

# UCSF

## UC San Francisco Previously Published Works

### Title

Patient and provider perspectives on preterm birth risk assessment and communication.

### Permalink

<https://escholarship.org/uc/item/9k2415mr>

### Journal

Patient education and counseling, 104(11)

### ISSN

0738-3991

### Authors

Tesfalul, Martha A  
Feuer, Sky K  
Castillo, Esperanza  
et al.

### Publication Date

2021-11-01

### DOI

10.1016/j.pec.2021.03.038

Peer reviewed



Published in final edited form as:

*Patient Educ Couns.* 2021 November ; 104(11): 2814–2823. doi:10.1016/j.pec.2021.03.038.

## Patient and Provider Perspectives on Preterm Birth Risk Assessment and Communication

Martha A. Tesfalul, MD<sup>1,2</sup>, Sky K. Feuer, PhD, MPhil<sup>1,2</sup>, Esperanza Castillo, MS<sup>1,2</sup>, Kimberly Coleman-Phox, MPH<sup>1,2</sup>, Allison O’Leary, MPH<sup>1,2</sup>, Miriam Kuppermann, PhD, MPH<sup>1,2</sup>

<sup>1</sup>Department of Obstetrics, Gynecology and Reproductive Sciences, University of California San Francisco School of Medicine, San Francisco, CA, USA.

<sup>2</sup>California Preterm Birth Initiative, University of California San Francisco, San Francisco, CA, USA.

### Abstract

**Objective**—To describe and compare how obstetric patients and care providers view preterm birth risk assessment and communication.

**Methods**—We conducted eight focus groups with obstetric patients (n=35) and 16 qualitative interviews with obstetric providers. Grounded theory was used to identify and analyze themes.

**Results**—Patients’ knowledge about preterm birth varied greatly. Similar benefits and risks of preterm birth risk counseling were discussed by patients and providers with notable exceptions: patients cited preparedness as a benefit and providers cited maternal blame, patient alienation, and estimate uncertainty as potential risks. Most patients expressed a desire to know their personalized preterm birth risk during pregnancy. Providers differed in whether they offer universal versus selective, and quantitative versus qualitative, preterm birth risk counseling. Many providers expressed concern about discussing social and structural risk factors for preterm birth.

**Conclusion**—While many patients desired knowing their personalized preterm birth risk, prenatal care providers’ disclosure practices vary because of uncertainty of estimates, concerns

---

**Corresponding Author** Martha Tesfalul, MD, 480 16th Street, 10th Floor, San Francisco, CA 94158, Phone: 415- 514-1082, Fax: 415-476-5372, martha.tesfalul@ucsf.edu.

Declarations of interest  
None

Authors’ Statement on Participant Details

We confirm all 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 Statement

**Martha A. Tesfalul:** Methodology, Investigation, Formal analysis, Writing - Original Draft. **Sky K. Feuer:** Conceptualization, Methodology, Formal analysis, Writing - Original Draft. **Esperanza Castillo:** Conceptualization, Methodology, Investigation, Formal analysis, Project administration, Writing - Review & Editing. **Kimberly Coleman-Phox:** Conceptualization, Methodology, Investigation, Formal analysis, Writing - Review & Editing. **Allison O’Leary:** Formal analysis, Writing - Review & Editing. **Miriam Kuppermann:** Conceptualization, Methodology, Investigation, Writing - Review & Editing, Supervision, Funding acquisition.

**Publisher's Disclaimer:** This is a PDF file of an unedited manuscript that has been accepted for publication. As a service to our customers we are providing this early version of the manuscript. The manuscript will undergo copyediting, typesetting, and review of the resulting proof before it is published in its final form. Please note that during the production process errors may be discovered which could affect the content, and all legal disclaimers that apply to the journal pertain.

about negative consequences and challenges of addressing systemic inequities and social determinants of health.

**Practice Implications**—Given the existing asymmetry of information about preterm birth risk, providers should consider patient preferences regarding and potential benefits and risks of such disclosure in their practice.

### Keywords

Preterm birth; risk assessment; risk counseling; social determinants of health; structural determinants of health

---

## 1. INTRODUCTION

Preterm birth, defined as delivery before 37 weeks' gestation, is the leading cause of morbidity and mortality in children under age five.[1] While 1 in 10 births in the United States occurs prior to term, rates differ by sociodemographic characteristics and clinical factors.[2] There is growing and promising work in predictive models for preterm birth to help identify pregnancies at highest risk.[3–7] Yet pregnant people are not always privy to the possibility of delivering early let alone their own individual chances.[8–10] Prenatal care providers therefore play a crucial role in assessing and communicating preterm birth risk.

Studies of actual and simulated counseling on imminent preterm delivery reveal that expectant parents have difficulty recalling information secondary to anxiety but also that counseling serves to lower their anxiety, underscoring the potential value of anticipatory counseling during prenatal care.[11] Variability in provider counseling, including by patient race and insurance status, with limited evidence regarding reasons for these variations, also has been reported.[11]

Understanding and integrating patient perspectives on preterm birth risk communication could help providers seeking to be responsive to patients' desire for awareness of this potential adverse outcome and knowledge on how to mitigate that risk. Similarly, greater insight into providers' challenges in imparting this information could help inform efforts to enhance their role in educating and empowering their patients. Understanding both patient and provider perspectives is also critical when considering how to optimize implementation of predictive models in real-world contexts. We utilized focus groups and individual qualitative interviews to investigate and compare patient and provider perspectives on the assessment and communication of individualized preterm birth risk.

## 2. METHODS

We sought to understand what pregnant patients and patients who have recently given birth know about preterm birth risk and the extent to which they would want information about their personalized risk during pregnancy from prenatal care providers. These findings were compared to prenatal care providers' knowledge, attitudes and practices regarding communication of preterm birth risk.

We utilized an inductive qualitative approach to develop focus group guides (for the patient component) and semi-structured individual interview guides (for the provider component) to gain nuanced insights into patients' and providers' perspectives on preterm birth awareness, knowledge, risk perception, and risk communication.

We recruited patient participants who were age 18 years or older, able to speak English or Spanish, and met at least one of the following additional criteria: 1) currently pregnant, 2) gave birth within the past 12 months, or 3) experienced a preterm delivery in the prior 3 years. Recruitment sites included an academic medical center (University of California, San Francisco (UCSF)), a community nonprofit resource center serving low-income pregnant people in San Francisco (Homeless Prenatal Program; of note it is not a shelter), and a database of patients who previously participated in pregnancy-related research at UCSF and expressed willingness to be contacted about other studies. We recruited provider participants who were actively providing prenatal care in a variety of practice types (e.g., academic medical center, federally qualified health center) in the San Francisco Bay Area. Trainees (e.g., resident physicians, midwifery students) were not eligible.

We held eight focus groups with patients, two of which were conducted in Spanish. Prior to the start of the focus groups, participants completed a brief sociodemographic survey. One of two trained, language-concordant moderators (E.C., M.K.) then facilitated each focus group as another team member took notes. Moderators informed participants of the confidentiality of sessions, including the need to refrain from sharing others' names or identifiable details, and encouraged discussion from each participant at the beginning of and throughout sessions. Focus group semi-structured discussion guides included questions such as:

- Have you or anyone you know given birth early? Can you tell me about that and what that was like for you/them?
- What are some things that might increase/decrease the chances of having a premature birth?

At the end of the focus group meetings, participants completed a brief exit questionnaire including questions about their desire to know their personal preterm birth risk and were remunerated with a \$50 gift card.

Semi-structured individual interviews with providers were conducted by trained interviewers (K.C., M.T., M.K.). The interview guide included questions such as:

- What types of patients do you consider to be at increased risk for preterm birth?
- What factors might make you more or less likely to counsel a patient about preterm birth?

At the end of the interviews, providers completed a brief questionnaire about their sociodemographic and practice characteristics and received a \$50 gift card.

All focus groups and individual interviews were audiotaped by the investigators and transcribed and translated (as needed) by an independent service. The transcripts were

reviewed by at least two members of the team while listening to the audio recordings to confirm precision and accuracy.

We relied on grounded theory to identify and analyze themes and patterns within the data through iterative coding and analysis of transcripts. A subset of the investigative team developed the initial set of codes for the transcripts. Each transcript was independently reviewed by two team members to apply the appropriate initial codebook as well as to identify additional codes. Using a consensus approach, the team reviewed the coding after the first few focus group and interview transcripts were independently coded in order to clarify concepts, discuss discrepancies, resolve ambiguities, and define any necessary new codes. This process was repeated with all subsequent transcripts. One team member oversaw adjudication of differences in interpretation. Working collectively, the team identified central themes, including commonalities and variations between patient and provider perspectives. Representative quotes were selected from the transcripts to illustrate the themes identified. We planned *a priori* to conduct focus groups and interviews until no new codes emerged to attain thematic saturation.

We used Dedoose version 8.3.17 (Los Angeles, CA) qualitative data analysis software for all data management and analysis. Descriptive statistics were used to present questionnaire data.

We obtained institutional review board exemption from UCSF.

### 3. RESULTS

Eight patient focus groups were conducted between November 2018 and June 2019, with each session averaging 55 minutes (range 40–75 minutes) with four participants (range 2–8 participants). Focus group participants constituted a sociodemographically diverse population (Table 1): 35% self-identified as Black, 38% as Latinx, and nearly two thirds (62%) had public insurance. The majority (79 %) had previously given birth with 17% reporting having experienced a prior preterm birth.

Sixteen provider interviews were conducted between March and December 2019, which averaged 50 minutes each (range 30–75 minutes). While most (94%) providers were female and nearly two thirds (64%) self-identified as white, they varied in their clinical specialties and years of practice (Table 2).

#### 3.1. Patient Knowledge and Perceptions of Risk of Preterm Birth

Focus group sessions commenced with discussion of the definition and implications of preterm birth. When asked how early in pregnancy a delivery needed to occur to be considered preterm, patients cited gestational time periods ranging from 24 weeks to the anticipated due date. They also described prematurity as being more of a reflection of having health problems related to lack of development rather than a specific gestational age. One participant explained:

... I think to me preterm means not necessarily before your due date but before the baby is fully developed and can come out without being in [the] ICU neonatal or something like that.

When asked how frequently preterm birth occurs, responses ranged from “rare, super rare” to 70%. After being informed that preterm birth refers to delivery prior to 37 weeks and occurs in approximately 10% of U.S. births, participants’ reactions varied. One participant stated that the figure “gives us hope” whereas another participant with a history of preterm birth said,

I don’t want to unnecessarily scare people, but 10% chance, I mean, if I had a 10% chance of anything, I would ... 10% chance of breast cancer would be a huge chance.

### 3.2. Views Regarding Risks and Outcomes of Preterm Birth

Focus group participants varied over how concerned they were about preterm birth risks and outcomes. Some participants asserted not being concerned, often because they knew children who were born premature and had good outcomes and that they had confidence in advances in neonatal care. While some participants noted the increased risk of health complications among preterm infants, many statements about prematurity conveyed optimism and a belief that good outcomes are likely. Conversely, other participants expressed a sense of fatalism, stress about and fear of a poor neonatal outcome, and guilt. One participant with a history of preterm birth disclosed:

But, yeah, I think emotionally was the hardest thing because ... emotionally it was like why is my body doing this? And like why I can’t I keep this baby in here?

### 3.3. Information Sources

With regard to sources of information on preterm birth, patient participants listed family members, friends, partners, providers, prenatal classes, social services (e.g., Special Supplemental Nutrition Program for Women, Infants, and Children), digital applications, internet (e.g., Google, YouTube), social media (e.g., Instagram, Facebook), and prior experience of preterm birth. At the same time, several participants highlighted a lack of information, including this participant, who remarked:

I think both of my friends [who had preterm births] were completely unprepared. Like they just didn’t have really any specific information. I mean I think they knew the signs of labor, and so knew like when they needed to call, but I don’t think they had any other information.

Lived experience as a salient source of information was repeatedly raised. One participant stated:

I think it’s one of the things you’re not really aware of unless you know somebody that it’s happened to or you experience it for yourself.

### 3.4. Preterm Birth Risk Factors

Both patient and provider participants were asked about risk factors for preterm birth (Table 3). Risk factors mentioned in patient focus groups -- but not in provider interviews -- included autism, too much physical activity, increased parity, and geographic variation. In contrast, risk factors mentioned by providers -- but not patients -- included birth spacing,

mode of conception (e.g., assisted reproductive technology), infection, uterine surgery (e.g., history of classical cesarean section) and anomalies (e.g., bicornuate uterus), and distrust/mistrust in the health care system. Both patient and provider participants acknowledged that some patients may not have clear risk factors.

### 3.5. Preterm Birth Protective Factors

Many of the protective factors suggested by participants were the converse of risk factors shared (e.g., history of term delivery, no substance use, healthy diet, engagement in prenatal care). Both patients and providers described medical interventions to lower risk of preterm birth (e.g., aspirin, progesterone injections, cerclage).

Focus group participants also highlighted knowledge as being protective. Providers distinctly highlighted interventions specific to preconception optimization (e.g., remission of conditions such as systemic lupus) and imminent preterm birth (e.g., betamethasone, magnesium sulfate). Multiple providers also suggested that enhanced prenatal care models that emphasize continuity (e.g., group prenatal care), racially-concordant providers, mental health services, and engagement of community resources (e.g., doulas, public health nurses) lower patients' risk. One obstetrician-gynecologist stated that:

...having providers who are part of your community is understood to be protective, so if you're a person of color, to be able to have access to midwives of color, doulas of color, doctors of color is protective.

### 3.6. Preterm Birth Risk Communication

Patient participants reported different experiences regarding whether they had ever discussed preterm birth with their providers. In the group of patients with a prior preterm birth, one participant shared that in the pregnancy during which she delivered early:

...it was like I was learning about it, and then it happened, and it was like, "Oh my gosh, I wasn't prepared," or "I don't know what they were saying." It was very quick, and I think a lot of prenatal care should address that right at the beginning.

Even patients who were counseled about preterm birth expressed a desire for more information:

They tell you do this so you don't have a premature baby, but no one really guides you, or rarely guides you in to saying if you do have a preemie baby, these are the times he could come, these are some of the things you might face.

Other patients reported that conversations about their preterm birth risks were disconcerting:

...I just kept getting news after news and I was just like, "This is a very depressing appointment. Where is the joy? Could you open up the blinds, so the sun can come in?"

Some patients who had not discussed preterm birth with their provider did not express concern about this absence. In contrast, one participant mentioned that she was:

... going to put it in my notes that my appointment is coming up tomorrow that how come no one's talked to me about it, especially I'm a first-time mom.

When asked if they desired explicit counseling about their preterm birth risk, most patients expressed an interest in knowing their individual risk. One participant noted that:

...[her providers] didn't say because you're African American, because your mother had premature babies that this is going to happen to you... I do have higher risk factors obviously... if I could've pinned it down to the chances, percentage-wise, and then the date, that would've been a great help.

Some individuals expressed conditional interest, with less desire to know their personal risk if it required an additional blood test or if the risks identified are not modifiable (e.g., maternal age). Others expressed little intrinsic interest but willingness to have such counseling if recommended.

In each focus group, patients' perspectives on preterm birth counseling spanned both positive and negative themes (Table 4). Among positive themes, patients highlighted the benefits of being able to optimize their knowledge, care, engagement in risk mitigation, resources and mental and emotional wellbeing. Participants highlighted that:

... education is definitely important. I think that makes you feel a lot better when you are educated or aware of what can happen during a miscarriage or something like that.

Knowing all your options and knowing how the process might be, because it's not always like here's what might happen, but preparing for options you might be confronted with.

However, they also noted concerns about anxiety, stress, and inability to change outcomes (Table 4). One participant in a Spanish-language focus group shared:

... if there are so many people who haven't had anything happen to them, then why are you getting that idea in your head? Here, everyone gets it in their head, so I say that it's psychological. They get so worried and even... here, with illnesses or things that happen—it's like it happened to you because you called it and were so worried about it.

Among the 31 participants who completed the exit survey, most indicated that they would definitely (68%) or probably (16%) want to know their personalized preterm birth risk if offered. Six participants (19%) reported being unsure and the remaining 2 (6%) were split between probably not and definitely not wanting to know.

Providers also expressed varying perspectives on preterm birth risk counseling, some of which overlapped with patient perspectives (Table 4). While all providers reported talking about preterm birth with high-risk patients — particularly those who had a history of preterm birth — some providers reported choosing not to talk to low-risk patients whereas others counseled all patients.

Providers did not cite the benefits of patients being able to gather resources and to prepare mentally, emotionally and physically, but they raised concerns about maternal alienation and blame, uncertainty of ultimate delivery timing, and their own discomfort in discussing



these issues (Table 4). Comfort in determining and sharing individualized preterm birth risk quantitatively and qualitatively varied:

I really hate the “oh, it’s going to increase your risk.” So basically I have to look these things up, so I actually look them up and go, “Okay, 1.5 [cm cervical length] at 18 weeks gives a 7 fold increase,” I have to look it up, or “the risk of you having another preterm birth doubles with your second pregnancy”...

I definitely don’t share a percentage because I don’t know that know it, but so I do talk about like I’m worried, which would be high risk, or I’m going to watch you very closely

Providers also highlighted the challenge of structural and social determinants such as racism and environmental injustice. One physician shared:

I don’t explicitly say, you know, because of who you are and where you live, you are at risk... There’s a lot of awareness of patients that they live in these communities. They’re exposed to certain toxins, trauma, violence, racism. They know that. And, you know, we know that. We’re not always acknowledging that we know.

## 4. DISCUSSION AND CONCLUSION

### 4.1. Discussion

Our findings illustrate important areas of alignment and misalignment between patient and provider knowledge and perspectives on preterm birth risk assessment and communication. While we found substantial variability in patients’ knowledge of the definition and frequency of preterm birth, patients and providers expressed comparable awareness of many but not all risk and protective factors. Notably, while most patients expressed desire to receive personalized information regarding their preterm birth risk, providers cited varying practices, with some explicitly not counseling all patients given concern about potential undesirable psychological consequences, concern about certainty of estimates, and lack of comfort in addressing risk factors such as racism, housing, and other structural and social determinants of health.

Heterogeneity in patients’ knowledge about preterm birth and some protective factors highlight an opportunity for initiatives to increase awareness, which has also been noted by others.[12,13] As evidence mounts regarding the potential effectiveness of optimal health prior to pregnancy,[14–18] midwifery care,[19–23] group prenatal care,[24,25] and doulas[26–29] in lowering preterm birth rates, dissemination of this information to birthing people should be prioritized so that they can make informed decisions regarding their health and care. A desire for such information has been reported among research priorities identified by women of color at higher risk of preterm birth.[8] However, it is important to emphasize is that while providers can review protective and risk factors as well as a patient’s predicted chance of a preterm delivery using a growing number of population-based estimates and/or models, they cannot predetermine delivery timing with complete certitude and thus need to help patients navigate that uncertainty.

Evident in our results is the tension between the desire to know one's preterm birth risk that was endorsed by the majority of patient participants and the practice of some providers to discuss preterm birth risk only with select patients. Patients and providers alike emphasized the importance of discussing modifiable risk factors, and the need to frame such risk factors in a way that avoids mother harm (e.g., blame) also emerged.[30–32] Both patients and providers additionally highlighted the potential for counseling to result in adverse maternal psychological outcomes including anxiety, stress, and guilt. Yet patients cited the potential increased risk for these adverse outcomes if one were to experience a preterm delivery without any warning. This aligns with other qualitative studies of women and men at risk of having or who had preterm neonates that found that they too desired more information from prenatal providers about their preterm birth risks.[9,33–35] Approaches that do not rely on prenatal providers might provide greater autonomy, including the ability to decide whether or not to learn more about one's preterm birth risk to the depth of one's interest. Use of smartphone technology to allow patients to learn at their own pace and comfort has been found to be feasible and acceptable among parents who identified as White and high socioeconomic status. [36,37] More work that also centers the needs and desires of patients should be conducted to determine if similar or distinct interventions are ideal among other groups who a disproportionate burden of preterm birth.

Both patients and providers recognized that structural and social determinants of health impact individual preterm birth risk, yet providers vocalized the challenge of addressing these determinants in the context of prenatal care. This is consistent with data from a recent systematic review on inquiring about socioeconomic circumstances in healthcare settings in which commonly cited barriers (e.g., lack of time, perception that it is beyond providers' scope, lack of provider knowledge and/or discomfort, and limited health system and external referral resources) undermined the ability to optimize patient circumstances and outcomes. [38] However growing recognition of the devastating pervasiveness of inequity in the lives of birthing people demands more active engagement from prenatal providers who are committed to health equity.[38–41] Continued research on and expansion of interventions such as relationship-centered care,[22,33,42] external partnerships,[43] implicit bias and antiracism training,[44–48] and training to address structural and social determinants of health[49–54] are necessary to achieve greater equity in birth outcomes for patients made unjustly vulnerable to adverse birth because of racism, limited economic opportunity, and other factors beyond their control.

Our findings need to be considered in the context of our study limitations and strengths. While we were able to recruit a diverse patient sample and a range of provider types for this study, we did not include patients' partners, whose perspectives are important to consider in counseling, nor providers not affiliated with hospitals, who may have differing perspectives. We did not ask about other adverse pregnancy outcomes (e.g., hypertensive disorder or pregnancy, stillbirth) and thus cannot speak to how they prioritize preterm birth risk relative to other risks in prenatal period. Additionally, whether our findings can be generalized to patients and providers outside of the San Francisco Bay Area is not known. Given initiatives in the region to advance group prenatal care and doulas, providers might have been more activated to consider potential protective factors such as enhanced prenatal care.[55–57] In addition to the diversity of our participants, notable strengths of our work

include the solicitation of both patient and provider perspectives on preterm birth, allowing for comparison of the two in order to identify key similarities and discrepancies that likely impact the patient-provider interactions throughout prenatal care.[58] We also sought out the perspectives of patients of varying preterm birth risk, which is distinct from other studies that have focused on the perspectives of higher risk patients, and thus provide greater generalizability to a broader prenatal population.

## 4.2. Conclusion

Patients' variable knowledge about preterm birth shines light on the opportunity for patient education. In juxtaposition to the majority of patients who expressed a desire to know their personalized preterm birth risk, prenatal care providers reported differing disclosure practices and often cited concerns about patients' reactions as part of the calculus that went into their decision-making. Encouraging greater education and empowerment of pregnant patients not only within but also outside of clinical encounters will likely both be necessary given the variation in provider approach and in patient preferences for extent of counseling.

## 4.3. Practice Implications

Given the asymmetry of information about preterm birth risk that currently exists, providers should consider patient preferences regarding and potential benefits and risks of such disclosure in their practice. Further work building on this study is necessary to determine approaches for conveying preterm birth risk to patients in a manner that minimizes harm (e.g., anxiety, stress) and maximizes self-efficacy to prevent and prepare for the possibility of this outcome.

## Acknowledgements

The authors thank Schyneida Williams for her contribution to study design and the participants who shared their invaluable insights.

### Financial Support

This research was supported by the University of California, San Francisco, California Preterm Birth Initiative, funded by Marc and Lynne Benioff. MT is supported by a University of California, San Francisco, Preterm Birth Initiative transdisciplinary post-doctoral fellowship, funded by Marc and Lynne Benioff and a T32 training grant (T32HD098057) from the National Institute of Child Health and Human Development entitled "Transdisciplinary Research Training to Reduce Disparities in Preterm Birth and Improve Maternal and Neonatal Outcomes."

## References

- [1]. World Health Organization. Preterm birth. (2018) <https://www.who.int/news-room/fact-sheets/detail/preterm-birth> (accessed June 12, 2020).
- [2]. Centers for Disease Control and Prevention. Reproductive Health: Preterm Birth (2020). <https://www.cdc.gov/reproductivehealth/maternalinfanthealth/pretermbirth.htm> (accessed March 5, 2021).
- [3]. Kleinrouweler CE, Cheong-See FM, Collins GS, Kwee A, Thangaratinam S, Khan KS, Mol BWJ, Pajkrt E, Moons KGM, Schuit E, Prognostic models in obstetrics: available, but far from applicable, American Journal of Obstetrics & Gynecology. 214 (2016) 79–90.e36.10.1016/j.ajog.2015.06.013. [PubMed: 26070707]
- [4]. Baer RJ, McLemore MR, Adler N, Oltman SP, Chambers BD, Kuppermann M, Pantell MS, Rogers EE, Ryckman KK, Sirota M, Rand L, Jelliffe-Pawlowski LL, Pre-pregnancy or first-

- trimester risk scoring to identify women at high risk of preterm birth, *Eur J Obstet Gynecol Reprod Biol.* 231 (2018) 235–240. 10.1016/j.ejogrb.2018.11.004. [PubMed: 30439652]
- [5]. Meertens LJE, van Montfort P, Scheepers HCJ, van Kuijk SMJ, Aardenburg R, Langenveld J, van Dooren IMA, Zwaan IM, Spaanderman MEA, Smits LJM, Prediction models for the risk of spontaneous preterm birth based on maternal characteristics: a systematic review and independent external validation, *Acta Obstetrica et Gynecologica Scandinavica.* 97 (2018) 907–920. 10.1111/aogs.13358. [PubMed: 29663314]
- [6]. Khatibi T, Kheyrikoochaksarayee N, Sepehri MM, Analysis of big data for prediction of providerinitiated preterm birth and spontaneous premature deliveries and ranking the predictive features, *Arch Gynecol Obstet.* 300 (2019) 1565–1582. 10.1007/s00404-019-05325-3. [PubMed: 31650230]
- [7]. Hebert CL, Nattino G, Gabbe SG, Gabbe PT, Benedict J, Philips G, Lemeshow S, Predictive Models for Very Preterm Birth: Developing a Point-of-Care Tool, *Am J Perinatol.* (2020). 10.1055/s-0040-1714423.
- [8]. Franck LS, McLemore MR, Williams S, Millar K, Gordon AY, Williams S, Woods N, Edwards L, Pacheco T, Padilla A, Nelson F, Rand L, Research priorities of women at risk for preterm birth: findings and a call to action, *BMC Pregnancy Childbirth.* 20 (2020) 1–17. 10.1186/s12884-0192664-1.
- [9]. McLemore MR, Altman MR, Cooper N, Williams S, Rand L, Franck L, Health care experiences of pregnant, birthing and postnatal women of color at risk for preterm birth, *Social Science & Medicine.* 201 (2018) 127–135. 10.1016/j.socscimed.2018.02.013. [PubMed: 29494846]
- [10]. Bryant AS, Riley LE, Neale D, Hill W, Jones TB, Jeffers NK, Loftman PO, Clare CA, Gudeman J, Communicating with African-American Women Who Have Had a Preterm Birth About Risks for Future Preterm Births, *J. Racial and Ethnic Health Disparities.* (2020). 10.1007/s40615020-00697-8.
- [11]. Pedrini L, Prefumo F, Frusca T, Ghilardi A, Counselling about the Risk of Preterm Delivery: A Systematic Review, *Biomed Res Int.* 2017 (2017). 10.1155/2017/7320583.
- [12]. Baldwin MA, Swamy GK, Wheeler SM, Pregnant Women’s Knowledge and Beliefs about the Safety and Outcomes of Delivery at Various Gestational Ages, *AJP Rep.* 08 (2018) e7–e12. 10.1055/s-0038-1624561.
- [13]. Goldenberg RL, McClure EM, Bhattacharya A, Groat TD, Stahl PJ, Women’s Perceptions Regarding the Safety of Births at Various Gestational Ages:, *Obstetrics & Gynecology.* 114 (2009) 1254–1258. 10.1097/AOG.0b013e3181c2d6a0. [PubMed: 19935027]
- [14]. Althabe F, Howson CP, Kinney M, Lawn J, World Health Organization, Born too soon: the global action report on preterm birth, 2012. <http://www.who.int/pmnch/media/news/2012/201204%5FBornTooSoon-report.pdf> (accessed June 15, 2020).
- [15]. Beckmann MM, Widmer T, Bolton E, Does preconception care work?, *Australian and New Zealand Journal of Obstetrics and Gynaecology.* 54 (2014) 510–514. 10.1111/ajo.12224. [PubMed: 25132235]
- [16]. Stephenson J, Heslehurst N, Hall J, Schoenaker DAJM, Hutchinson J, Cade JE, Poston L, Barrett G, Crozier SR, Barker M, Kumaran K, Yajnik CS, Baird J, Mishra GD, Before the beginning: nutrition and lifestyle in the preconception period and its importance for future health, *The Lancet.* 391 (2018) 1830–1841. 10.1016/S0140-6736(18)30311-8.
- [17]. Temple R, Preconception care for women with diabetes: is it effective and who should provide it?, *Best Practice & Research Clinical Obstetrics & Gynaecology.* 25 (2011) 3–14. 10.1016/j.bpobgyn.2010.10.001. [PubMed: 21094095]
- [18]. Dean SV, Mason EM, Howson CP, Lassi ZS, Imam AM, Bhutta ZA, Born Too Soon: Care before and between pregnancy to prevent preterm births: from evidence to action, *Reprod Health.* 10 (2013) 1–16. 10.1186/1742-4755-10-S1-S3. [PubMed: 23279882]
- [19]. Weisband YL, Klebanoff M, Gallo MF, Shoben A, Norris AH, Birth Outcomes of Women Using a Midwife versus Women Using a Physician for Prenatal Care, *Journal of Midwifery & Women’s Health.* 63 (2018) 399–409. 10.1111/jmwh.12750.
- [20]. Carlson NS, Neal JL, Tilden EL, Smith DC, Breman RB, Lowe NK, Dietrich MS, Phillippi JC, Influence of midwifery presence in United States centers on labor care and outcomes of

- low-risk parous women: A Consortium on Safe Labor study, *Birth*. 46 (2019) 487–499. 10.1111/birt.12405. [PubMed: 30414200]
- [21]. Sandall J, Soltani H, Gates S, Shennan A, Devane D, Midwife-led continuity models versus other models of care for childbearing women, *Cochrane Database of Systematic Reviews*. (2016). 10.1002/14651858.CD004667.pub5.
- [22]. Hardeman RR, Karbeah J, Almanza J, Kozhimannil KB, Roots Community Birth Center: A culturallycentered care model for improving value and equity in childbirth, *Healthcare*. 8 (2020) 100367. 10.1016/j.hjdsi.2019.100367.
- [23]. McRae DN, Janssen PA, Vedam S, Mayhew M, Mpofo D, Teucher U, Muhajarine N, Reduced prevalence of small-for-gestational-age and preterm birth for women of low socioeconomic position: a population-based cohort study comparing antenatal midwifery and physician models of care, *BMJ Open*. 8 (2018) e022220. 10.1136/bmjopen-2018-022220.
- [24]. Byerley and Haas - 2017 - A systematic overview of the literature regarding .pdf, (n.d.). <https://bmcpregnancychildbirth-biomedcentral-com.ucsf.idm.oclc.org/track/pdf/10.1186/s12884-0171522-2> (accessed June 12, 2020).
- [25]. Carter EB, Temming LA, Akin J, Fowler S, Macones GA, Colditz GA, Tuuli MG, Group Prenatal Care Compared With Traditional Prenatal Care: A Systematic Review and Meta-analysis, *Obstet Gynecol*. 128 (2016) 551–561. 10.1097/AOG.0000000000001560. [PubMed: 27500348]
- [26]. Thomas M-P, Ammann G, Brazier E, Noyes P, Maybank A, Doula Services Within a Healthy Start Program: Increasing Access for an Underserved Population, *Matern Child Health J*. 21 (2017) 59–64. 10.1007/s10995-017-2402-0. [PubMed: 29198051]
- [27]. Kozhimannil KB, Vogelsang CA, Hardeman RR, Prasad S, Disrupting the Pathways of Social Determinants of Health: Doula Support during Pregnancy and Childbirth, *The Journal of the American Board of Family Medicine*. 29 (2016) 308–317. 10.3122/jabfm.2016.03.150300. [PubMed: 27170788]
- [28]. Kozhimannil KB, Hardeman RR, Attanasio LB, Blauer-Peterson C, O’Brien M, Doula Care, Birth Outcomes, and Costs Among Medicaid Beneficiaries, *Am J Public Health*. 103 (2013) e113–e121. 10.2105/AJPH.2012.301201. [PubMed: 23409910]
- [29]. Kozhimannil KB, Hardeman RR, Escudero F, Alarid, Vogelsang CA, Peterson C, Blauer, Howell EA, Modeling the Cost-Effectiveness of Doula Care Associated with Reductions in Preterm Birth and Cesarean Delivery, *Birth*. 43 (2016) 20–27. 10.1111/birt.12218. [PubMed: 26762249]
- [30]. Richardson SS, Daniels CR, Gillman MW, Golden J, Kukla R, Kuzawa C, Rich-Edwards J, Society: Don’t blame the mothers, *Nature*. 512 (2014) 131–132. 10.1038/512131a. [PubMed: 25119222]
- [31]. Winett LB, Wulf AB, Wallack L, Framing Strategies to Avoid Mother-Blame in Communicating the Origins of Chronic Disease, *Am J Public Health*. 106 (2016) 1369–1373. 10.2105/AJPH.2016.303239. [PubMed: 27310351]
- [32]. Scott KA, Britton L, McLemore MR, The Ethics of Perinatal Care for Black Women: Dismantling the Structural Racism in “Mother Blame” Narratives, *The Journal of Perinatal & Neonatal Nursing*. 33 (2019) 108–115. 10.1097/JPN.0000000000000394. [PubMed: 31021935]
- [33]. Altman MR, Oseguera T, McLemore MR, Kantrowitz-Gordon I, Franck LS, Lyndon A, Information and power: Women of color’s experiences interacting with health care providers in pregnancy and birth, *Social Science & Medicine*. 238 (2019) 112491. 10.1016/j.socscimed.2019.112491.
- [34]. Edwards BN, McLemore MR, Baltzell K, Hodgkin A, Nunez O, Franck LS, What about the men? Perinatal experiences of men of color whose partners were at risk for preterm birth, a qualitative study, *BMC Pregnancy Childbirth*. 20 (2020) 91. 10.1186/s12884-020-2785-6. [PubMed: 32041561]
- [35]. Davis Dána-Ain, *Reproductive Injustice: Racism, Pregnancy, and Premature Birth*, NYU Press, 2019.
- [36]. Kim UO, Barnekow K, Ahamed SI, Dreier S, Jone C, Taylor M, Hasan K, Basir MA, Smartphonebased prenatal education for parents with preterm birth risk factors, *Patient Educ Couns*. 102 (2019) 701–708. 10.1016/j.pec.2018.10.024. [PubMed: 30396713]

- [37]. Pizur-Barnekow K, Kim UO, Ahamed SI, kamrul M. Hasan K, Dreier S, Leuthner SR, Rau N, Basir MA, Giving Voice to Parents in the Development of the Premie Prep for Parents (P3) Mobile App, *Advances in Neonatal Care*. 20 (2020) E9–E16. 10.1097/ANC.0000000000000669. [PubMed: 31567181]
- [38]. Ades V, Goddard B, Pearson Ayala S, Chemouni Bach S, Wu SX, ACOG Committee Opinion No. 729: Importance of Social Determinants of Health and Cultural Awareness in the Delivery of Reproductive Health Care, *Obstet Gynecol*. 131 (2018) 1162–1163. 10.1097/AOG.0000000000002660.
- [39]. Hardeman RR, Medina EM, Kozhimannil KB, Structural Racism and Supporting Black Lives — The Role of Health Professionals, *N Engl J Med*. 375 (2016) 2113–2115. 10.1056/NEJMp1609535. [PubMed: 27732126]
- [40]. Hardeman RR, Medina EM, Boyd RW, Stolen Breaths, *N. Engl. J. Med.* (2020). 10.1056/NEJMp2021072.
- [41]. ACOG Committee Opinion No. 649: Racial and Ethnic Disparities in Obstetrics and Gynecology, *Obstet Gynecol*. 126 (2015) e130–134. 10.1097/AOG.0000000000001213. [PubMed: 26595584]
- [42]. Hardeman RR, Karbeah J, Kozhimannil KB, Applying a critical race lens to relationship-centered care in pregnancy and childbirth: An antidote to structural racism, *Birth*. 47 (2020) 3–7. 10.1111/birt.12462. [PubMed: 31630454]
- [43]. Community impact, (n.d.). <https://www.marchofdimes.org/mission/community-impact.aspx> (accessed June 15, 2020).
- [44]. Sukhera J, Watling CJ, Gonzalez CM, Implicit Bias in Health Professions: From Recognition to Transformation, *Academic Medicine*. 95 (2020) 717–723. 10.1097/ACM.0000000000003173. [PubMed: 31977339]
- [45]. Acosta D, Ackerman-Barger K, Breaking the Silence: Time to Talk About Race and Racism, *Academic Medicine*. 92 (2017) 285–288. 10.1097/ACM.0000000000001416. [PubMed: 27655050]
- [46]. Hardeman RR, Burgess D, Murphy K, Satin DJ, Nielsen J, Potter TM, Karbeah J, Zulu-Gillespie M, Apolinario-Wilcoxon A, Reif C, Cunningham BA, Developing a Medical School Curriculum on Racism: Multidisciplinary, Multiracial Conversations Informed by Public Health Critical Race Praxis (PHCRP), *Ethn Dis*. 28 (n.d.) 271–278. 10.18865/ed.28.S1.271.
- [47]. Association of American Medical Colleges, Anti-racism in Medicine Collection, (2020). [mededportal.org/anti-racism](https://mededportal.org/anti-racism) (accessed June 15, 2020).
- [48]. Black Lives Matter: Antiracism and Health Suggested Resources | Countway Library, (n.d.). <https://countway.harvard.edu/news/black-lives-matter-antiracism-health-suggested-resources> (accessed June 15, 2020).
- [49]. Metz J, Hansen H, Structural competency: Theorizing a new medical engagement with stigma and inequality, *Soc Sci Med*. 103 (2014) 126–133. 10.1016/j.socscimed.2013.06.032. [PubMed: 24507917]
- [50]. Neff J, Holmes SM, Knight KR, Strong S, Thompson-Lastad A, McGuinness C, Duncan L, Saxena N, Harvey MJ, Langford A, Carey-Simms KL, Minahan SN, Satterwhite S, Ruppel C, Lee S, Walkover L, De Avila J, Lewis B, Matthews J, Nelson N, Structural Competency: Curriculum for Medical Students, Residents, and Interprofessional Teams on the Structural Factors That Produce Health Disparities, *MedEdPORTAL*. 16 (n.d.). 10.15766/mep\_2374-8265.10888.
- [51]. Neff J, Knight KR, Satterwhite S, Nelson N, Matthews J, Holmes SM, Teaching Structure: A Qualitative Evaluation of a Structural Competency Training for Resident Physicians, *J Gen Intern Med*. 32 (2017) 430–433. 10.1007/s11606-016-3924-7. [PubMed: 27896692]
- [52]. Committee on Educating Health Professionals to Address the Social Determinants of Health, Board on Global Health, Institute of Medicine, National Academies of Sciences, Engineering, and Medicine, A Framework for Educating Health Professionals to Address the Social Determinants of Health, National Academies Press, Washington, D.C., 2016. 10.17226/21923.
- [53]. Doobay-Persaud A, Adler MD, Bartell TR, Sheneman NE, Martinez MD, Mangold KA, Smith P, Sheehan KM, Teaching the Social Determinants of Health in Undergraduate Medical Education:



- a Scoping Review, *J Gen Intern Med.* 34 (2019) 720–730. 10.1007/s11606-019-04876-0. [PubMed: 30993619]
- [54]. Hunter K, Thomson B, A scoping review of social determinants of health curricula in post-graduate medical education, *Can Med Educ J.* 10 (2019) e61–e71. [PubMed: 31388378]
- [55]. Interventions Across the Reproductive Lifecourse: Prenatal and Intrapartum Care, *Pretermbirthca.Ucsf.Edu.* (n.d.). <https://pretermbirthca.ucsf.edu/interventions-across-reproductivelifecourse-prenatal-and-intrapartum-care> (accessed June 15, 2020).
- [56]. University of California, San Francisco National Center of Excellence in Women’s Health. UCSF EMBRACE: Group Prenatal Care for Black Families. <https://obgyn.ucsf.edu/national-center-excellencewomens-health/ucsf-embrace-group-prenatal-care-black-families> (accessed June 15, 2020).
- [57]. McBride A, With black babies, moms at high risk in SF, project pairs them with caregivers, *SFChronicle.Com.* (2019). <https://www.sfchronicle.com/bayarea/article/Black-babies-mothers-die-at-astaggering-rate-in-13745368.php> (accessed June 15, 2020).
- [58]. Salmon P, Young B, Qualitative methods can test and challenge what we think we know about clinical communication – if they are not too constrained by methodological ‘brands,’ *Patient Education and Counseling.* 101 (2018) 1515–1517. 10.1016/j.pec.2018.07.005. [PubMed: 30037663]

### Highlights

- Patients are often unaware of their personal risk for preterm birth
- They noted the importance of knowing their risk to be able to prepare
- Providers often cited not disclosing risk due to concern for patient anxiety
- Naming social and structural determinants of health also was barrier to counseling
- Patients deserve greater insight into their preterm birth risk



**Table 1.**

Self-reported sociodemographic and clinical characteristics of patient participants.

<b>Patient Characteristic</b>	<b>N = 35 n (%)</b>
<b>Race/ Ethnicity *</b>	
African American or Black	12 (35%)
Asian or Pacific Islander	3 (9%)
Caucasian, White or European American	8 (24%)
Latina, Latin American, or Hispanic	13 (38%)
Native American, American Indian, Alaskan Native or Indigenous Person	1 (3%)
<b>Preferred Language</b>	
English	24 (69%)
Spanish	11 (31%)
<b>Age</b>	
18–24	4 (12%)
25–29	8 (24%)
30–34	12 (35%)
35–39	9 (26%)
40	1 (3%)
<b>Education</b>	
Less than high school	2 (6%)
High school graduate / GED	11 (32%)
Some college	9 (26%)
College graduate	5 (15%)
Professional or graduate degree	7 (21%)
<b>Annual household income</b>	
<\$25,000	15 (43%)
\$25,001 - \$50,000	6 (17%)
\$50,001 - \$100,000	3 (9%)
\$100,001 - \$200,000	3 (9%)
>\$200,000	4 (11%)
Don't know	4 (11%)
<b>Relationship status with partner</b>	
Married / living together	23 (68%)
Significantly involved, but not living together	5 (15%)
Not significantly involved	6 (18%)
<b>Insurance type</b>	
Private	13 (38%)
Public	21 (62%)

<b>Patient Characteristic</b>	<b>N = 35 n (%)</b>
<b>Recruitment Site</b>	
Academic medical center	15 (43%)
Community partner site	15 (43%)
Research database	5 (12%)
<b>Parity</b>	
0	7 (21%)
1	9 (26%)
2-3	14 (41%)
4	4 (12%)
<b>Obstetric History</b>	
Previous preterm delivery	6 (17%)

\* Participants were allowed to select more than one race / ethnicity

Author Manuscript

Author Manuscript

Author Manuscript

Author Manuscript

**Table 2.**

Self-reported demographic and professional characteristics of provider participants.

<b>Provider Characteristic</b>	<b>N = 16 n (%)</b>
<b>Race/ Ethnicity *</b>	
African American or Black	2 (13%)
Asian or Pacific Islander	1 (6%)
Caucasian, White or European American	10 (63%)
Latina, Latin American, or Hispanic	1 (6%)
Native American, American Indian, Alaskan Native or Indigenous Person	0 (0%)
Other	2 (13%)
<b>Gender</b>	
Female	15 (94%)
Male	1 (6%)
<b>Specialty</b>	
Family Medicine	1 (6%)
Obstetrics Gynecology (generalist)	7 (44%)
Maternal-Fetal Medicine	3 (19%)
Certified Nurse Midwifery	4 (25%)
Nurse Practitioner	1 (6%)
<b>Number of Years Providing Prenatal Care</b>	
0–10	3 (19%)
11–20	9 (56%)
21–30	2 (13%)
31–40	2 (13%)
<b>Number of Prenatal Patients in Prior Year</b>	
0–100	6 (38%)
101–500	5 (31%)
>501	3 (19%)

\* Participants were allowed to select more than one race / ethnicity

**Table 3.**

Risk factors for preterm birth identified in patient focus groups and provider interviews with sample excerpts

	<i>Patient Focus Group Quotes</i>	<i>Provider Interview Quotes</i>
<b>Maternal age</b>	<i>I mean, we're always told age is a factor.</i>	<i>...women that are greater than – about like 35 are considered at higher risk because of probably other comorbidities and increased prevalence of other medical problems.</i>
<b>Race/ethnicity</b>	<i>...I'm looking on my phone and that's when I found that Black women have the highest rate of preterm birth...</i>	<i>I mean obviously there's also the issue of racial disparities.</i>
<b>Body mass index/size</b>	<i>[My friend is] like naturally a small lady... like really, really skinny, and they just told her she can't hold her babies... both of her kids were premature.</i>	<i>...really low BMI...</i>
<b>Maternal comorbidities</b>	<i>I know if you have any health issues like diabetes or high blood</i>	<i>Women with underlying medical conditions, like diabetes,</i>
	<i>pressure... there's different health situations that can factor into premature births as well.</i>	<i>hypertension, renal disease, lupus, any of those...</i>
<b>Anatomic concerns</b>	NA	<i>... anatomical issues...[u]terine anomalies</i>
<b>Prior uterine procedure</b>	NA	<i>history of vertical incisions</i>
<b>Prior cervical procedure</b>	<i>[my provider] was like, "are you done having kids?" And I said, "yes, thankfully," but he was like, "because this procedure is going to really increase your chance of having a premature baby," because my cervix would be so compromised.</i>	<i>previous history of excisional procedures on the cervix</i>
<b>Substance use</b>	<i>People that use drugs and things like that, have a greater risk of having a premature birth.</i>	<i>... substance use like maybe alcohol, stimulants, especially now, or even opiates often are kind of seen as more urgent and acute...</i>
<b>Family history</b>	<i>...it was just surprising at how many people are like, "I was a preemie and my kid was a preemie."</i>	<i>When they tell me that they have a family history, I don't know the direct link, but like some people have very significant family histories of preterm labor...</i>
<b>Structural and social determinants of health</b>	<i>... insurance availability, education level.</i>	<i>If you have cash, your life is going to be a little easier, and if you don't, you're not going to eat as well, you're probably not going to sleep as well, you might be living in a neighborhood that gives you stress. [Patients that are] exposed to certain toxins, trauma, violence, racism.</i>
<b>Stress</b>	<i>Stress or stuff like I'm sure can affect it.</i>	<i>... it's tougher times today, so patients are struggling more than I've seen in the past. There's more helplessness, more substance use, just more poverty, more stress, more anxiety, more depression. So, all of this I think probably contributes.</i>
<b>Trust in medical system</b>	NA	<i>The problem is if people don't trust us... they are not going to have good dialogue around why we're recommending things. They're probably not going to listen to what we're saying, et cetera.</i>
<b>Birth spacing</b>	NA	<i>closely spaced pregnancies</i>
<b>Mode of conception</b>	NA	<i>...assisted reproduction...</i>
<b>History of preterm birth</b>	<i>Like you've had a preterm birth, you're at really high-risk for you[r] age and for having another one.</i>	<i>I think the history of preterm delivery for me is the people with the highest risk.</i>
<b>Multiple gestation</b>	<i>typically twins are born premature...</i>	<i>also multiple gestation, if they have twins, triplets</i>
<b>Pregnancy complications</b>	<i>there are moms who have placenta previa... Yes, it is a condition that happens to us during pregnancy.</i>	<i>placenta previa or vasa previa</i>
<b>Infection</b>	NA	<i>...infections. You know, BV, UTIs, et cetera.</i>

	<i>Patient Focus Group Quotes</i>	<i>Provider Interview Quotes</i>
<b>Fetal growth</b>	<i>...a person I know... gave birth at seven months. Everyone thought it made sense because she was so huge, but I don't know if that contributed or not.</i>	<i>... growth restriction...</i>
<b>Poor nutrition</b>	<i>My diet probably with [child born premature]. All I ate was Wingstop... So that's probably where that came into -- that probably played a major part.</i>	<i>... women who have food insecurity...</i>
<b>Physical activity</b>	<i>I don't know about regular exercise... if this would affect preterm to be honest... But maybe around that time, I don't know, it influences that.</i>	NA
<b>Access to/utilization of prenatal care</b>	<i>... some people just don't get healthcare. They don't get their prenatal visits.</i>	<i>It's access. It's can't get to the clinic between 8:00 and 5:00. Can't get to the hospital. Don't have transportation. Other competing interests.</i>

NA, Not Applicable

Author Manuscript

Author Manuscript

Author Manuscript

Author Manuscript

**Table 4.**

Perspectives on preterm birth counseling identified in patient focus groups and provider interviews with sample excerpts

Major Theme • Subthemes	Patient Focus Group Quotes	Provider Interview Quotes
<b>POSITIVE THEMES</b>		
<b>Optimize Care</b> • Informed selection of providers/hospitals • Proximity to care	<i>...you want care, and the people you're dealing with to be educated on high-risk and everything, and have experience dealing with people who are at high-risk so it makes you feel comfortable.</i>	<i>...there are times when I introduce a topic but then I also make a referral to my perinatologist and kind of rely on them to focus on the particular problem...</i>
<b>Empowerment through Education</b> • Awareness of warning signs • Knowledge of potential care and outcomes	<i>...be better aware of the symptoms and the signs, and what it looks like.</i>	<i>I think also empowering them that they can have some sort of control, not maybe complete control, but there are some things that you can do is very empowering for patients. And then just giving them good precautions.</i>
<b>Risk Modification</b> • Avoid modifiable risk factors (e.g. smoking cessation) • Engage in preventative treatments	<i>...you could stop maybe if you are doing something that is a self risk factor, something that you can control I'm taking insulin and I'm on a diet and trying to do everything I can so that my baby gets to term.</i>	<i>Particularly for the preventable modifiable things, I feel like I have the obligation to share that information and people can do with it what they will... ...for women who have kind of softer risk factors, I feel like it really depends in some ways on how much agency I think she feels she has over those risk factors. Like is it something that I actually have an ability to modify, in which case I feel like it lands more on the sort of like "alright, let's do this,"</i>
<b>Resource Preparedness</b> • Gather resources for hospital and baby • Determine contingency plans	<i>But now I am prepared to say... I do have higher risk factors obviously, and then packing my bag early getting ready for the hospital... ...having the information is very valuable, especially if it's a first-time mom or a fifth-time mom, you still need the information so that you can be better prepared at home</i>	NA
<b>Mental and Emotional Preparation</b> • Engage support network and resources (e.g., family, faith system) • Adjust expectations	<i>...spiritually getting myself together as well. I think that might help a lot of people, whoever you pray to. Just being able to pray or meditate... I think if you were not prepared and you had no idea and you were going to give birth to a baby left now or whenever, then it scares moms... I think now you can look</i>	NA
	<i>things up... I think that's helpful to security.</i>	
<b>Self-care</b> • Stress reduction • Improved nutrition and exercise	<i>...if you're at really high risk, maybe you take it easy, maybe you do get checked...</i>	NA
<b>NEGATIVE THEMES</b>		
<b>Fatalism</b> • Cannot change outcome • Reliance on faith rather than medical information	<i>it's seems to me like in preterm -- in this case of preterm labor, if it's going to happen, there's not much you can do about it. I am a strong believer in God as well, so I know for a fact that He is going to make sure that I and the baby are healthy and is going to make sure that we go all the way, all 40 weeks...</i>	<i>I don't really talk too terribly much about [preterm birth] because if somebody is going to have a preterm birth, there's nothing I can do about it, and I don't want to scare anybody. There's no reason that I feel to talk to somebody about all the kind of horrible things that a preterm baby might experience. It doesn't make any sense.</i>
		<i>...what is challenging for me is that my personality is one where I, I struggle with the concept of giving people information when there's nothing I can tell them to do with it. And, and if they were</i>

Major Theme • Subthemes	Patient Focus Group Quotes	Provider Interview Quotes
<b>POSITIVE THEMES</b>		
		<i>to ask me, like, well what can I do, I'd be like, nothing. Just as long as you know.</i>
<b>Anxiety and Stress</b> • Increased burden on patient • Self-fulfilling prophecy	<i>Maybe knowing what's happening helps you like psychologically, but I just have enough stress in my life, so I thought we're going to follow the steps, take all the tests and be responsible. But it brings a lot of anxiety to read about all the things that can happen to the baby.</i>	<i>I think that can be just a very overwhelming experience for all patients, those who are of limited resources, limited educational attainment, and high-powered "I'm in control of everything" people, you know?                      ...there is that concern of how much information you really want to give someone, because to say congratulations, you're pregnant, however, because you're Black, because you're young, because you</i>
		<i>live in east Oakland, because you don't have good food to eat, you're not exercising and your relationship with your babies' father is not great, you're really, you know, at super high risk. Like, that's stressful and that's like now we're causing some other problem.</i>
<b>Blame</b> • Guilt with poor outcome	NA	<i>...it's like we're kind of walking this fine line, but I really try to avoid anything that puts blames on moms because I just feel like society's already done a good job at that, and we have too frankly, even the way we ask questions when people come in with preterm deliveries, like "well, did you do any...", you know. Even if we aren't implying that they did anything, even just the line of questioning has a different</i>
		<i>meaning to certain people, and the way we ask questions I think sometimes implies that they have some role in it and often they don't, and most often they don't.</i>
<b>Lack of Certainty</b> • Limitations to data	NA	<i>...you're at increased risk because of this, this, this and this factor....                      How much higher we don't know.                      Like, you can't just say you are Black, therefore you are at increased risk. It's also age, and it's also, left? So, like, that's, that's where I start getting like, do not mess, don't start coming up with numbers, because we don't know that data...</i>
<b>Alienation</b> • Discouraging engagement in care	NA	<i>I worry a lot about creating that negative relationship that will discourage women from coming back to clinic for care as being really problematic.</i>
<b>Provider Discomfort</b> • Challenge in counseling	NA	<i>A lot of what I want to be is I want to focus on strength and positivity and all of that, and I have not been able to figure out how to incorporate the risk piece into it.                      I don't want to just alarm people when I don't have anything to offer them. We're already trying and we're offering them social workers and nutritionists and things, and trying to do what little we can to help with the structural things, and not enough, I will say that.</i>

NA, Not Applicable

Author Manuscript

Author Manuscript

Author Manuscript

Author Manuscript