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Healthcare Experiences of Low-Income Women with Prior Gestational Diabetes

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Abstract

Introduction An important yet understudied component of postpartum type 2 diabetes risk reduction among high risk women is experiences with the healthcare system. Our objective was to describe the healthcare experiences of a diverse, low-income sample of women with prior GDM, including their suggestions for improving care. *Methods* Focus groups were conducted among African American, Hispanic, and Appalachian women who were diagnosed with GDM within the past 10 years. Participants were recruited from community and medical resources. Twelve focus groups were conducted, four within each race-ethnic group. *Results* Three broad themes were identified around barriers to GDM care, management, and follow-up: (1) communication issues; (2) personal and environmental barriers; and (3) type and quality of healthcare. Many women felt communication with their provider could be improved, including more education on the severity of GDM, streamlining information to be less overwhelming, and providing additional support through referrals to community resources. Although women expressed interest in receiving more actionable advice for managing GDM during pregnancy and for preventing type 2 diabetes postpartum, few women reported changing behaviors. Barriers to behavior change were related to cost, transportation, and competing demands. Several opportunities for improved care were elucidated. *Discussion* Our findings suggest that across all racial and ethnic representations in our sample, low-income women with GDM experience similar communication, personal, and environmental barriers related to the healthcare they receive for their GDM. Considering the increased exposure to the health care system during a GDM-affected pregnancy, there are opportunities to address barriers among women with GDM across different race-ethnic groups.

Keywords Gestational diabetes · Type 2 diabetes · Prevention · Low income · African-American · Appalachian · Hispanic · Health care · Barriers

Significance

What is already known on this subject? Women with previous gestational diabetes mellitus (GDM) underestimate their risk of type 2 diabetes, which may minimize their motivation to overcome barriers to adoption of preventive behaviors.

What this study adds? This study extends previous literature by going beyond individual risk perception and describes the healthcare experiences of a diverse sample of low-income women with a history of GDM. We found that interactions with the health care system and providers appear to be a significant component of improving postpartum care and promoting type 2 diabetes prevention among these women.

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Introduction

Gestational diabetes mellitus (GDM) affects 7–18% of pregnancies (Centers for Disease Control and Prevention 2011) and increases type 2 diabetes mellitus (T2DM) risk, with 3–24% of women developing T2DM within 1 year of a GDM-affected pregnancy and up to 50% of GDM pregnancies resulting in T2DM within 5 years.(Bellamy et al. 2009) The period after a GDM diagnosis and pregnancy represents an opportunity for initiation of lifestyle interventions to manage and improve long-term maternal and infant health (Tieu et al. 2013). Women with previous GDM underestimate their risk of T2DM,(Kim et al. 2007; Zera et al. 2012) which may minimize their motivation to overcome barriers to adoption of preventive behaviors (Kim et al. 2007).

An important, understudied component of postpartum T2DM risk reduction is women's experiences and interactions with the healthcare system during and after pregnancy. Preparing a woman with GDM for long-term self-care includes information on which provider(s) to see, routine tests/screenings, and T2DM risk reduction. However, confusion on provider responsibility regarding interconception care remains an obstacle (Oza-Frank et al. 2014; Smirnakis et al. 2005): obstetricians focus on delivery and reproductive health, rather than non-reproductive chronic health issues (Stormo et al. 2014), which could result in a critical missed opportunity for T2DM prevention education during prenatal care. Furthermore, poor communication exists between obstetricians and primary care providers (Stuebe et al. 2010) in relaying GDM diagnosis, and primary care providers rarely ask about GDM history, resulting in a gap in appropriate preventive care (Rodgers et al. 2014). Finally, minority (Solomon et al. 1997) and low-income (Anna et al. 2008; Cullinan et al. 2012) women are at highest risk of being diagnosed with GDM yet the importance of culturally specific care (Metzger et al. 2007) is understudied among low-income women with prior GDM in the US. This study extends previous literature by describing the healthcare experiences of a diverse sample of low-income women with a history of GDM, including suggestions for improving care.

Methods

Focus group discussions (FGDs) were conducted February–May 2012 with African American, Hispanic, or Appalachian (residing in counties designated as Appalachian (Appalchian Regional Commission 2016)) women, aged 18–45 years, and with GDM diagnosis within the past 10 years. Women were eligible for only one FGD. Women were recruited from urban and rural sites representing five regional areas across the entire state of Ohio (Table 1), through flyers placed in OB/GYN clinics affiliated with academic institutions, state health department funded clinics (e.g., WIC, family planning), and local providers serving low-income women, and for a small subsample, through online advertising. Demographics and history of diabetes were collected during scheduling phone calls. FGDs of participants matched for ethnicity were led by trained moderators from a similar ethnic background using a semi-structured interview guide with open-ended questions in English or Spanish. A market research firm was hired to conduct all FGDs. Discussions lasted up to 2 h and topics included community-level views on:

Table 1 Number of focus groups by region of recruitment

Region of state	Racial or ethnic make-up of focus group[a]		
	African-American	Hispanic	Appalachian[a]
Northwest	0	2	–
Southwest	2	1	2
Central	1	0	0
Southeast	0	0	2
Northeast	1	1	0
Total	4	4	4

[a] Participants self-identified race/ethnicity as African-American or Hispanic, or self-identified with Appalachian background

- Healthcare history (type of physician used before, during and after pregnancy, barriers to seeking care, experience at the post-partum visit)
- Knowledge about GDM and GDM-related risk for T2DM
- GDM-related health information received (before, during, and after pregnancy)
- Post-GDM T2DM prevention and testing
- Feedback on educational outreach materials for GDM and T2DM prevention (the primary aim of the FGDs)

All groups were audio-recorded, however, the marketing research firm was only able to provide the audio recordings for 8/12 of the FGDs. These discussions (two Hispanic, three Appalachian, and three African American groups) were transcribed verbatim. One of these groups was conducted in Spanish. The Spanish language transcript was translated to English for analysis by contractors not affiliated with the study and verified by a bilingual member of the study staff. Transcripts for an additional four FGDs (two Hispanic, one African American, and one Appalachian group) were available from the market research company. These transcripts were not verbatim and contained a "smoothing over" of text (e.g., correcting grammatical errors, removing pauses, etc.).

Since the topical content remained intact, these transcripts were also included in the analysis.

A codebook was developed which included both deductive codes (drawn from the questions themselves and the interests of the research team) and inductive codes (drawn from a review of the transcripts). After an initial codebook was developed, the team discussed the codes and their definitions on several calls and the codebook was refined for clarity and completeness. A final refinement of the codebook was completed after coding a subset of the data (e.g., codes that were too broad and resulted in extensive use were broken down into more specific codes; subcodes were not used).

Codes were applied to the textual data using MaxQDA (Verbi Software). A thematic analysis of the data (Guest et al. 2012) was conducted around barriers to and suggestions for successful GDM care, management, and follow-up. Structured comparisons (side by side reviews of coded segments and associated summaries for each code for Appalachian, Hispanic, and African American women) were used to identify issues relevant to individuals from different race-ethnic groups. Women provided informed consent to participate and were provided $50 as compensation for their time. The study protocol was approved by the Ohio Department of Health Institutional Review Board.

Results

The analysis included four FGDs with participants from each race-ethnic group (mean participants/group = 7.2). Group demographics by race-ethnicity are shown in Table 2. Three broad themes emerged around barriers to GDM care, management, and follow-up: (1) communication issues; (2) personal and environmental barriers; and (3) type and quality of healthcare.

Communication Issues

Communication issues with providers affected the quality and quantity of care received, including women's knowledge, management, and follow-up of GDM. African American women reported missed appointments because of systems-issues such as unanswered phones and unreturned calls. Also at a systems-level, African American participants noted that only women with a strong family history were offered T2DM testing at 6 weeks post-partum. At the provider-level, African American women felt people within their community underestimate the severity of T2DM. Even though T2DM is perceived to be a "predominately African American disease," women felt providers need to stress its importance. One African American woman declared, "So I think they need to make it more serious like AIDS taken serious, diabetes can be taken serious."

African American participants additionally explained that young women in their community are especially likely to underestimate the severity of GDM and need a "coach" to force them to pay attention to GDM advice and offer support. Examples of a "coach" specifically mentioned by participants included an African American physician who understands the community's needs or other health care providers:

> It's up to you to know about diabetes, it's up to you to educate yourself, it's up to you to take it serious and ownership for what you need to do and exercise but if you have those who are in similar situations as you to work with you and to help you, it's easier. Like I had my mom help me you know, my grandmother who's a nurse helped me. But everyone doesn't have that type of support to help them so they don't care about it you know, and it's not as easy for them to work towards gettin' rid of it or to manage it if you don't have someone to encourage you and to help you who knows what you're going through.—African American Woman

African American women specifically requested information from their providers about their community with a focus on data and risks to facilitate addressing these communication issues.

Appalachian participants noted that medical forms at the primary care provider rarely asked about history of GDM, a system issue that could resultin underreporting of the diagnosis and missed opportunities for testing and education around T2DM. Like African American women, some Appalachian women felt that their physicians downplayed GDM and did not respond to concerns about their health history. Conversely, other Appalachian women were turned off by overly dogmatic styles and physicians that were too harsh. One Appalachian women shared that her doctor "will

Table 2 Demographic characteristics of focus group discussions by race-ethnic group

Ethnicity	Number of groups	Mean number of participants	Mean number of children	Mean age (years)	Current T2DM (%)	Time since GDM diagnosis		
						≤ 1 year (%)	2–5 years (%)	6–10 years (%)
African American	4	8.0	2.8	34	17.6	23.5	55.9	20.6
Appalachian	4	5.8	2.4	32	4.2	20.8	54.2	25.0
Hispanic	4	7.8	2.5	34	16.7	10.0	60.0	30.0

flat out tell you you're gonna kill your child. So I was very careful with what I told him but that made me feel uneasy that I HAD to be! I felt like I should be able to be open and honest with my doctor of what was going on and I wasn't able to do that." Appalachian women suggested that patient education and empowerment would be greater if providers went through brochures with patients: "If you had a d- nurse or something that went through all of it maybe just pointed out things and explained further into it. It might stick in people's heads more and actually cause them to read through the little thing."

Like African American women, Appalachian women talked about the need for additional support, including from the medical staff, to help them overcome barriers and facilitate lifestyle behavior changes. One woman described how her dietician was a key player in her success at improving her diet after being diagnosed with GDM: "And um she gave me ownership of it too. She gave me empowerment. You know, this is for your baby, you can do this."

Hispanic women emphasized being provided with little actionable information from their providers. One Hispanic woman shared "And I was borderline so he kinda was just like watch your sugar intake. And that was kinda pretty much it. It wasn't too detailed." Many Hispanic women reported feeling that information on GDM got lost in the over-whelming amount of information provided during pregnancy and what they did receive was "very vague. It was more like… a lot of just pamphlets," while they would prefer "more detail, more caring" (Hispanic woman).

There were some similarities in reporting communications issues across all race-ethnic groups. Appalachian and Hispanic groups reported that if they had known the connection, particularly between breastfeeding and T2DM in their children, they "obviously" would have breastfed or breastfed for longer. Appalachian and Hispanic women also reported that physicians needed to be more informed about existing programs for pregnant women. One Appalachian woman shared a story about only discovering a WIC program for GDM a week before delivery.

Women from all groups reported that they did not understand the risks to their children from GDM and wanted more information on risk factors from their providers. Additionally, few participants from all groups were told by their doctor about the importance of glucose tolerance testing in the postpartum period after GDM. All women who reported this felt they would have attended this visit if they had known this information. Among women attending the postpartum visit, many were not tested for T2DM. Similarly, few participants heard from their doctor about the relationship between breastfeeding, glucose management and T2DM prevention.

Personal and Environmental Barriers to GDM Care and Management

All groups discussed personal and environmental issues that made it difficult to manage their GDM and reduce T2DM risk. Participants found changing their diet overwhelming and craved the foods they were told to avoid. African American participants reported that young African American women who have the greatest need for information on GDM would be the least likely to seek it out, listen to physicians, or make the necessary changes for managing their GDM. One African American woman described her experience: "I think for me was um a-a an age thing … you're tryin' to enjoy your pregnancy and you know? … I really do, I think it was, it was age, and uh lack of knowledge, and just as you said, each pregnancy is different so I think as you grow older, you start to mature more and you you read more and you want to become healthier."

African American participants frequently stopped breastfeeding upon returning to work or school: "I tried [breastfeeding], but then after I had my son I had to go back to school, so I was like I ain't trying to be going in the bathroom" (African American woman). Other women stopping breastfeeding because of misinformation, for example, that a woman cannot take T2DM medications while breastfeeding or breast milk cannot be frozen. On the other hand, some breastfeeding women ate healthier because they perceived their own nutrition was important for the baby.One African American woman shared, "And that [breastfeeding] helped me maintain the special diet too, because I had to eat healthy." Common motivating factors for breastfeeding, were weight loss and saving money. Finally, African American women cited lack of transportation as a barrier for poorer women, as they need to travel to providers' offices or the library to do research on GDM, and suggested home visits from providers as a solution.

Across all groups, women discussed cost and transportation barriers to seeking healthcare and managing their GDM. Specifically, Appalachian and Hispanic women without health insurance did not schedule medical appointments, and Hispanic women specifically addressed the need for Medicaid to allow them to access care during and after pregnancy. Program and gasoline costs kept Appalachian women from utilizing community exercise programs. Women were particularly upset that, although many of these programs offered income-based fee scales, they were often ineligible even though they were struggling to "make ends meet." Similarly, the cost of healthy foods was a barrier to changing diet: one Appalachian woman shared, "Just like whole grain bread, you can get a little loaf of the healthy bread like this for like $2.50. I can get a giant loaf of Hiner's like this for like $2…It goes so much further, that little bit counts towards the end of the week."

Conflicting priorities affected women's ability to manage their GDM. For Hispanic and Appalachian women, the need to care for family and home made it difficult to follow physician's advice or attend follow-up visits. One Hispanic woman shared, "I even had a problem with bleeding…the doctor used to tell me I had to stay in best and rest. I tried to not go down the steps, and at home I tried to clean not perfectly but some, I had to cook for my kids, and send them to school." Another Hispanic woman shared, "I do not eat a lot of vegetables, what I eat is rice, beans, and beef, so she [the dietician] was demanding me to eat salads, and things like that, and I don't eat that. So it was very hard for her to give me a meal plan so that I could eat it..."

Type and Quality of Healthcare

All groups reported that dieticians were the best source of information for GDM management. Women suggested that dieticians should provide tailored meal plans that account for personal and cultural preferences. African American women felt doctors did not respond to their needs by not performing requested tests on themselves or their children, leading these women to believe that low-income women received lower quality care than privately insured women. African American women, like women across all groups, and felt they learned more from the dietician. One Appalachian women described, "I was shocked how much I learned from the dietician…even having had you know nutrition classes in nursing school. And it was just amazing." Appalachian women reported a less positive experience with their physicians. At large practices, Appalachian women reported they did not receive consistent support and felt "lost in the shuffle". On the other hand, doctors who specialized in high-risk pregnancies were perceived to provide great care and comprehensive information on GDM. For Hispanic women, physicians from the same race-ethnic background were perceived to provide better care: for example, "He was Hispanic so he could understand me more … I would feel more comfortable with him. I didn't have to explain him too much."

Discussion

Study participants reported communication issues with providers, personal and environmental issues, and type and quality of healthcare were barriers to GDM care, management, and follow-up. Barriers were similar across groups, indicating there are opportunities to address barriers among women with GDM across different race-ethnic groups. For example, many women felt more education on the severity of GDM, streamlining information to be less overwhelming, and working with healthcare professionals other than physicians would improve their healthcare experiences. Although women expressed interest in receiving more actionable advice for managing GDM during pregnancy and for preventing T2DM postpartum, few women reported changing behaviors due to barriers related to competing demands.

Our study confirms barriers identified in previous studies persist. For example, personal and environmental barriers to seeking healthcare and managing glucose prenatally and postpartum is a common problem among low-income women and may impede care (Blank 2007; Dennis et al. 2013). In order to address these barriers, women identified the use of other healthcare professionals, and their own social networks, as opportunities to overcome these barriers.

The importance of social support for behavioral change is consistent with prior studies (Dasgupta et al. 2013; Razee et al. 2010). Social support enhances self-efficacy for lifestyle changes (Kim et al. 2008) like increasing physical activity (Booth et al. 2000; Sternfeld et al. 1999). The idea of using a health "coach" for postpartum GDM management has been studied with mixed results (Ferrara et al. 2011; Nicklas et al. 2014), which may be due to differences in how the patient engaged in the intervention. The accessibility and guaranteed response from an available coach, rather than an inconsistent resource, may be what empowers and motivates patients to move from contemplation to action (Ferrara et al. 2011; Nicklas et al. 2014; Yarrington and Zera 2015).

Most participants felt their provider did not educate them on the severity of GDM or on recommended postpartum care for diabetes prevention. We have previously shown that prenatal education on postpartum care can be improved using simple quality improvement approaches to educate both the provider and the patient (Shellhaas et al. 2016). By using similar education materials for both parties, the provider may find it easier to guide patients through the materials, as was suggested in this study. Such an approach may reduce feeling overwhelmed at the amount of information provided during pregnancy, while also emphasizing the importance and extent of management necessary.

Lifestyle modification programs that achieve weight loss of even 2.5% confer a 60% reduction in T2DM risk (Ackermann 2015; Balk et al. 2015), reiterating the importance of engaging in postpartum lifestyle change. However, results from previous lifestyle change interventions tailored for women with GDM have been modest (Ferrara et al. 2011, 2016; Nicklas et al. 2014), indicating new approaches are needed. Competing priorities are a commonly cited barrier to self-care during and after pregnancy (Lie et al. 2013; Peacock et al. 2014; Tang et al. 2015) with child care, family obligations, and return to work prioritized above self-care behaviors (Albright et al. 2006; Downs and Hausenblas 2004; Groth and David 2008; Hedderson and Ferrara 2014;

Lie et al. 2013), negatively impacting a new mother's ability to implement lifestyle changes (Lie et al. 2013).

Although many women are aware of breastfeeding benefits for reducing chronic disease risk in their infants (Ip et al. 2007), women in our study were not. Women generally lack knowledge of maternal health benefits of lactation (Ross-Cowdery et al. 2016), including T2DM risk reduction (Gunderson et al. 2015). Providing brief, structured, prenatal counseling has been shown to increase both awareness of the maternal health benefits of lactation and strength of pregnant women's intentions to breastfeed (Ross-Cowdery et al. 2016). This is a clinically meaningful message considering that women with strong prenatal intentions to breastfeed are more likely to successfully breastfeed (Bai et al. 2010; Donath et al. 2003; Wambach 1997). Furthermore, based on our results, women who breastfeed may make healthier nutrition decisions to ensure optimal nutrition for their infant, which also aligns with T2DM risk reduction strategies.

This study had some limitations. Since we recruited women who were diagnosed with GDM within the past 10 years, there may be recall bias regarding the questions or their experiences may not be relevant to current clinical practice. Also, the use of marketing firm to conduct FGDs may have resulted in a larger focus on the educational outreach materials given their expertise. Additionally, moderators from the firm may not have been well versed on the literature and may have missed key opportunities to probe on issues of scientific interests. Finally, not all transcripts were verbatim due to missing audio-recordings. However, we do not believe that this affected our thematic analysis as the information should have remained topically consistent.

This study had several strengths. First, we recruited women from across the entire state of Ohio, the 7th most populous state in the US with a growing Hispanic population (Mackun and Wilson 2011; Richards 2014, US Census Bureau 2010). Previous qualitative studies recruited women from just one city (Collier et al. 2011; Kim et al. 2007; Nicklas et al. 2011). Groups with Hispanic women were conducted in English, Spanish, or a combination of the two to increase generalizability among Hispanic women. Additionally, Appalachian women with GDM have not previously been represented in the literature, yet Appalachia is a region that spans 13 states in the US, from southern New York to northern Mississippi (Appalachian Regional Commission 2016). Living in an Appalachia geographic area is associated with specific health behaviors related to increased risk for T2DM (Behringer and Friedell 2006).

Findings from this study can be useful in designing programs (e.g., quality improvement) or research studies for interventions to improve healthcare experiences of women with GDM history (e.g., providing more visits with a dietician). Our findings indicate that low-income Ohio women with GDM experience similar communication, personal, and environmental barriers related to the healthcare they receive for their GDM. Women with GDM appear eager for knowledge on how to improve their own and their family's health.

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