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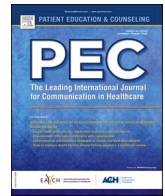
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"A patient should not have to ask": Women's experiences of patient education about preconception care for type 2 diabetes

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ABSTRACT

Objectives: To characterize perspectives and experiences regarding preconception care (PCC) patient education among women with type 2 diabetes.

Method: Descriptive, qualitative research design. Thirty-two English-speaking women with type 2 diabetes identifying as Black and/or Latina, ages 18–40 years old, participated. We conducted semi-structured interviews about PCC perspectives and experiences which we analyzed with conventional content analysis. To enhance rigor, we collected freelisting data from which we calculated salience scores. We triangulated our qualitative findings with salience scores.

Results: We identified three themes. Our first theme concerned mismatch between women's desires for PCC counseling to be frequent in contrast with their experiences of its infrequency. Our second theme captured how women felt responsible for initiating care in the clinical encounter but uncertain about what they "should" be asking for. Our third theme characterized women's perspectives on receiving information about PCC and pregnancy planning.

Conclusions: Young adult women with type 2 diabetes who are Black and/or Latina welcome more education about how PCC can prevent obstetrical complications associated with diabetes, which disproportionately affect their communities.

Practice implications: Our findings provide actionable suggestions for improving acceptability and accessibility of PCC patient education in the United States where PCC awareness and uptake are low.

1. Introduction

Diabetes mellitus affects more than 34 million United States (US) adults [1], and 3.4% of women who had a recent live births [2]. Type 2 diabetes (T2DM), established before conception, increases risks of adverse obstetrical outcomes, including perinatal loss, fetal malformation, preterm birth, and preeclampsia [3–5]. Racial and ethnic disparities are evident: compared to White women with diabetes, Black and Hispanic women are more likely to have diabetes in young adulthood (3% vs 8.2% vs 5.9%) [6]. Among women with diabetes, Black and Hispanic women have higher rates of elevated blood glucose levels [7], comorbid hypertension [8] and higher rates of adverse obstetrical outcomes [9] than White women. Disparities in chronic illness may contribute, in part, to the racial and ethnic inequities in maternal and infant morbidity and mortality that exist in the US [10].

Preconception care (PCC) can prevent adverse obstetrical outcomes

due to diabetes [11,12]. Starting at puberty and continuing through the reproductive years, the American Diabetes Association (ADA) and National Institute for Health and Care Excellence (NICE) recommend that clinicians offer PCC patient education, which includes increasing understanding about how blood glucose management, folic acid supplementation, smoking cessation, and modification of teratogenic medication regimens before pregnancy can improve obstetrical outcomes [13,14]. Universal utilization of PCC by women with diabetes would prevent an estimated 8000 preterm births, 3700 birth defects, and 1800 perinatal deaths in the USA yearly, with an annual savings of $973 million in direct medical costs and $4.5 billion in lost productivity [15]. However, only about half of US women with diabetes receive PCC (rates ranging from 29% to 53%) [2,16]. Reasons include not knowing about PCC and unintended pregnancies precluding the opportunity to make intentional changes before conception [17]. An estimated 45% of pregnancies in the US are unintended [17] and the likelihood of unintended pregnancy may be higher among women with diabetes as they have lower rates of highly effective contraception use compared to women without diabetes [18].

There is insufficient empirical evidence regarding the optimal method to deliver PCC [19]. Although evidence-based PCC patient education materials are available for adolescents with T1DM [13,20] and extensive research has been conducted about the attitudes towards PCC of women outside of the US [21–27], an evidence gap remains about improving patient education about PCC for adults in racial and ethnic groups that are disparately affected by diabetes and diabetes-related adverse obstetrical complications in the US. Therefore, the objective of this study was to characterize the perspectives, experiences, needs, and preferences regarding patient education about PCC among adult women with T2DM who are Black and/or Latina in the US.

2. Methods

2.1. Study procedures

This study used a qualitative descriptive approach which is appropriate for characterizing a phenomenon about which little is known [28, 29]. We purposively sampled individuals who self-identified as: 1) a woman; 2) Black/African-American/of African origin, Latina/Latinx/Hispanic, or both (referred to as "Black" and/or "Latina" for brevity); 3) 18–40 years old; 4) English-speaking; and 5) with T2DM. We excluded women with gestational diabetes (GDM) because PCC recommendations are specific to diabetes established before pregnancy. Women with type 1 diabetes mellitus were also excluded because differences in their disease trajectory and healthcare management may affect their perspectives on PCC. We recruited participants though the online classified advertisement platform Craigslist in New York, New Jersey, and Connecticut, as well as Columbia University's participant recruitment platform. We also allowed snowball referrals where participants referred peers who met the eligibility criteria. When interested individuals contacted us, we provided more information about the study, answered questions, and screened for eligibility.

All study procedures were conducted by phone, including obtaining informed consent and collecting data. Participants received a $30 gift card. The Columbia University institutional review board approved all study procedures. First, we characterized the sample by collecting demographic and health information which included Newest Vital Sign [30] to measure health literacy (6 items), Diabetes Distress Scale (17 items) [31,32], and Perceived Stress Scale (10 items) [33].

Second, participants completed four freelists related to diabetes self-management and pregnancy intentions (questions listed in Table 2). Freelisting is a semi-structured anthropological interviewing technique for understanding of a group's shared conceptualization of a particular phenomenon or concept [29,34]. We conducted freelisting to gain insight into perspectives in participants' communities, which contextualizes their individual responses. To construct a freelist, participants

are prompted to list all words or short phrases that describe a specific domain in response to a prompt, followed by two identical probes. We piloted the wording of freelisting questions with the first two participants before further data collection.

Third, to better understand women's perspectives on PCC patient education, we used a semi-structured interview guide which we iteratively developed using best practices including expert assessment with healthcare professionals, internal testing by the research team, and field-testing with the first two enrolled participants to confirm clarity and appropriateness [35,36]. Life course theory informed how interview guide probed experiences distinct to this phase of life for women [37, 38]. The investigator (LB) conducted interviews by phone. Audio recordings were professionally transcribed.

A fourth exploratory goal of the study was to explore opinions about health visualizations (pictures, images, or graphics that illustrate health information) as a possible future strategy for patient education about PCC. In other studies, health visualizations have been found to be acceptable and appealing forms of health communication to urban minority adults at all levels of health literacy [39,40]. Participants responded to publicly available visualizations about related topics: generic visualizations of birth control effectiveness (i.e., not tailored to an individual [41,42]) as well as tailored visualizations of blood pressure, reflecting an individual's clinical values [43], which were viewed online during the call.

2.2. Data analysis

We analyzed freelists with Anthropac software to calculate the salience index (Smith's *S*), which indicates the degree that an item is salient to a group of people when they consider a shared experience [44, 45]. Per convention, the salience score was calculated for each construct based on the length of the list, the rank of an item in that list, and the number of lists in the sample. Higher salience scores indicate that the item was more central to how a group understands an experience or concept. A minimum of 20 participants is needed for freelisting analysis [44,46].

We analyzed semi-structured interview data concurrently with data collection using conventional content analysis [47]. We created a codebook to guide analysis and a data saturation table to establish when data adequacy had been reached, signaling the end of data collection [48]. Each coder (LB, OS, and GK) read the transcripts independently to get a sense of the whole and identified codes, which were collapsed into themes. Coders discussed and resolved coding discrepancies in weekly meetings. The coders generated a codebook containing operational definitions, boundaries for applying the code, and exemplars. Data were managed with NVivo 12 (QRS International). We present salience scores and themes separately in the Results, with commentary on their triangulation in the Discussion when the freelisting provided insight into shared attitudes that contextualize what women describe in their interviews.

2.3. Rigor

We used strategies to enhance trustworthiness of the qualitative data [49,50]. To enhance credibility, we performed peer debriefing, member checking during data collection, and created an audit trail documenting data collection and analysis decisions. To foster confirmability, we used a debriefing reflexive practice in which researchers discussed any possible preconceived biases they might bring to the project. Triangulating the freelisting and interview data reduced the risk of introducing bias into our analysis.

3. Results

3.1. Participants

Between March 2020 and April 2021, we enrolled 32 women (Fig. 1). Participant characteristics are in Table 1a and 1b. Participant age ranged from 21 to 40 years old (mean age 33 years). Average duration since diabetes diagnosis ranged from less than a year to 23 years (mean duration 11 years). Almost two third of participants identified as Black (n = 20, 62.5%), while 21.9% (n = 7) identified as Latina, and 15.6% (n = 5) identified as Black Latinas. Thirteen women had never been pregnant (40.6%), while 18 women were parenting a biological child (51.3%) and one had been pregnant but never had a live birth (3.1%). Most participants had low diabetes distress (n = 19, 59.4%) and low or moderate stress (n = 30, 93.8%). Just under half of the sample exhibited adequate health literacy (n = 15, 46.9%).

3.2. Salience scores

We report the items with the ten highest salience scores in Table 2. The most salient *health complication from diabetes* was vision problems (S = 0.539). Of interest, "pregnancy complications or reproductive problems" was ranked 27th (S = 0.054). The most salient *things that make it hard for women to manage their diabetes* were financial challenges (S = 0.432). The most salient responses to the prompt *what makes a woman ready for pregnancy* was having a stable, supportive relationship (S = 0.575). The most salient *reason why women have unplanned pregnancies* was not using contraception (S = 0.555).

3.3. Themes

Our inductive coding of the semi-structured interviews identified three primary themes related to preconception care, summarized in Table 3 and described below.

Our first theme was: *divergence between experiences and desires for PCC patient education*. Women wanted more providers to discuss PCC and the impact of diabetes on reproductive health long before they decided to get pregnant: "The patients within the [childbearing] age – they [the providers] can just mention it – even if they haven't expressed, like, wanting to get pregnant just so that the patient knows, 'Oh, I can talk to him about this'" (Age 34, Latina). Women specified that PCC content was appropriate in any care setting, including pediatric care and primary care. Women expressed respect for lateral knowledge transmission in the community, such as the woman who said, "You might not be

Table 1a

Participant characteristics, n (%).

	N = 32
Age	
18–24	2 (6.3%)
25–29	6 (18.8)
30–34	8 (25)
35–40	16 (50.0)
Race and ethnicity[1]	
Latina	7 (21.9)
Latina and Black	5 (15.6)
Black	20 (62.5)
Educational attainment	
High school graduate or GED	6 (18.8)
Some college or associate's	7 (21.9)
Bachelors degree or more	19 (59.4)
Health Literacy (Newest Vital Sign score)	
High likelihood of limited literacy (Score of 1–2)	4 (12.5)
Possibility of limited literacy (Score of 3–4)	13 (40.6)
Adequate literacy (Score of 5–6)	15 (46.9)
Annual household income	
$20,000 or less	4 (12.5)
$21–50,000	13 (40.6)
$51–90,000	12 (37.5)
$91,000 or more	3 (9.4)
Currently working	
Yes	12 (37.5)
No - COVID-19 related	10 (31.3)
No - not COVID-19 related	4 (12.5)
No - maternity leave	6 (18.8)
Health insurance	
Public	21 (65.6)
Private	11 (34.4)
Religion	
Protestant	8 (25.0)
Catholic	12 (57.5)
None/Atheist	12 (37.5)
Relationship status	
Single	10 (31.3)
Cohabitating	7 (21.9)
Married	12 (37.5)
Dating but not cohabitating	3 (9.4)

[1] Of the Black women, eight were born outside of the continental United States in Uganda, England, Ghana, or Kenya. Of the Hispanic women, one was born outside of the continental United States. Half of the Hispanic participants reported their family originated in Puerto Rico, while the other half reported that their families originated from Brazil, the Dominican Republic, Ecuador, Mexico, or Venezuela.

having diabetes but maybe someone in your family might have. If you have information, you might help them" (Age 27, Black). Two participants, whose children were teenagers, emphasized the importance of disseminating general information about PCC, including but not exclusively related to diabetes, at locations where adolescents would see it, including at public transit stops and in school-based sexual health curriculums.

We identified triggers for PCC patient education in the narratives of the nine women who knew about PCC (28.1%). Women sought information when trying to get pregnant or before an intimate relationship became more serious. Providers offered PCC patient education when a T2DM diagnosis coincided with a reproductive diagnosis, including polycystic ovarian syndrome (PCOS) diagnosis, or when a T2DM
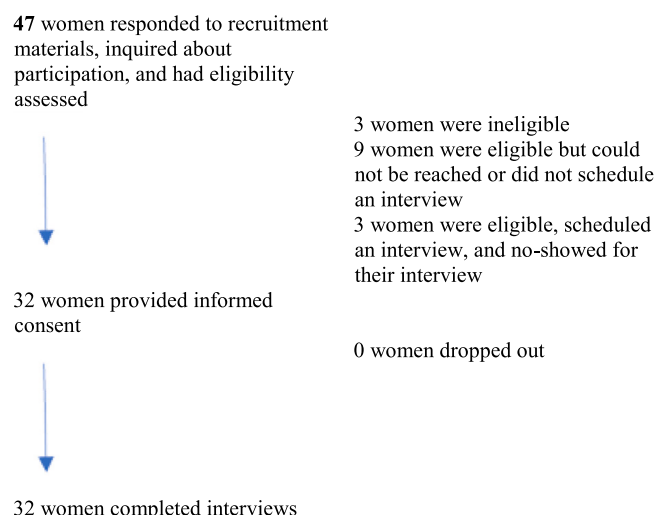
47 women responded to recruitment materials, inquired about participation, and had eligibility assessed

3 women were ineligible
9 women were eligible but could not be reached or did not schedule an interview
3 women were eligible, scheduled an interview, and no-showed for their interview

32 women provided informed consent

0 women dropped out

32 women completed interviews

Fig. 1. Enrollment flow diagram.

Table 1b

Participant reproductive health-related and diabetes-related characteristics, n (%).

	N = 32
Desires to be pregnant in the next year?	
No	27 (84.4)
Yes	1 (3.1)
Don't know	4 (12.5)
Pregnancy and parenting history	
Never pregnant	13 (40.6)
Pregnancy history but no lives births	1 (3.1)
Parenting one biological child	10 (31.3)
Parenting two or more biological children	8 (25.0)
Of women with previous pregnancies (n = 19)	
Miscarriage	5 (26.3)
Unintended pregnancy	16 (50.0)
Age at diabetes diagnosis	
Under 18	12 (37.3)
18–24	7 (21.9)
25–29	5 (15.6%)
30–34	3 (9.4)
35–40	5 (15.6)
Duration since diabetes diagnosis	
1–5 years	11 (34.4)
6–20 years	14 (43.8)
20–25 years	7 (34.0)
Current diabetes management in addition to diet and exercise	
None	12 (37.5)
Medication (not insulin)	9 (28.1)
Insulin (with or without other medications)	11 (34.4)
Most recent A1c	
5.8–7.5%	8 (25.0)
7.51–9.0%	5 (15.6)
9.01–15.0%	14 (43.8)
Don't know	5 (15.6)
Patient education about PCC at diagnosis	0 (0)
Patient education about PCC ever	9 (28.1)
Implemented PCC before a pregnancy	4 (12.5)
Diabetes distress scale (DDS)[1]	
Low diabetes distress (<1.9)	19 (59.4)
Moderate diabetes distress (2.0–2.9)	9 (28.1)
High diabetes distress (>3.0)	4 (12.5)
Perceived stress scale (PSS)[2]	
Low stress (0–13)	15 (46.9)
Moderate stress (14–26)	15 (46.9)
High stress (27–40)	2 (6.3)

Table 2

Freelisting results. The ten most salient items are listed in decreasing salience (n = 30).

(1) Please list health complications or problems that diabetes can cause.			(2) Please list what makes it hard for women to manage their diabetes.		
Item	n	Salience Score	Item	n	Salience Score
Vision problems	26	0.539	It is costly	21	0.432
Foot damage/ amputation	22	0.422	Negative attitude	19	0.375
Cardiovascular disease	22	0.395	Diet is challenging	17	0.303
Kidney problems	17	0.303	Lack of knowledge	16	0.279
High or low blood sugar	13	0.292	Lack of access to care	11	0.269
Fatigue	17	0.275	Lack of support	14	0.26
High blood pressure	14	0.271	Life is busy	8	0.21
Weight problems	13	0.253	Women take care of others first	11	0.209
Stroke	10	0.2	Feeling left out	8	0.209
Skin problems	11	0.197	Medical management is challenging	6	0.119

(3) Please list what is the right time in a woman's life to get pregnant and have a child.			(4) Please list the reasons why unplanned pregnancies occur in women's lives.		
Item	n	Salience Score	Item	n	Salience Score
Stable supportive relationship	27	0.575	Not using contraception	24	0.555
Financially ready	26	0.552	Carelessness	13	0.235
Psychologically ready to be a mother	14	0.231	Lack of knowledge	10	0.219
Health	13	0.219	Rape, coercion, or abuse	13	0.193
Married	13	0.205	Contraceptive failure	8	0.164
I don't know/it's individual	7	0.2	Caught up in the moment	5	0.155
Planned the pregnancy	12	0.182	Contraceptive coercion	7	0.136
Wants a baby	8	0.139	Drugs or alcohol	4	0.112
Timing compatible with career	8	0.131	Does not think she can get pregnant	4	0.97
Has a strong support system	4	0.052	Social pressure	6	0.91

diagnosis followed a pregnancy with GDM. Women learned about PCC after unintended pregnancies ended in miscarriages attributable to high blood glucose, which women found problematic: "I just wish I had this information prior. Like being pregnant, like I had researched on it, it would have been better. Maybe I wouldn't have lost the pregnancy" (Age 32, Black).

Women wanted clinicians to provide patient education about PCC routinely. One woman said, "Me personally, I would bring it up. I think some of my friends, they would like if the doctor would bring it up because they're not used to bringing things up" (Age 29, Latina). One woman learned about PCC after GDM converted to T2DM. Years later, when she had a toddler and was trying to become pregnant again, she forgot about PCC and wished she had been reminded of it.

Participants did not believe PCC patient education should be

provided exclusively to women planning pregnancies. One participant said, "They asked me, 'Are you planning?' I said no and then that was it… I would have loved to maybe hear and get more information so I would know for the future" (Age 29, Black). Knowing about PCC, regardless of their pregnancy intention, could confer a feeling of autonomy, particularly for women who exhibited medical mistrust. Participants with positive provider relationships felt like PCC patient education could build more trust, saying, "Oh wow, they really do have my best interest in mind if they're already thinking of how my health is going to be affected by my pregnancy, which is probably years out at this point but is something I think nice to hear" (Age 22, Latina). A participant noted that she had ended a long-term same-sex relationship and was now casually seeing men and did not want her providers to think PCC information was irrelevant to sexual minority patients.

Our second theme was *why providers should not wait for women to request PCC counseling.* Most participants believed they had to request patient education about preventive health (including but not limited to PCC) because of clinicians' time constraints and competing clinical priorities. This category captures reasons why some participants did not trust providers to offer "future knowledge" they would need to prevent complications (Age 29, Black). If providers did not initiate conversations

Table 3

Interview questions, primary themes and exemplar quotations.

Sample Interview Question	Sample Interview Probes
Question: I'd like to hear about your experience with diabetes.	Probes: - I'd like to know more about your diagnosis. - Can you tell me more about how diabetes management is going? What's been challenging? - What does "being healthy" mean to you? - What are your goals?
Theme	Exemplar
Theme 1: Divergence between experiences and desires for PCC counseling	"I just think as soon as you're diagnosed, um, medically that they should sit you down and literally tell you everything, you know, everything about the disease. You know what if I get pregnant that, you know, it needs, I don't know. I just feel like it wasn't given enough, um, enough information about it. Like a lot of "what ifs." Like what if this happens. Now, if they had taken care of that, um, when, you know, I was first diagnosed, I, you know, it would be, I would be better, um, educated about the situation… I don't feel like I was given enough information" (Age 28, Black and Latina) "I don't know if the medical practitioners assume that diabetes is only affecting mainly the older people such that there's no need of giving information about diabetes and pregnancy. They kind of don't pay attention to that" (Age 33, Black)
Theme 2: Why providers can't wait for women to request PCC counseling	"I don't know. I mean, I don't know what I need to be told. I'm not a doctor. I don't know what to complain about not being told. I don't know what I need to be told" (Age 39, Black) "Once you've been through two or three or four or five kids, I mean, you already know about pregnancy…. Once they get past a certain age, they know about pregnancy but they don't know about the effects of having any type of disease…. So, I think that, the only way I would see of educating them, is through their doctor's appointment" (Age 38, Black)
Theme 3: Perspectives on receiving information about PCC and pregnancy planning	Subtheme 1: How women learn about PCC "I was just using my prior knowledge like okay, if you're pregnant, you have to know that, you've got to do this, but now I know I have diabetes so I know it's probably double my chances [of complications]" (Age 29, Black) Subtheme 2: PCC and Perspectives on Healthcare "A lot of women like to be on their own and seeing the doctor minimally … The clinic is depressing, medical, so it's good if you could do it and not go as much. Take your medicine from CVS [a pharmacy] and do your own thing so you can be as healthy as you can be" (Age 29, Latina) Subtheme 3: PCC and Unintended Pregnancies "Everyone wants to kind of make sure that they planned it out, but it's just like with anything in life, anything could happen" (Age 21, Black and Latina)

reluctant to ask for help if they worried that their pregnancy intentions were stigmatized.

Women indicated that they might not inquire about PCC if they felt knowledgeable about pregnancy and did not realize there are diabetes-specific concerns. Conversely, another participant, raised in a conservative household, said she had never had sexual education and knew so little about pregnancy that it never occurred to her to ask. Women familiar with GDM mistakenly thought they had comprehensive knowledge about diabetes and pregnancy, not realizing that T2DM introduces the importance of glycemic control before conception. Seeing family members suffer from diabetes complications motivated women to avoid complications. Two participants knew women with T2DM-related pregnancy complications, and this fear motivated them to work closely with providers before and during their pregnancies.

Our third theme was *perspectives about receiving information about PCC and pregnancy planning*. Here, we present subthemes related to women's perspectives on patient education about PCC.

The first subtheme was how women learn about PCC. Women hearing about PCC for the first time expressed confidence in that they could integrate this new information into what they already knew about pregnancy and diabetes. However, many were confused about when to start PCC. Some questioned why women would pay attention to information about PCC before they wanted to conceive: "Why would they care about how to have a healthy pregnancy when they're not planning?" (Age 25, Black).

Participants provided sample scripts for tactful, individualized patient education and suggestions for health visualizations (Table 4). Women wanted health communication to consider how "[PCC] can be very stressful and a lot of pressure" (Age 39, Black). Participants believed tailoring health visualizations could accomplish multiple goals: help women overcome denial about their health status; remind them about the information given in a clinical encounter; and motivate them

Table 4

Resources for patient-provider discussions of PCC.

Suggestions and sample scripts for providers to discuss PCC with women who are not intending pregnancy
Suggestions for introducing PCC - Offer education but let patient control level of detail - Provide pamphlets, which let patient control flow of information about PCC - Provide individualized care by explaining the relationship between lab values and readiness for pregnancy Sample Scripts - "Listen, I know you're not planning to become pregnant but this is information that could be useful to you in the future." - "I just want to make you aware if you are planning to, or you want to, this is some risk, this is certain things you should know: you would be greater at risk for this in the future." - "Are you familiar with some of the complications of diabetes?" Recommendations for health visualization features and utilization by Black and/or Latina women with type 2 diabetes [1]. How health visualizations can be used in the clinical encounter - Provider should walk patients through what they mean - Providers should send patients home with print-outs - Follow up and having a "mini quiz" on what the visualization means Recommendations for health visualization features - Clear indications of who the recommendations are for (i.e., gender, age group) - Color-coding to associate health values with symptoms or complications - Indicate action to take when values are out of healthy range - Avoid excessive information - Optimize graphics for screens to have attractive colors and legibly large type - Give general explanations before getting specific (i.e., discuss T2DM generally, then T2DM in pregnancy) - Important to indicate the source is credible (i.e., CDC) - Recommends presenting the more common, short-term, mild risks as well as long-term, extreme risks - Be aware that certain images have strong connotations (i.e., stars suggest customer satisfaction) ₁ Health visualization include use of pictures, images, or graphics that illustrate tailored or general health information

about PCC with every woman, how would women know to request PCC counseling "if they don't know how to ask, um, or if it never crossed their mind because it was never brought up?" (Age 28, Black and Latina). One participant felt like providers negatively judged women with T2DM who desired to become pregnant, so women might be

to engage in health behaviors, like a "check engine light" (Age 22, Latina). Two participants disagreed, believing that a verbal exchange was sufficient.

Our second subtheme was PCC and perspectives on healthcare. Women's openness to PCC reflected their general stance towards engagement with their healthcare providers. PCC implied increasing engagement with providers, which was welcomed by women who had positive attitudes about collaborating closely in their diabetes management. Others found it worrisome that starting PCC would require intensification of provider engagement and possibly their medication regimen, which was unappealing because "I don't like medicine. I feel like it's a foreign thing in your body that you can get addicted to and hard to get off of… [I don't want to be a] slave to medicine" (Age 40, Black). Increasing provider engagement for PCC could feel at odds with the goal of achieving decreased provider engagement overall through successful self-management: "They want to be on their own and not listen to an authority figure. They just want to listen to their own body" (Age 29, Latina).

Our third subtheme was PCC and unintended pregnancy. Half of our participants who had been pregnant had an unintended pregnancy. Some viewed planning pregnancies as feasible and ideal, others saw it as unrealistic. Participants largely felt like they and their peers did not view improving their health as part of pregnancy planning. A participant who worked in healthcare critiqued the emphasis on social factors, rather than pre-pregnancy health, she saw in her community: "A lot of times we think of finances first, but I think health needs to be the first thing in order for a person to get pregnant, and secondary, finances" (Age 38, Black and Latina). One participant felt planning was irrelevant if married.

Other women had pregnancies without PCC because they believed that they were infertile after conception took longer than expected. They were happily surprised by a subsequent unplanned pregnancy. One said, "One has been wanting a baby for a very, very long time. Then, it takes a long time for that to conceive such that you even drift away from that, you feel like hopeless. … then this happened when you don't even expect" (Age 27, Black).

4. Discussion and conclusion

4.1. Discussion

In this study, we characterize how adult women with T2DM in the US who are Black and/or Latina perceive patient education about PCC. Our participants viewed PCC as an important but neglected topic. New approaches to care are needed because, similar to what has been observed elsewhere [51], our participants were not often asking for more information about PCC before trying to conceive despite a general high interest level in the topic.

Importantly, by using a life course perspective and recognizing that unintended pregnancy is common, our findings suggest that it is erroneous to assume that PCC patient education is a low priority for women not trying to become pregnant. Offering information about PCC can reduce the novelty and high cognitive load of learning how to manage diabetes in pregnancy, which women can find overwhelming [52,53]. Increasing disease familiarity can increase self-efficacy, which is associated with better perinatal diabetes management [52,53]. If PCC patient education can help women with T2DM adjust more quickly to managing diabetes in pregnancy, even when not initiated before conception, then making certain all women receive PCC patient education may positively influence outcomes.

Our participants' communication preferences were consistent with studies that unsupportive, pessimistic, or paternalistic communication discourages women with diabetes from seeking PCC [22–24]. Women may be more responsive to an assets-oriented focus on health behavior benefits rather than harms because negative obstetrical outcomes can be distressing and disempowering [23,54]. It is worrisome that our

participants believed that providers may not address PCC when they had more urgent clinical issues, which is a double-edged sword as the women struggling to manage their blood sugar are at higher risk of obstetrical complications. There is also more work needed to increase the salience of PCC among women who are planning pregnancy. As in other convenience [55] and population [25] samples, we observed that relationship and financial stability was more salient than health for participants' idea of "being ready" for pregnancy despite their chronic illness.

Our findings highlighted the importance of future research about overcoming the challenges to delivering PCC consistently in primary care and pediatrics. Barriers to the delivery of PCC patient education to all women include lack of consensus about who should provide it, insufficient clinician training, time, and reimbursement, and a belief that women do not view PCC as important [56]. Integration of PCC into primary care could avoid adding more specialist healthcare appointments, which women found burdensome. Community-based [57] and mHealth [58,59] solutions also show promise for increasing PCC awareness while minimizing patient burden.

Improving PCC patient education in pediatric care is important because youth-onset T2DM appears to be particularly aggressive, with microvascular and macrovascular complications already present at time of diagnosis [60,61]. Culturally-sensitive patient educational materials targeting adolescents have shown promise in meeting the needs of the racially diverse patient population with T1DM and T2DM in adolescence [62–65], but our participants' experience suggests the need to improve the integration of PCC patient education into pediatric care for youth with T2DM.

Our study produced useful insight about the importance of educating women that their health *before* pregnancy affects their health *during* pregnancy. Innovative health communication strategies such as health visualizations show promise for messaging about timing – for both improving understanding of general patient education about PCC (i.e., women with diabetes generally benefit from starting PCC even before they want to have a child) as well as tailored patient education (i.e., when you should start PCC based on your current blood glucose and pregnancy goals). Our participants noted that future health visualization work could be mobilized for digital or analog informational materials which women can share in their social networks, in person or online, and consult privately to control the flow of information. A strength of our study was the diversity of health literacy levels. It will be valuable for future intervention development to test acceptability and efficacy with stratification by health literacy level. This is particularly salient for increasing equity in PCC patient education because low health literacy in diabetes is associated with poor comprehension of nutrition labels [53], unplanned pregnancy and lack of PCC among pregnant women [66]; and disproportionately affecting adults who are Black or Latina [67].

"Pregnancy complications or reproductive problems" had low salience among our participants. As in other studies [68], our participants learned about diabetes from relatives who were not in their childbearing years, which likely explains why blindness and amputation were the most salient diabetes complications reported in freelisting exercise as well as the interviews.

Echoing our first theme, these findings suggest that increasing awareness of PCC in women's social networks, friends and family could increase the salience of pregnancy risks in their communities. Structured peer education, peer support, and diabetes online communities can improve self-management and clinical outcomes [69,70] and potentially reduce stress in this phase of life [70]. This, in part, may explain why some women who themselves are not planning pregnancies valued learning about PCC and welcomed educational materials they can share in their social networks. Our findings suggest that more research is needed to develop culturally appropriate and acceptable educational materials and counseling approaches for PCC. Subsequent research should measure whether improving PCC educational materials and

service delivery can reduce maternal and child health inequities.

We acknowledge limitations. Without medical record linkage, we were unable to verify clinical information, such as diagnosis, medication regimen, medication adherence, or most recent A1C. Taboos around exposing a fetus or child to harm may make this topic particularly susceptible to social desirability bias. We were unable to interview individuals without English-language fluency. We designed this study to address the paucity of qualitative evidence about women from groups highly affected by diabetes in the US. Future work could expand to include other communities where T2DM rates are high (for example, Native American women) and include comparative analyses to better understand heterogeneity of perspectives and experiences within the Black and Latina communities. Self-selection bias may also have been a factor as women who agreed to participate likely have different perceptions of PCC than women who did not. Our sample was largely women nearing the end of their reproductive years with higher educational attainment and thus do not represent the breadth of experience. Our sample gives little insight into experiences in sexual minority and gender diverse communities.

Another important caveat is that our participants, much like pregnant women in other studies, do not characterize information needs as the sole or most important barriers to self-management [68]. Our participants indicated that financial barriers to health were highly salient in their communities, and we recommend future research address structural barriers to diabetes management while improving PCC patient education.

4.2. Conclusion

Improving access to and quality of PCC patient education may likely help women achieve their reproductive goals while reducing their risk of adverse obstetrical outcomes and maternal and child health inequities. As the rates of T2DM increase in the US, it is increasingly important to build the evidence base about women's perspectives and preferences to ensure acceptable and equitable delivery of PCC patient education in all communities.

4.3. Practice implications

Our findings suggest that women with T2DM want clinicians to make PCC patient education available, regardless of reproductive plans, age, or status of diabetes management. Participants also emphasized the importance of word of mouth outside the traditional dyadic patient encounter, the implication of which being that if clinicians make sure that patients are informed enough to become the messenger of good health information, those women will be prepared to help other women in their communities.

I confirm all patient/personal identifiers have been removed or disguised so the patient/person(s) described are not identifiable and cannot be identified through the details of the story.

CRediT authorship contribution statement

Laura Britton: Conceptualization, Methodology, Formal analysis, Investigation, Data curation, Funding acquisition, Project administration, Writing – original draft. **Adriana Arcia:** Writing – review & editing. **Guneet Kaur:** Data curation, Formal analysis, Writing – review & editing. **Oluwatomisin Sontan:** Data curation, Formal analysis, Writing – review & editing. **Cassondra Marshall:** Writing – review & editing. **Maureen George:** Supervision, Writing – review & editing.

Declaration of Competing Interest

Authors have no financial and personal relationships with other people or organizations that could inappropriately influence (bias) their work. Dr. Maureen George is a speaker and consultant with AstraZeneca and Sanofi Regeneron and a consultant for Genentech and Teva for related to her expertise in asthma, which is unrelated to this project. Britton, Arcia, Kaur, Sontan, and Marshall report no conflict of interest.

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