal investigators and qualitative methods experts. Using open-ended questions about the Reproductive-health Education and Awareness of Diabetes in Youth for Girls (READY-Girls) booklet and video clips, AI/AN health care system administrators and elected tribal leaders attending the 2015 National Indian Health Board Conference in Washington, DC, made recommendations on adaptation for an AI/AN audience. The focus group was recorded, transcribed verbatim, and analyzed by two researchers using an inductive coding technique with constant comparison method as supported by the grounded theory approach.

Results: Recommendations from the 12 participants included: (1) the best ways to communicate with AI/AN teenagers, (2) the importance of parental, family, and community education and engagement to support AI/AN teenagers in GDM risk reduction, and (3) building on traditional AI/AN cultural values and practices, while accommodating differences between tribes and regions.

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AUTHOR CONTRIBUTIONS

KRM, SS, and DCP developed the study aims, provided oversight to the study, and wrote the manuscript. HA contributed to writing and editing the manuscript. MAT and SS conducted the data analyses. GM and KRM conducted the data collection and contributed to data interpretation. All authors approved the final manuscript.

The Stopping GDM Study Group members are provided in Appendix.

CONFLICTS OF INTEREST

KRM was a consultant for Novo Nordisk, Inc. The remaining authors declare no conflicts of interest.

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Conclusion: Findings from this focus group were used to inform the iterative development of a GDM risk reduction and preconception counseling intervention for AI/AN teenagers.

Keywords

adolescents and young adults; American Indian/Alaska Native; gestational diabetes; preconception counseling

1 | INTRODUCTION

American Indians and Alaska Natives (AI/ANs) are disproportionately affected by gestational diabetes mellitus (GDM),[1] as Indigenous women are twice as likely to have GDM than non-Hispanic Whites.[2] GDM, the most common medical complication of pregnancy,[3] presents additional maternal and fetal risks, including pre-eclampsia, cesarean delivery, pre-term birth, and stillbirth.[4] GDM also increases the risk for developing type 2 diabetes for both the mother postpartum and the offspring.[1,2,5] Efforts are needed to increase awareness of GDM[6,7] and to decrease its risk in AI/AN communities, including more culturally responsive preconception counseling programs. However, to our knowledge, no preconception counseling programs exist that are focused on GDM risk reduction for AI/AN teenagers or at-risk teenagers from other ethnic groups.

Tribal leaders have informed the cultural adaptation of pediatric asthma screening procedures[8] and diabetes education materials.[9] Consultation with tribal leaders and community members is identified as a requirement for conducting research in tribal communities and as a strategy toward eliminating health disparities for AI/ANs.[10–13] Moreover, involving tribal leaders in the design of health-related studies promotes the research experience and builds and maintains trust with tribal members.[11] Indeed, these community gatekeepers are often vital to the success of research projects conducted in Indigenous communities, as they impart teachings on Indigenous ways of knowing to members of the research community.[14]

Preconception counseling is evidence-based advice on preventing complications during pregnancy for all women with diabetes of childbearing age.[4] The American Diabetes Association recommends that preconception counseling start at puberty for all women with diabetes.[4] Reproductive-health Education and Awareness of Diabetes in Youth for Girls (READY-Girls) is the only theory-driven, developmentally appropriate, evidence-based, and cost-effective preconception counseling program that aims to increase awareness of reproductive health issues and decrease pregnancy-related complications among adolescents with diabetes.[15–17] READY-Girls is based on the Expanded Health Belief Model,[18] which encompasses dimensions related to adolescents' perceived susceptibility and severity of unplanned pregnancies and pregnancy-related complications; benefits and barriers to seeking preconception counseling and using effective family planning; motivational cues and social support; preconception counseling-seeking intentions and behaviors; and initiating preconception counseling-related discussion with clinicians.[16,17] We adapted READY-Girls into Stopping GDM to address reducing the risk for GDM prior to pregnancy among adolescents without diabetes.

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READY-Girls has also been culturally adapted for Black and Latina adolescents with diabetes.[19,20] In these cultural adaptations, we have considered the perspectives of mothers, daughters, and clinicians to increase the acceptance and effectiveness of the program among different racial and ethnic groups. We gathered perspectives from these same key stakeholders for AI/ANs,[7,21] as well as AI/AN women with a history of GDM[6] in culturally tailoring the materials for AI/AN teenagers. Tailoring health education materials to be culturally responsive for AI/ANs is a well-established method to improve the acceptance and effectiveness of health programs created for AI/AN communities.[9,21]

Examining perspectives from key stakeholders is essential when tailoring health education programs on sensitive health topics for different ethnic groups.[22] This is perhaps even more important when designing programs that are national in their scope, as in our GDM risk reduction through preconception counseling intervention. The aim of the present study was to gain the perspectives and recommendations of a diverse national sample of elected tribal leaders and AI/AN health program administrators who participated in a focus group to inform the development of an innovative gestational diabetes risk reduction intervention for AI/AN teenagers called Stopping GDM.

2 | MATERIALS AND METHODS

This study was conducted during a Phase 1 qualitative needs assessment of a larger 5-year, multi-phased study. Further details on the larger study and the other stakeholders involved in Phase 1 have been published elsewhere.[6,7] To appeal to a broader audience than the five AI communities participating in the Phase 2 randomized controlled trial, we obtained a national AI/AN stakeholder perspective on Stopping GDM. In Phase 3, we are disseminating the intervention to clinicians serving AI/AN teenagers, their families, and communities across the nation.

We recruited 12 participants and conducted this focus group in a meeting room at the 2015 National Indian Health Board Conference hotel in Washington, DC. Participants received a light snack and a $40.00 gift card. The focus group was moderated by two experienced Native researchers (KRM, GM).

Participants were aged 18 years or older, AI and/or AN, and attendees at the 2015 National Indian Health Board Conference. Participants were recruited from Alaska, Arizona, Michigan, Minnesota, Oklahoma, Texas, Washington State, and Wisconsin. Four participants were elected tribal leaders. An intertribal health board member, a tribal business organization employee, and six tribal or urban Indian health program administrators made up the remainder of the participants.

Recruitment was conducted through word-of-mouth on site and a summary brochure in each conference attendee's information packet. As a waiver of informed consent was granted by the University of Colorado Multiple Institutional Review Board, participants were provided with an information sheet in lieu of signing an informed consent. A semi-structured moderator guide included general questions and questions about the existing READY-Girls education booklet and video. Booklet and video excerpts were shared with the focus group

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participants to generate conversation and elicit first impressions about the existing READY-Girls program. The full moderator guide can be found in Table 1.

The focus group was digitally recorded and transcribed verbatim. Two qualitative researchers analyzed the data using a codebook constructed by the lead qualitative researcher. The codebook reflected both inductive and deductive codes drawn from the moderator guide questions, the literature, and supporting theoretical framework. Coding was conducted using qualitative thematic analysis and themes emerged as codes were collapsed and defined into categories. These categories then led to overarching themes.[23]

3 | RESULTS

Three primary themes emerged from this focus group: (1) the best ways to connect and communicate with AI/AN adolescent girls, (2) the importance of parental, family, and community education and engagement to support AI/AN teenagers in GDM risk reduction, and (3) building on traditional AI/AN cultural values and practices, while accommodating differences between tribes and regions.

3.1 | Best ways to connect and communicate with AI/AN adolescent girls

First, participants discussed ways to communicate and engage teenaged girls and cautioned against using directive language or 'telling them what to do.'

> When I read 'you will need to know' – you're talking to a teenager, when you start a sentence with 'You …' they will not respond at all, so I would rephrase and redirect some of this.

Second, participants were not supportive of using the concept 'ready' as it sounded 'suggestive' and 'encouraging' with regard to sexual activity.

> Just the 'ready' – like ready for what? Ready for sex? I don't like that way of saying it. I don't like the idea of the 'ready' stuff…

Third, participants indicated that most teenagers do not plan ahead and teenagers specifically would not consider 'planning' a pregnancy. One participant explained:

> One of the things that I picked up when they were talking about 'well when you're planning on doing this and when you're planning on getting pregnant and when you're planning on' … I don't know that any teenager plans on getting pregnant – and like teenagers have a like 'it will never happen to me' and 'I'm indestructible.' 'I will just be really careful'."

Fourth, participants suggested that teenagers need to know why they are at risk and what the risk factors for GDM actually are – and that providing 'statistics' or an 'explanation' of 'why' this topic is relevant would be helpful.

> I would say put it right up front – that yeah, it's important to prevent gestational diabetes, and maybe if you have some stats on this, how much more likely Native Americans are to be affected by it, and … what it can do to the baby.

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Finally, participants suggested showing teenagers ‘doing things they always do’ and using actors who look like AI/AN teenagers. The participants highlighted social media usage as an activity that would resonate with teenagers. When asked about the format of a GDM risk reduction program, participants shared:

> I would say … if you put something up there that they can’t relate to – or, that they only see once or twice a year, like a pow wow, … it’s quickly forgotten – rather than showing them, you know, in a hall at school, or standing around … they’re all, you know, texting or tweeting.

> The other thing is that I would add pictures that they can relate to, that are from their communities … because pictures – there’s not a whole lot in here.

3.2 | Importance of parental, family, and community education and engagement to support teenagers in GDM risk reduction

Participants emphasized the importance of involving parents, extended family, and the entire community in GDM risk reduction. They advised community-inclusive education as best-suited to support healthy GDM risk reduction behaviors. Participants discussed ‘balance’ and ‘interconnectedness’ as traditional values to engage communities, families, and teenagers.

> A larger picture about healthy relationships within [an] American Indian community … for me as an *Anishinaabe*, the role of men and women and that balance, and that is what I would want to promote as a tribal elder/grandma/mother for my daughter.

> … true Navajo is a long healthy life, you know, living in balance and harmony with yourself, your clan, your family, your community – and somehow depicting that. If I were a teenager, I would probably recognize what healthy is, because it’s something that’s [taught by] the community. And it [would help] to reinforce what the community is trying to teach.

> What about the hoop dancers where it shows the connection, where they’re all interconnected, the hoops, you know, showing the connections between all of us?

Participants also recommended a family and community emphasis rather than using only teenagers, as in the READY-Girls video.

> I think it would be kind of good if it was more of a family setting – you know, a family setting with parents.

3.3 | Building on traditional AI/AN cultural values and practices, while accommodating differences between tribes and regions

Participants shared concerns about a national program for all AI/ANs and suggested that the diversity among tribes, their cultures, and geographical locations should be addressed in any health education program created for AI/ANs.

> Sure, there is culture, but it’s still different from region to region and area to area and tribe to tribe.

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Participants acknowledged the difficulty in making a different program for each tribe. Suggestions for customization for a particular tribe or community included 'placeholders' to insert images specific to a region or a cultural practice. They also suggested providing space to tailor the nutrition and physical activity examples, based on traditional practices in each region.

> On the pictures, maybe if you could use some place keepers and let communities put their own pictures?

Participants also shared how traditional Native cultural practices address issues of wellness and prevention; these should be considered in a 'Western' medical model education program.

> It doesn't have to be these specific stories but the value systems, the customs and the practices and the beliefs … for our American Indian population, but embedded in that book for the mothers, fathers, too, teens – [they] can learn to embrace that – it's really hard but … those teachings are the original prevention, they're our protective barriers.

> And so I think, that a lot of the tribes have their own prevention measures, and that … we don't have to go into the … ceremonies or the songs, but more of a general perspective of you know, we want our people to be healthy, we want a long life, let's live in balance, and somehow carefully bring that out.

> This program can be tailored for our community to be more holistic and [to include] all parts of your life…the physical, emotional, and spiritual."

4 | DISCUSSION

Recommendations from this focus group of tribal leaders and AI/AN health system administrators emphasized traditional AI/AN cultural values and practices, while accommodating differences between tribes and regions; strategies for optimizing communication with AI/AN teenagers; and including parents, families, and communities to support AI/AN teenagers in GDM risk reduction.

The need to accommodate differences between tribes and different tribal cultures for a national preconception counseling program on GDM risk reduction for AI/AN teenagers is consistent with a prior study conducted with a diverse group of tribal leaders. They expressed a strong preference for relevance to their own specific tribe or culture in diabetes education materials.[9] Our participants acknowledged this difficulty in creating a national program for all tribes and suggested allowing for local customization of the education materials. Stopping GDM includes a general resource toolkit on physical activity, healthy eating, and reproductive health resources. As Stopping GDM is more widely disseminated, this toolkit could be adapted even further with local images, recipes, and traditional cultural practices by Indigenous communities interested in using the Stopping GDM materials. Further action on customization of the Stopping GDM materials will be considered in the final revision of Stopping GDM at the end of the overall larger study.

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Our focus group participants also recommended talking to teenagers in a positive way rather than using directive language. Literature on strength-based communication with teenagers supports this recommendation. To foster resilience and support healthy adolescent development, it is important to nurture the strengths of youth that promote positive changes and build confidence.[24]

Furthermore, our focus group participants shared the need to involve parents and families in Stopping GDM and recommended a community-based and holistic approach to 'healthy pregnancy' and 'planned pregnancy' concepts. Participants also shared the importance of conveying this message with balance to instill healthy Indigenous family values. We recruited mother/daughter dyads as randomized controlled trial participants and provided mothers with an e-booklet to enhance communication with their daughters on reproductive health topics. As further refinements are made to Stopping GDM, the application of Indigenous ways of knowing and learning, another principle of research in an Indigenous context,[14] will result in an even more effective and culturally sensitive program.

Finally, our focus group participants indicated that teenagers need to know the factors that increase their risk for GDM. The Expanded Health Belief Model, a health behavior change theory used as a basis for READY-Girls, supports engaging risk perception in healthy behavior change promotion.[18] The risk factors for GDM are included in the Stopping GDM materials and are the same as those associated with type 2 diabetes.[4,25] Modification of risk by achieving a healthy body weight prior to pregnancy with healthier lifestyle choices is emphasized in Stopping GDM.

The primary limitation of this study was the small sample size. As with all qualitative studies, another limitation was the lack of ability to generalize beyond the context of this sample. Nonetheless, AI/AN leaders from across the USA have provided an important national perspective. Clinical expert and lay panels of AI mothers and daughters are other key stakeholder perspectives that have been used to ensure that the content of Stopping GDM is clinically accurate, culturally responsive and appropriate, and includes skill-building to target behaviors to reduce risks for GDM, unplanned pregnancies, and pregnancy complications. Our next steps for Stopping GDM include culturally tailoring for Native Hawaiian and AN communities. The free Stopping GDM intervention for AI/AN teenagers can be accessed at www.stoppinggdm.com.

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APPENDIX

The Stopping GDM Study Group includes: Aletha Akers, Sandra Beirne, Angela G. Brega, Laura Chalmers, Denise Charron-Prochownik, Jean Howe, Andrea Fischl, Heather Garrow,

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TABLE 1

Moderator guide questions

General questions	Are you familiar with gestational diabetes or GDM?
	Are there effective/successful programs in your community that address sexual health/sex education with Native teen girls? Mothers? If so, what makes them effective/successful?
	What do you know about teens in your community that would help us to modify this intervention to help them understand the importance of managing healthy lifestyles to prevent GDM?
	What do you know about your tribal culture that would help us as we modify this intervention to make it more culturally relevant? How should it be included?
Booklet and video questions	Tell me about any 'coming of age' traditions which are practiced in your community.
	Tell me things about the booklet/video that you like or don't like.
	Do you have any other initial comments or feedback?
	Is there any information that seems culturally offensive? How could it be modified to be more culturally sensitive?

Abbreviation: GDM, gestational diabetes mellitus.