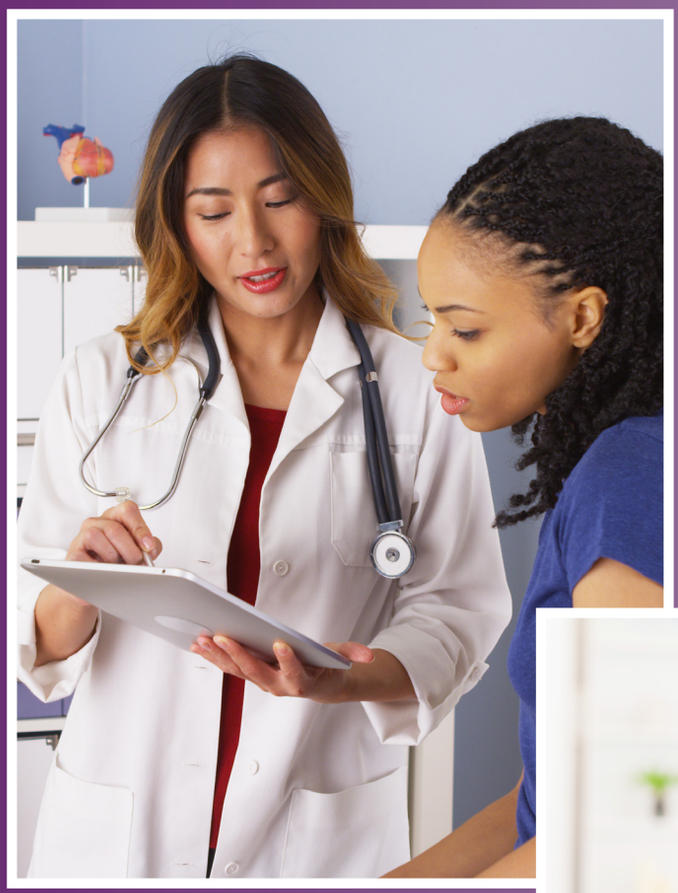

African American Women Speak:

Can We Hear & Respect their Voices?

Karla J. Finnell, JD, MPH, PhD

Pregnant and Parenting African American Women Speak:
Can We Hear and Respect their Voices?

From late January to June, 2018, the Infant Mortality Alliance conducted focus groups and interviews with African American women who were pregnant or had delivered babies within the past 12 months (N = 30). We heard their stories, listened to their triumphs, felt their anguish, witnessed their tears, and marveled at their resilience. Their testimonies support our belief that critical systemic changes are needed to ensure quality, accessible health care for pregnant African Americans. However, meaningful change can only begin if their voices are heard and respected by decision makers and those who deliver services. What follows is a synopsis of some of the findings from this study.

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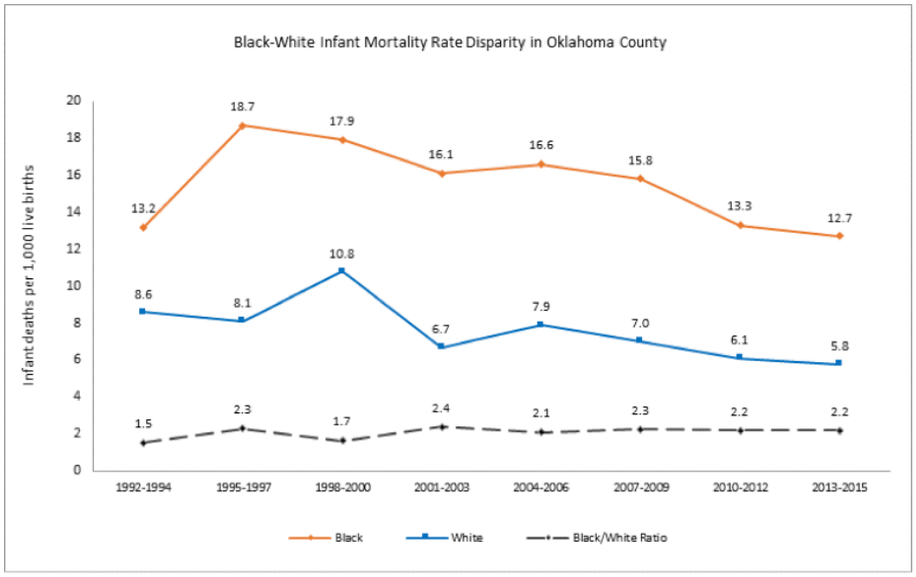
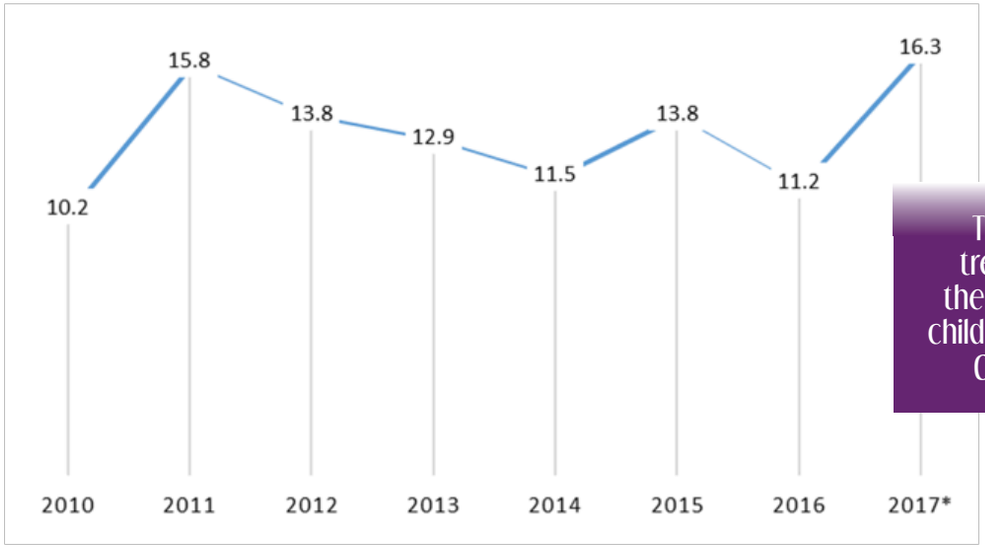


The infant mortality rate among children born to non-Hispanic black women in Oklahoma County is 2.2 times higher than that of children born to non-Hispanic white women.

Figure 1: Trend of black/white infant mortality rate disparity in Oklahoma County [3].

Infant Mortality—Our Community

The infant mortality rate in Oklahoma is 6.9, the fifth-highest in the United States [1]. The Oklahoma infant mortality rate among children born to non-Hispanic black women is 12.9 per 1000 births, which is 1.7 times higher than the infant mortality rate of 7.4 per 1000 births among those born to non-Hispanic white women [2]. While Oklahoma fairs poorly on this key indicator, Oklahoma County fairs worse (see Figures 1 and 2). The infant mortality rate among children born to non-Hispanic black women in Oklahoma County is 12.7, which is 2.2 times higher than that of children born to non-Hispanic white women (5.8 deaths per 1,000 live births) [3].



There is no significant trend of improvement in the infant mortality rate of children born to AA women in Oklahoma County, OK.

Figure 2: Trend in black non-Hispanic infant mortality rates in Oklahoma County [3].

**2017 data are preliminary and subject to change*

Prenatal Care

The construction of the value and meaning of prenatal care cannot be understood without appreciating the individual and societal expectations of pregnancy. The attitudes of the women participating in this study reflected deeply embedded social norms, among them the belief that a woman becomes responsible for the health and well-being of the fetus upon becoming aware of the pregnancy, if not earlier. These women sought to nourish and protect their unborn.

> Try to have the best health possible and create the best environment inside my body possible for the baby...

Seeking and attending to medical care was only one component of the wide range of activities that these women undertook. Notably, the women in this study engaged in self-care while pregnant that they would not have otherwise done for themselves, which is confirmation that they were willing to do more for the fetuses than for themselves and that the fetuses are the intended beneficiary of pregnancy related self-care (see Table 1). Factors moderating self-care included excessive demands of daily life, social determinants of health, racism and bias, lack of social support, depression and anxiety, pregnancy symptoms, and skills. A few participants mentioned the need for preconception care, but most seemed unaware of it as an option.

Table 1: Construction of what constitutes prenatal care

Theme	Explanation
Prenatal care	*"Prenatal care to me is mentally, physically, emotionally preparing my body for my child; that's what it means to me."* *"It's the lifestyle that you change and start to live when you find out you're pregnant."*
Social support	*"For me it's like more than a medical support system. I have family and I have my kids…My friends…It's my unborn baby's support."* *"I just knew that I had to get out of it [bad relationship] for the sake of my health and for the baby's health, I had to get out of it if I wanted to continue to have a healthy pregnancy. I had to leave."*
Physical activity	*"I kept moving, I got on my exercise ball, I think, health-wise, knowing that you're about to give birth and you have to prepare your body for that too, physically.* *"...exercise, well, walking a lot."*
Prenatal vitamins	*"I want to say prenatal vitamins." [Response when asked what prenatal care is.]*
Cessation of "bad" habits	*"I immediately changed… I have a [marijuana] smoking habit."* *"I just took it upon myself …to cut out the bad habits and started to change my life, like the way I was eating, living, and that sort of thing."*
Eating "right"	*"I was cooking at home and tried to do everything right."* *"Like added sugar can be junk food. So, just consume as much fruits and vegetables and healthy lean meat as possible."*
Stress management	*"Mine was just to make sure that I actually get sleep and not to stress and worry, because I'm a worrier."*
Support groups	*"It's good to have a sisterhood through pregnancy and not be alone through it."* *"We would feel more empowered [if we had] support circles for women that were pregnant. We could go to talk about our experiences, and be heard and be understood at the same time."*

Benefits of Medical Prenatal Care

The women participating in this study found it very important (80%) or important (13.3%) to see a doctor during their pregnancy. Fathers-to-be (33.3%), mothers (26.7%), aunts or grandmothers (9.1%), and friends (20%) encouraged participants to see a doctor. Moreover, they valued the expertise of the medical care system, acknowledging that "doctors know more." Women did not just rely on medical providers for advice; they sought information from internet resources, books, family members, and friends for advice and information. The primary perceived benefit of prenatal medical care was the assurance that nothing was wrong, and if something did go wrong, the assurance they had done their part in safeguarding the pregnancy.

> *"It was definitely a benefit to make sure that everything is the way it should be and if problems were to come, we address it and we...decide what needs to happen or what's going to happen."*

> *"I don't want to be...responsible for anything that, any birth defects that did not have to be there beforehand."*

This need for assurance was felt most strongly among expectant first-time mothers who were uncertain of what to anticipate.

> *"It gave me a peace of mind to know that she was developing...it was my first pregnancy. I didn't know what actually to expect."*

I didn't know what actually to expect.

For multiparous women, the perceived relevance and benefits of prenatal care for their most recent pregnancies were shaped by their prior experiences with pregnancy. Medical care was perceived as less important by those whose prior pregnancies and deliveries were uncomplicated, but not by those who had experienced complications or infant loss.

> *"I don't know if... I feel like it was pointless going to the doctor I had…like if there's nothing wrong don't fix it. My first pregnancy...was just so smooth."*

> *"Well, I'm high risk, so I don't have a choice. ...So that I won't go into preterm labor as I did before."*

In addition to medical expertise and assurances, participants valued other aspects of prenatal care including identifying fetal sex, hearing the fetal heartbeat, ultrasound imaging, and delivery planning, as well as access to other resources. Previous research has documented these types of tangible benefits.

Timely Initiation of Care

Most of the women who participated in this study felt it was best to initiate medical care immediately after pregnancy is recognized or confirmed. But in fact, almost a third of participants expressed that they could not get care when wanted (30%). Specific challenges included finding a practice that was accepting new patients (20%); finding a doctor (10%); and finding a provider that would take their insurance (16.7%). If uninsured prior to becoming pregnant, 13.3% expressed difficulty in identifying a provider, doctor availability, and insurance enrollment (see Table 2). In addition, even if appointments were available, based on what the women participating in this study described, it seemed that the protocol or practice among many obstetricians is to schedule appointments at 12 weeks.

A minority view was that it was up to the pregnant individual to decide the appropriate time to initiate care, but these same participants cautioned that everyone should consider their own family and personal medical history when making the decision. This latter view may reflect a preference for self-determination or a dislike of being told what to do.

Most pregnancies were confirmed with home tests, although a few learned of their pregnancy in a hospital emergency room because of an unrelated issue or because they associated pregnancy symptoms with an illness. Usually if the participant did not suspect that they were pregnant, family members, friends, or co-workers raised the possibility of pregnancy within the first trimester, affording them time to enter care within the recommended time-frame.

Table 2: Description of barriers to initiating prenatal care

Theme	Explanation
Identifying a provider	*"I wish, with the insurance I had, there was some database that I could search to find OBGYNs based off of the credentials, their ethnicity, their location, their experience rather than just settling for somebody who's close by who I don't feel comfortable with."* *"I feel like the whole time on the phone was really long when I was calling to find an OB accepting new patients."*
Scheduling first appointment	*"Doctor availability, like he was so busy that the first appointment you could get was 2 months later."* *"I had set up an appointment. I thought it was the main hospital, and they're like,'no we told you to come to the women's clinic, but we'll have to reschedule you,' and stuff like that makes me so mad. So I was just like, forget it."*
Lack of insurance	*"Trying to get enrolled. ...You know that takes the most time."* *"I do think it's important within the first three months to start prenatal care. But for me, it was, it was a matter of having insurance at first, or not having insurance at first." [Awaiting open enrollment period to obtain coverage through parent's insurance plan.]*

Another barrier to accessing appropriate care was the referral system for accessing a high-risk provider. One woman's story capsulized much of the problem. She had experienced three prior losses attributable to miscarriages and pre-term birth, and one live birth. She was now pregnant for the fifth time. Given her medical history, she was well aware of the risk of loss and that preventive therapeutic measures included bedrest, progesterone treatments, and a surgical cerclage (stitch). She contacted a high-risk provider immediately upon becoming aware of her pregnancy, only to be denied access until she obtained a referral by an obstetrician. However, the obstetrician's schedule was too booked for her to begin care within the first trimester. Driven to save her pregnancy and avoid another loss, she called daily to check for cancellations.

Because of the persistence, she saw her obstetrician at 11 weeks and did obtain the requisite referral to the high-risk provider. However, she then had to wait weeks for an appointment at the high-risk specialist. This woman was aggrieved that her efforts to be an active participant in her own healthcare were minimized and that her understanding of the risk of loss was dismissed. Meanwhile, she bore the stress of knowing that these delays increased the risk of yet another loss, alone and without the support of a medical provider. Moreover, progesterone treatments, the only effective drug therapy for pregnancies at risk of pre-term birth, must be initiated between 16 to 19 weeks of pregnancy. Timely initiation of care was urgent.

Adequacy of Care

Established patients experienced other barriers to accessing care. These included office wait time, office hours, transportation, the cost of deductibles and co-payments, and the interruption or termination of SoonerCare. Almost one in four of the African American women participating in this study did not have consistent work schedules, which could limit their ability to predict their availability when scheduling appointments (36.7%). In their own words, these are their voices describing barriers they experienced accessing care (see Table 3).

Table 3: Description of barriers to maintaining prenatal care

Theme	Explanation
Waiting time	*"I took time off of work and somebody is watching my child, and then, when I go back to this room after sitting there for an hour and 25 minutes, the doctor doesn't come into the room for another 30 to 45 minutes."* *"Especially when you're pregnant, no one wants to wait for two hours..."*
Accessible appointments	*"If you're working... just trying to work with your availability and the doctor's schedule."* *"I think after a point you can only miss so much work and then they'll really fire you."* *"And my schedule, too, 'cause I was in school from 8 to 2:45, I'd go after school.. and ride the bus. Also, they close at 4 or 4:30 so."*
Interruption of benefits	*"I had SoonerCare and... usually have it throughout your whole pregnancy, but I had to go re-apply for it, 'cause like randomly they just cut it off."*
Benefits	*"Well, I have SoonerCare and I just wish it was more open to alternative options, like I want to see a chiropractor, or a nutritionist. I feel like it's just like one model for so many types of pregnancies."* *"Everything that falls under pregnancy is not necessarily covered, basically. And not knowing that, being blindsided by random bills [private insurance]."*
Transportation	*"You could call SoonerRide, they can like, a week ahead to make, to make that ride, you can't make it the day before, it's too late."* *"And my car had stopped on me and I haven't got it fixed. I have to take care of my baby so and pay bills, that's a lot."*

Provider/Patient Relationship

"I don't want to be just a number."

An important theme that emerged was the desire for a relationship with one's health care team, a felt need to be at the center of one's care. Without exception, all of the African American women participating in this study wanted to be seen and heard at all points of interaction with the health care system—from scheduling appointments, to waiting rooms and patient rooms, to the delivery room. A portion of those participating in this study did report satisfaction with the health care services received. Distinguishing aspects of these visits included validation of concerns, a discussion of options, attentiveness, and shared respect. These excerpts reflect these priorities.

"My appointments were ideal, even if I had to wait a little bit, there was always a nurse to at least get me in and do my urine test and check the heartbeat. There was somebody working with me while I was waiting for the doctor, so it was not like I was just sitting and idling. She [the provider] gave me my time when I had questions. If we didn't, we chit-chatted about whatever; it wasn't always just about pregnancy. We built that relationship."

"I mean, as long as the doctor listens to me like when I told her I had high blood pressure, and things like that, she took it into account and referred me to a specialist. I felt like she was listening to me and was respecting me as a person."

37.5% of first-time mothers did not want to go the doctor because they did not trust them.

Others participating described maltreatment, and failures of personnel at all levels of the health care delivery system. These women felt their questions were ignored or that the answers given were belittling or dismissive of their interest in their own care. They recalled that treatment for pain was denied, direct requests for assistance were ignored, and health care workers were insensitive to the emotional distress resulting from the loss of an infant.

Depersonalized Care

"You are just a number. You are not a human."

Discontinuous Care

"I lost my baby right here in this office, and going to sit up here and ask me if I need high risk, I just saw you, you don't see me in your books?"

Autocratic Care

"It wasn't a relationship, like it was when I was in Texas, it was 'this is what you are going to do, this is what you are going to take' and I was like uh, no, how about we talk about this and let's look at alternatives."

Dismissive Care

"I remember telling her that I wasn't comfortable, which that took a whole lot just to be able to speak up for myself, um, and she ignored it, she didn't even acknowledge me saying it at all."

These women believed biases regarding age, race, gender, marital status, social class, number of pregnancies, and mental health were behind this maltreatment. In their own words, they were clearly and profoundly conscious of these biases.

Respect is earned, it's not given. Talk to me like I'm equal."

Table 4: Perception of bias experienced receiving health care

Theme	Explanation
Age	*"[the provider] treats you like an adult even if you are young. People in their 20s, that's a healthy age to conceive, and sometimes I think it's perceived that you should be 45."*
Race	*"Because I felt like the patients that were not African American would not have gotten those kinds of responses, they wouldn't have been so snappy at them. They assume because I'm a black woman that I'm going to be argumentative or I'm going to cause them problems or I'm going to ask too many questions…you know, be an issue for them."* *"We know we live in a country that has discriminated against people of color."*
Gender	*"Because black women are definitely, I don't think, considered when it comes to health care as much as they should be because of the way our society is."*
Marital status	*"They're not going to listen to you because you're a black unwed single mother."*
Insurance	*"It's very difficult to trust doctors and I have a lot of reasons for that. One is that many of them have prejudice against insurance [Medicaid]."*
Number of pregnancies/ unplanned pregnancy	*"They also judge us because of the number of kids that we have, and because we have a pregnancy we didn't plan. When we assert ourselves, there's concern we're being reactive."* *"Like you can't tell me I have too many kids. You can't say that to me, that is offensive."*
Mental illness	*"I don't even know if I had my tubes tied. I'd ask questions and they'd say, we'll go look at it...I have a diagnosis of bipolar depression and PTSD, and I feel like they look at my chart and they automatically feel like they can overlook me."*

Aware of interactions of racism with other forms of bias in our society, some participants took it upon themselves to actively monitor the clinic environment for signs of disparate treatment, while others tried to assume the best. One young African American woman proactively assessed whether the practice was likely to be welcoming and respectful by observing the interactions between other clients and front desk staff, as well the reactions of front-desk staff and other clients to her presence in the waiting room. It was common to rely on the advice of friends or Facebook groups to select providers with whom they could "feel comfortable."

In a health care setting, interpersonal racism can occur between a patient and provider, a patient and receptionist, or a patient and another patient [4]. Often these types of biased interactions are implicit, meaning that we unconsciously hold stereotypical views or negative associations of groups of people. The manner in which African American women are treated in the clinical setting affects their decision to return for care or to adhere to care recommendations [5]. Other research has shown that when women from minority ethnic groups did not feel involved in health-related decisions, they lack confidence and trust in their providers [4]. Whether explicit or implicit, racism and biases contribute to racially patterned disparities in outcomes.

That fact is that some degree of bias is common even if we highly value equity and consciously support anti-discrimination and it is necessary to actively work against these biases. These focus group participants shared how healthcare providers can build rapport and engage patients in their own care. Advice included remembering something about the patient, asking open-ended questions, sharing decision making, and being available to teach them.

You want to feel like they're going to care about you as much as they would for themself or their family member.

"The ideal doctor is an available doctor -- available emotionally, mentally, in presence, all of that."

"I feel like when you're attentive & actually looking at me in my eyes, you're engaging with me and you asked me something that's not related to the appointment."

"I [can] actually feel comfortable when I go see you again and I can trust you to listen to me and actually take me seriously."

"She addresses something that I mentioned at my last appointment. That makes me feel like she does remember me, she did hear..."

Maternal Stress

Beyond the anxiety, distrust, and frustration attributed to discriminatory treatment, there were other sources of stress for the African American women participating in the focus group discussions and interviews. In fact, 60% of participants reported five or more stressors which included financial strain; depression or sadness; job loss; sleeping outside, in a car or in a shelter; drinking or drug dependency; or relationship strain, and 33.3% reported one to four stressors.

More specifically, 80% of participants indicated some type of financial strain, and most of those also reported some type of social stress, of which feeling alone and little interest in doing things were most common. Moreover, job loss or having hours cut occurred among 44.8% of participants or their partners. First-time mothers (75.0%) were four times more likely to report that they experienced a job loss, had their hours cut, or could not find a job than multiparous mothers (33.3%). Adding to the significance of this trend, half of first-time mothers and 9.1% of multiparous mothers reported housing insecurity. Employment challenges were associated with housing insecurity (sleeping in their car, outside, or in a shelter, as well as staying with family or friends because of an inability to afford a place to live). In addition, one in five pregnant women reported not having enough food to eat (20.0%).

From the interviews and focus group discussion, we gleaned that some working in the service industry or in housekeeping jobs quit because they were unable to fulfill the physical demands of their jobs in the later months of their pregnancies, and others were terminated. Another woman with a desk job approached human resources fearing termination if her pregnancy was discovered by management. The human resource manager transferred her to a different department, and she then felt secure in her employment. More research is needed to fully understand the prevalence of pregnancy discrimination, its impact on women and children's lives, and viable solutions.

However, we know that the way we live, work, and play shapes our health. Poverty is not only a lack of resources, but it acerbates stress, increasing the risk of delivering a low-birth weight infant [6]. Psychological or social stress is twice as common among women who gave birth pre-term than in those who haven't [7]. The American College of Obstetricians and Gynecologists recommends inquiring about and documenting social determinants of health [SDOH] risk factors including housing stability, access to food and safe drinking water, utility needs, safety, and employment conditions [8]. Another recommended best practice is forming multi-sector partnerships to address SDOH risk factors, getting to know patients which may help with scheduling issues or other challenges, and extending Medicaid postpartum care for a year for women with risk factors such as depression, anxiety, or substance dependency.

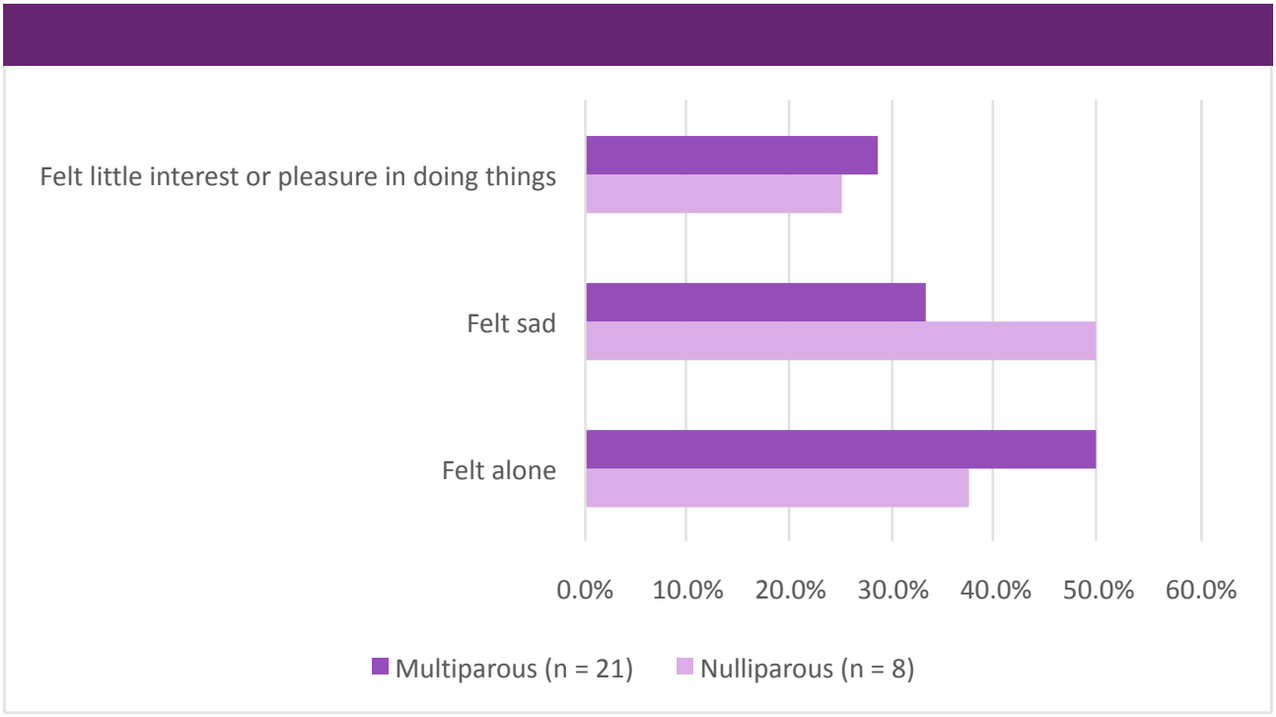


Figure 3: Frequency of depressive symptoms among nulliparous and multiparous participants

Pregnancy Unwantedness

Wantedness of a pregnancy is a significant predicator of the timing of prenatal care initiation, with women whose pregnancies are unwanted having reduced odds of entering care early [9], and poor infant health at birth [10]). The delay, in part, is attributed to expectant parents weighing the social consequences of pregnancy and private factors [11]. Social consequences may include others judging them for having an unplanned pregnancy or judging them because the pregnancy is unwanted. These societal judgments likely emerge from social norms of "individual responsibility", as well as the high value placed on motherhood. The impact is that some may avoid seeking care because of judgment.

This supposition was supported by the findings from this study. Women with unwanted pregnancies expressed concern that they would be judged poorly by providers, their friends, and their families because of the "choices" they had made. They expressed strong feelings of self-doubt, and judged themselves harshly. Several focus group participants expressed concern that a health care provider would pressure a woman interested in exploring termination options into carrying the pregnancy to term, and not provide unbiased medical information.

> "I felt myself just shut down. I didn't want to talk to anyone. . . . I was just kind of a lost cause. I would lose it, and break down crying because I didn't know what to do."

Private factors included feeling that they could not care for the infant financially, that they were personally ill-suited for motherhood, or that the mistimed pregnancy would derail their future aspirations. Their dreams of college completion, careers, and preferred lifestyle were dashed, or now felt unattainable. In addition, it seemed that anticipated societal judgment only reinforced those feelings of shame. We can support these women by not "assuming" that congratulations are in order, but assist by listening actively and screening for depression, anxiety, and social determinant of health risk factors. Notably, in this study, those who did not want to be pregnant were continuing the pregnancy, in part because termination was not an affordable option. One intended to pursue adoption within the family, and the others intended to parent.

Another strategy to reduce unwanted pregnancies is by promoting assessible birth control. This study revealed barriers to accessible birth control in our local health care system. Challenges identified included securing long-term reversible contraception (LARC), or at least not leaving the office visit with a different form of birth control while awaiting a subsequent visit for the LARC placement. Another participant reported being denied follow-up care after her LARC was implanted because of inadequate insurance coverage. Continuing to improve access to LARCs and follow-up care may reduce unwanted pregnancies, and if an unwanted pregnancy occurs, providing trusting, nonjudgmental, and supportive relationships.

Drug-Enforcement Polices

Two participants in this study reported experiencing a problem with drugs or alcohol while pregnant. However, most participants had opinions about whether drug-enforcement policies were a barrier to seeking care, asserting "I feel like [a substance-dependent woman] wouldn't want to go at all," and predicted that women abusing substances would fear losing custody of the infant when born, as well as other children in their care. Most recommended a compassionate approach to the problem of substance abuse, as well as treatment options.

However, we identified another challenge. A participant reported being denied care because of drug use. She stated that she openly admitted her addiction to the provider before the blood test revealed the issue, and requested help dealing with her substance abuse. The provider terminated the patient/provider relationship, and did not provide a referral to another medical or mental health provider. ACOG recommends the development of drug treatment services for all women, especially pregnant women, and their families [12].

"We hope that this report sparks discussion and is a call to action for meaningful, and substantive change."

Conclusion

In Oklahoma County, children born to African American women are half as likely to survive to one year of age than those born to non-Hispanic white women, and there has been no sustained improvement for almost twenty years. This study of African American women confirmed systemic barriers to accessing timely, and quality comprehensive prenatal health care services in our city and community, and gave voice to their lived experiences. We found failures at all levels of the health care system. Moreover, not only was there a lack of resources, but the conditions where these women lived and worked increased maternal stress and the burden of accessing care. As a city, and as a community, we must intervene at multiple levels to create equity in the lives of all babies and parents. We hope that this report sparks discussion and is a call to action for meaningful and substantive change.

Table 5: Sociodemographic characteristics of participants		
Characteristics	**N**	**%**
Maternal Age (M)	29	M = 29.3; SD 5.9
Maternal Education		
Some High School	1	3.3%
High School Graduate	4	13.3%
Some College or Trade School	13	43.4%
College Graduate	4	13.3%
College Graduate (4-year)	7	23.3%
Household Income (when first pregnant)		
<$15,000	13	44.8%
$15,000 - $24,999	2	6.9%
$25,000 - $34,999	4	13.8%
$35,000 - $49,999	3	10.0%
$50,000 or more	7	24.1%
Parous		
Nulliparous	8	26.7%
Multiparous	22	73.3%
Pregnancy Unwantedness		
Right time or later than wanted	10	33.3%
Ambivalence (“It happened.”)	11	36.7%
Too soon	5	16.7%
Unwanted	4	13.3%
Type of Insurance		
Private	13	43.3%
SoonerCare	14	46.7%
Tricare	1	3.3%
Uninsured	1	3.3%
Initiated Care Early (self-report)	26	89.7%

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