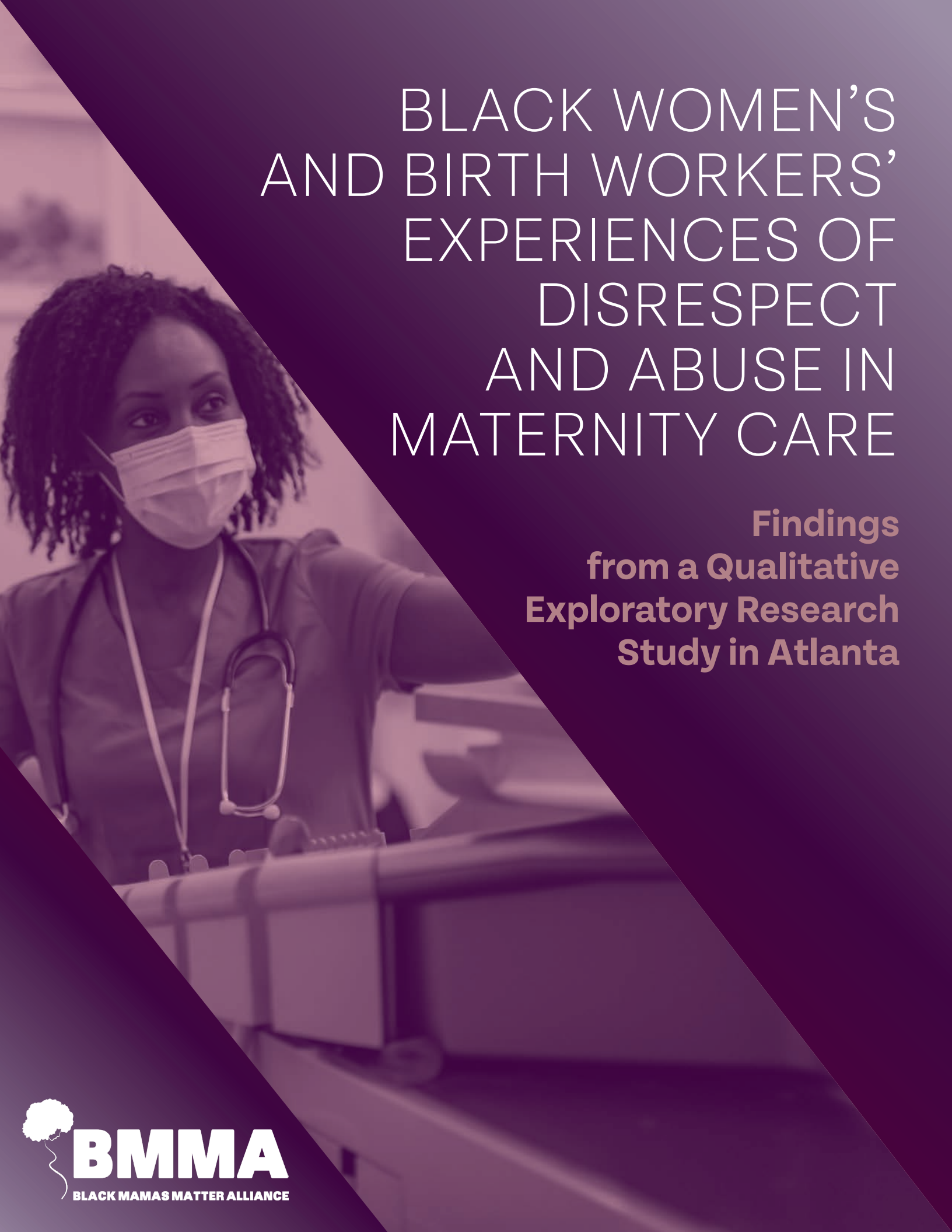

BLACK WOMEN'S AND BIRTH WORKERS' EXPERIENCES OF DISRESPECT AND ABUSE IN MATERNITY CARE

Findings from a Qualitative Exploratory Research Study in Atlanta

BMMA
BLACK MAMAS MATTER ALLIANCE

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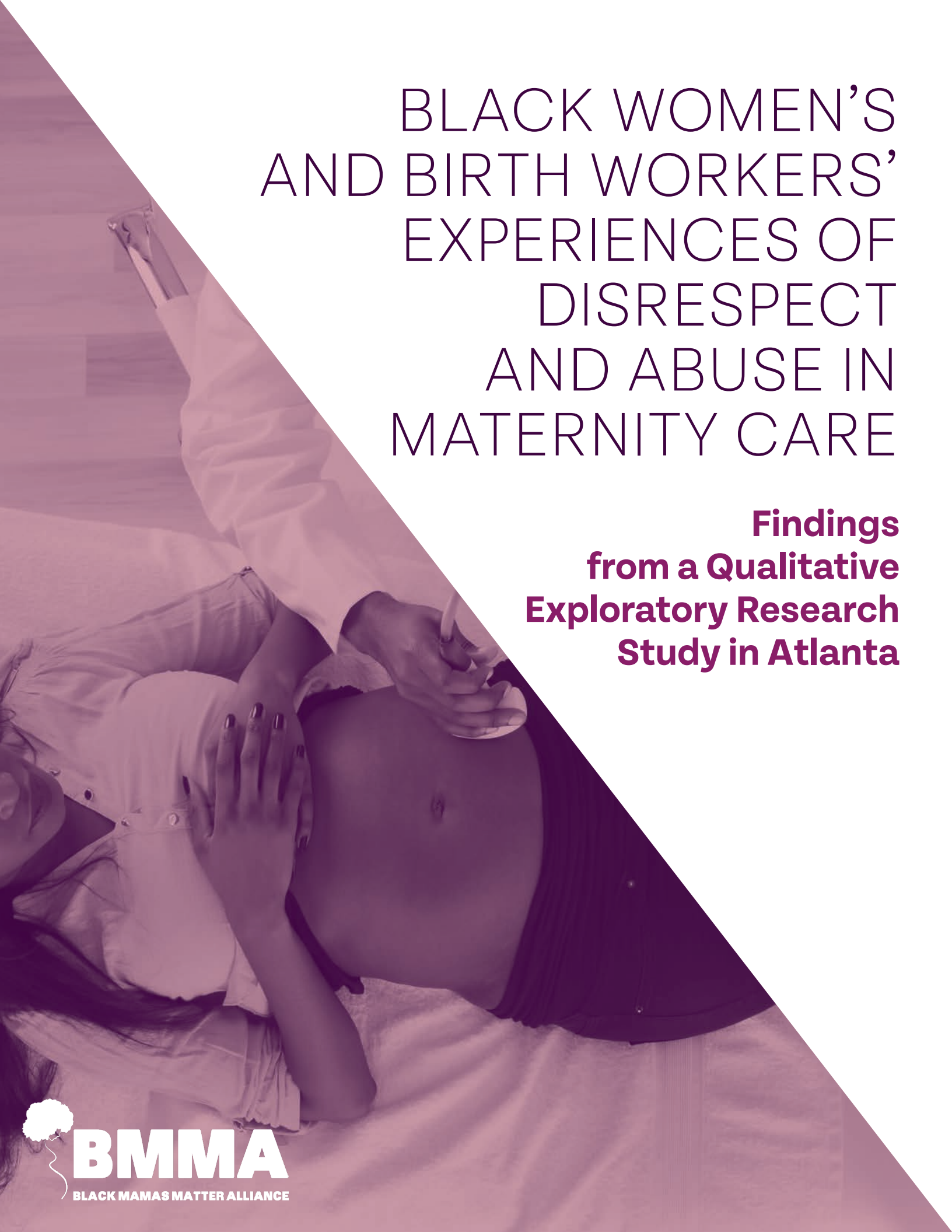

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> [T]he epidemiology of the health consequences of discrimination is, at heart, the investigation of intimate connections between our social and biological existence. It is about how truths of our body and body politic engage and enmesh, thereby producing population patterns of health, disease and well-being.
>
> **— NANCY KRIEGER (2014)**

> [T]his is something to celebrate. Even if you didn't plan it, you're excited about it. I expected for that to translate. I know you don't have to have a party, but bedside manner, like you mentioned, is important. If I'm pleasant to you, I'm expecting that in return. If I'm kind, and I say, "How are you? How is your day?" You don't have to tell me a joke, but you can at least be professional. ...you're being rushed, and you're not even seeing the same person. It's whoever's available, so now you feel like a burden...
>
> **— WOMAN, FOCUS GROUP PARTICIPANT**

INTRODUCTION

Public health research has generated increasingly sophisticated theories and methods for linking the biological to the social, and for understanding how historical and current forms of discrimination, trauma and injustice find expression in health outcomes. Stark racial disparities in maternal mortality and severe maternal morbidity are particularly appropriate for this exploration because women's sexuality and reproduction has always been a crucial battleground for social control of disadvantaged groups, for assertions of biomedical dominance and professional hierarchies, and for humiliation—and selective celebration—of individuals to further promote specific gender and racial ideologies.

Yet, simultaneously, women's sexuality and reproduction has also provided the setting for women to assert their personhood, express their community and cultural solidarity, and define and demand their political and social citizenship. Over the last four decades, women of color have built social movements to link this profound understanding of the personal and political meaning of reproduction to the wider struggle for social justice across a broad range of social institutions where racism finds different forms of expression–schools, police and courts, voting rights and political representation, media and social discourse. The recent surge of attention to what advocates, scholars, politicians and journalists now routinely call the "Black maternal health crisis" helps to create an important opportunity for research to link to action, indeed for research to **be** action.

Black women are 2.5 times more likely to die due to pregnancy-related causes and significantly more likely to suffer from life-threatening complications during childbirth than white women.

The maternal health crisis in the United States is characterized by deep and worsening disparities. Black women are 2.5 times more likely to die due to pregnancy-related causes (Hoyert & Miniño, 2020) and significantly more likely to suffer from life-threatening complications during childbirth (Admon et. al., 2018) than white women. In places like Georgia, which has one of the highest maternal mortality

rates of any state (United Health Foundation, 2018), this disparity is even greater; Black women are more than three times likely to die during pregnancy than white women (Georgia Department of Public Health, 2014). Early studies of racial disparities in health focused on race as a demographic risk factor, implicitly conceptualizing race as an innate biological category (Krieger, 2014). However, more recent scholarship and consensus within the social sciences, specifically within maternal health scholarship (Crear-Perry et. al., 2020; Liu et. al., 2019; Novoa & Taylor, 2018), adopts the view that race is socially constructed and that therefore racism—not race—is responsible for racial disparities (McLemore et. al., 2019). Most recently, this view has been publicly adopted by the Biden Administration. This year, the President and Vice President reaffirmed their commitment to improving Black maternal health by stating that "our Nation must root out systemic racism everywhere it exists, including by addressing unequal social determinants of health that often contribute to racial disparities" (Biden, 2021). Only when racism is recognized as the modifiable risk factor to poor maternal health outcomes can we work to improve the lives of Black women and their families (Crear-Perry, 2018).

This report is just one step towards recognition of the role of racism in maternal health. It describes findings from an exploratory, qualitative research study of Black women's experiences during pregnancy and childbirth in Atlanta, which was conducted in 2018 in partnership between Black Mamas Matter Alliance (BMMA), the Averting Maternal Death and Disability (AMDD) program of Columbia University Mailman School of Public Health, Center for Black Women's Wellness (CBWW), and other local community-based organizations. This was part of a larger study conducted in New York City in 2017 (Freedman et. al., 2020).

Specifically, the study in Atlanta sought to understand Black women's perceptions of the disrespect and abuse they experienced during pregnancy and childbirth. By focusing on disrespect and abuse during childbirth, the study links to a wider global movement that is mobilizing around the concept of respectful maternity care (Armbruster et. al., 2011). It also constitutes initial steps in pursuit of a wider agenda led by BMMA and women of color organizations that seek to transform knowledge and how it is generated, and by doing so, build power and shift culture, bending the arc of history toward social justice (Aina et. al., 2019).

ON DISRESPECT AND ABUSE IN MATERNITY CARE

Disrespect and abuse (D&A) of women during childbirth has gained global attention since it was first formally documented by human rights groups in 2007 (Amnesty International, 2010; Ogangah et. al., 2007), and has since been reported and studied around the world in high-, middle- and low-income countries (Grilo Diniz, et. al., 2018; Morton et. al., 2018; Okafor et. al., 2015). D&A, sometimes referred to as mistreatment, obstetric violence, or dehumanized care, is defined generally as "interactions or facility conditions that local consensus deems to be humiliating or undignified, and those interactions or conditions that are experienced as or intended

to be humiliating or undignified" (Freedman et. al., 2014). A 2015 systematic review of the global literature identified seven categories of D&A: (1) physical abuse; (2) sexual abuse; (3) verbal abuse; (4) stigma and discrimination; (5) failure to meet professional standards of care (e.g. lack of informed consent and confidentiality, failure to provide pain relief, neglect and abandonment); (6) poor rapport between providers and patients; and (7) health systems constraints (Bohren, 2015). These categories are not mutually exclusive. They overlap along a continuum of actions which can and do lead to deadly consequences, especially for Black women who are often demeaned, dismissed and devalued during childbirth. Identifying Black women's experiences as D&A, and understanding its roots in racism and discrimination, is an important first step towards recognition of the impact that mistreatment can have on maternal health outcomes. Listening to women narrate their own experiences of how they were treated, regardless of providers' intent, is essential in shifting the health system towards one that values the dignity and bodily autonomy of Black birthing people.

While the goal of this study was not to confirm or measure the prevalence of the seven categories of D&A, we sought to understand to what extent Black women were experiencing D&A in Atlanta, GA and our findings reflect what women felt and said. Ultimately, we hope this report will help amplify the voices of Black women and contribute to a cultural shift where Black women have the rights, respect, and resources to thrive before, during, and after pregnancy.

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METHODOLOGY

BMMA and AMDD were committed to using a research approach that prioritized partnering with communities and involving Black women as active and equal participants to elevate their lived experiences. Thus, the research was informed by the principles of community-based participatory research (CBPR) and participatory action research (PAR). CBPR is an approach to research for co-learning and ensuring the data collected is meaningful to the population being studied. CBPR goes beyond partnering with community-based organizations to involve community members in each part of the research process (ISRAEL ET AL., 1998). Decision-making power and ownership of the research are equally shared between the community and researchers. PAR explicitly uses research processes to generate and refine actions that are prioritized by directly-affected communities to create change in their circumstances (Baum et. al., 2006).

As part of this process, BMMA and AMDD convened an introductory meeting with local community-based organizations, maternal health advocates, birth support workers, and other Atlanta-based key stakeholders in November 2017. The purpose of the meeting was to better understand the landscape of maternal health in Atlanta, discuss the utility of conducting maternal health research in this location, identify the type of data that would be most useful to the community, and explore methodological considerations for the research. For the next several months, BMMA and AMDD worked with partner organizations and adapted the approach to meet the needs of the invested partners. Additional partnerships with the Center for Black Women's Wellness (CBWW) and the Atlanta Healthy Start Initiative (AHSI), who serve pregnant and parenting women of color in Atlanta, were further formed after this initial meeting to help refine the research project and recruit eligible participants.

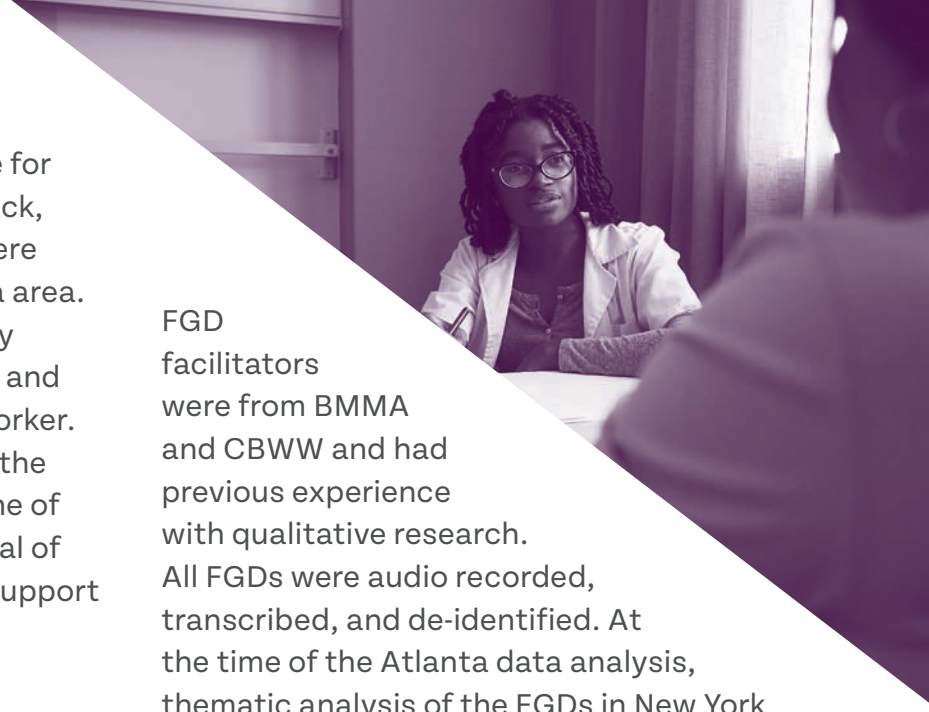
SETTING AND SAMPLE

Focus group discussions (FGDs) were conducted with Black women and birth support workers in Atlanta in April 2018. Recruitment was led by partner organizations, which included CBOs, non-governmental organizations, researchers, clinicians, and advocates who served pregnant and parenting Black women. Recruitment flyers were distributed through mailing lists, social media platforms, community group meetings,

and word-of-mouth. Women were eligible for participation if they self-identified as Black, had given birth in the last three years, were over 18 years old, and lived in the Atlanta area. Birth support workers were eligible if they assisted Black women during pregnancy and childbirth as a doula or family support worker. Eligible participants were screened over the phone and scheduled to participate in one of the FGDs. Five FGDs were held with a total of 30 women, and two FGDs with six birth support workers were held.

Semi-structured focus group discussion guides that were first created by AMDD with community partners for the larger study in New York City were further adapted for use in Atlanta with BMMA, CBWW, and AHSI. The women's focus group guide centered on women's experiences of pregnancy and childbirth in a hospital setting. Women were asked about their expectations, desires, and perceptions of treatment during their pregnancy and childbirth. The birth support worker discussion guides asked about their experiences supporting women, their impressions of the health system, and their perceptions of women's treatment during pregnancy and childbirth by hospital-based staff. All participants received a $25 gift card and travel vouchers.

Women were asked about their expectations, desires, and perceptions of treatement during their pregnancy and childbirth.



FGD facilitators were from BMMA and CBWW and had previous experience with qualitative research. All FGDs were audio recorded, transcribed, and de-identified. At the time of the Atlanta data analysis, thematic analysis of the FGDs in New York City had already been conducted to identify codes related to women's and birth support workers' experiences during pregnancy and childbirth. Codebooks that were created in New York City were shared with the research team in Atlanta and reviewed with the Atlanta transcripts. Upon review, the research team discussed refinements and additions to the Atlanta codebook. AMDD staff coded two transcripts to assess inter-coder reliability. Any differences in coding were discussed and resolved. Coding was completed by AMDD staff and all partners worked to refine the themes. All transcripts were coded in Nvivo 11 software.

The study protocol was approved by the Columbia University institutional review board, and verbal informed consent was obtained from all study participants.

FINDINGS

The findings are presented below in four main sections that highlight women's:

1) **Prenatal care-seeking preferences and the challenges they faced;**
2) **Expectations and desires for pregnancy and childbirth;**
3) **Experiences with disrespectful and abusive care; and**
4) **Positive experiences.**

There was significant overlap between what women experienced and what birth support workers witnessed. Both perspectives are presented below.

CARE-SEEKING PREFERENCES AND CHALLENGES

Women were asked to share their experiences seeking prenatal care and identifying health care providers for their childbirth. Women described the practical considerations that informed their care-seeking behaviors, the characteristics they were looking for in a provider, the information sources they trusted, and the challenges they faced in navigating care.

Practical Considerations

Women in our study reported having some choice in where they went for prenatal care or to give birth, and their choices were heavily influenced by practical considerations. Women stressed the importance of geographic convenience and valued facilities that were close to where they lived, worked, or went to school. As one woman stated, ***"when I found out I was pregnant, I went to [the clinic that] was across the street…It was across the street from my school"*** (WOMAN, FOCUS GROUP PARTICIPANT). The co-location of several social services in one building was also an arrangement that women appreciated: ***"I liked that they did the Medicaid right there, and they fill that all out for you, and WIC is right there, and everything's right there as soon as I come in"*** (WOMAN, FOCUS GROUP PARTICIPANT). Cost and insurance coverage were also important considerations for women as many said they went to the first doctor that their insurance would cover.

Provider Characteristics

Women wanted providers they could relate to and build a relationship with. They wanted to have continuity of care so that providers would have a clear understanding of their preferences and desires before they gave birth. As one woman explained:

> ***It was really important to me that I could have a relationship with the doctor, that I wouldn't be going in and seeing a different doctor every time I went in, that they could kind of develop some kind of knowledge of me instead of just coming in and just reading something off a piece of paper and, "Okay, well, you're who," but I wanna actually know who's gonna deliver my baby. I wanna know you understand what I wanna do and how I wanna go about it.*** (WOMAN, FOCUS GROUP PARTICIPANT)

Racial and cultural concordance were valued because women wanted providers who could relate to their lived experiences and needs. One woman explained, ***"I also wanted to be with a practice where there were people of color, just because I feel like a lot of times, there's more attentiveness and sensitivity to the things that me, as an African-American woman, deal with"*** (WOMAN, FOCUS GROUP PARTICIPANT). Birth support workers felt that racially-concordant providers were better able to communicate and understand the cultural dynamics at play during pregnancy and birth, as explained below:

> ***Maybe they're only seeing white folks as teachers in school, and now they're in a very fragile, vulnerable place just because emotionally everything is happening. I mean, you're giving birth. That adds in to what's happening. There's a communication difference. I'm telling you the name of the child, and you're like, what—how do you spell that name? I've seen that happen…there's a cultural dynamic that's also very important because birth is one of the most sacred things that you can do, which means it's connected to your culture.*** (DOULA, FOCUS GROUP PARTICIPANT)

Trusted Information Sources

Women sought information about prenatal care and childbirth from a range of sources. However, they were most influenced by recommendations from family, friends, trusted medical providers, followed by the facility's reputation or online reviews. One woman explained how watching her sister's positive experience impacted her decision-making:

> ***I piggy backed off of my sister's experience. It was basically word of mouth, and I would go to her visits. I was used to going to the doctor and having an appointment, but spending so much time in the waiting room where you're aggravated, and versus going with her, and you go in, and it's your appointment time, and that's the time that you were seeing the doctor. I was like, "Oh, let me try this."*** (WOMAN, FOCUS GROUP PARTICIPANT)

Women often did their own research to inform their decisions by researching hospital reviews and maternity care services (e.g. use of midwives, water births, and baby-friendly designations). One

woman shared how she relied on online reviews to decide where to seek care, ***"I looked on Google a lot. I looked at the reviews on a lot of places…I ended up going through about two or three different places before I found the right one"*** (WOMAN, FOCUS GROUP PARTICIPANT).

For women who had previously given birth, past experiences were an important consideration for future care. Positive past experiences with providers often encouraged women to continue care from the same providers in subsequent pregnancies while women who had negative experiences often chose to change providers. One woman shared how a negative experience led her to avoid the same hospital despite its good reputation, saying, **"That's the main reason why I don't go there; I sat at [Clinic Q] in the waiting room having a miscarriage for almost two hours. They put me in the room. It took an hour for the doctor to come down there"** (WOMAN, FOCUS GROUP PARTICIPANT).

Challenges to Prenatal Care

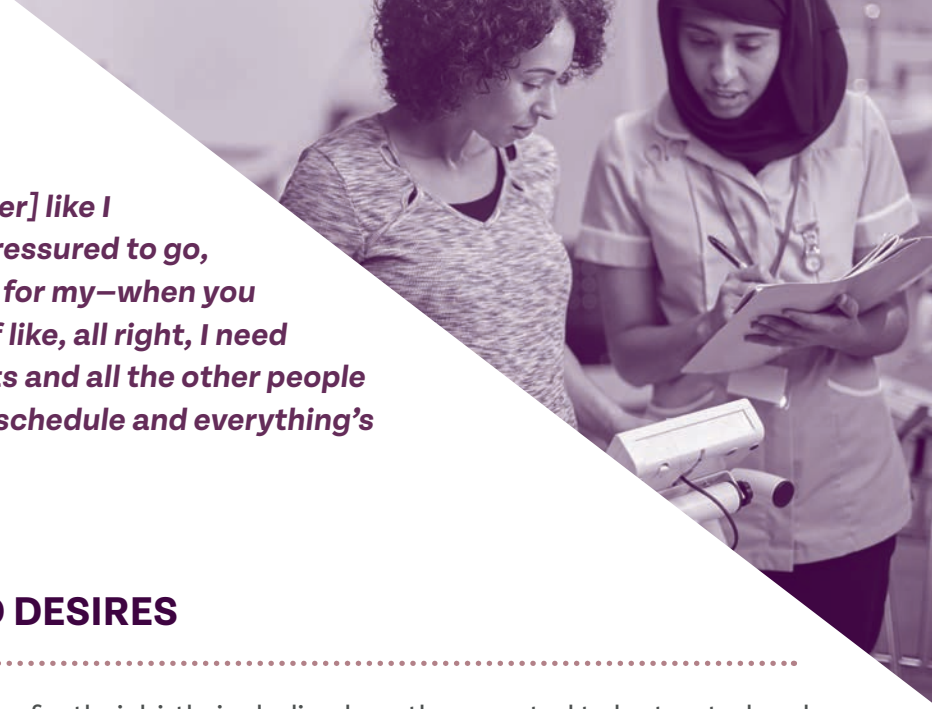
Women reported feeling overburdened by the frequency and quantity of prenatal care appointments, especially since women had to endure long wait times when they got to their appointments. One prenatal appointment could become an all-day affair as discussed by three women from a focus group below:

> **RESPONDENT A:** ***[Hospital X] is slow with ultrasounds. I can tell you that. We'll go in at 9:00 and leave at 3:00.***
>
> **RESPONDENT B:** ***Sometime, they still be having in the morning, a patient there that's trying to get it done, and then they'll move to the afternoon.***
>
> **RESPONDENT C:** ***Yeah, I would agree. I didn't go to [Hospital X]. I was at [Hospital Y], but ultrasounds was an experience that I felt always took a long time. Just took forever.***

For working women, this proved to be particularly challenging, as women had no choice but to prioritize their jobs over their prenatal appointments. As one woman stated, ***"I wasn't able to really keep the schedule cause I was working, so they wanted me to come in all these certain amount of times. I was just like, "Yeah. No, I'm not," cause I had to work"*** (WOMAN, FOCUS GROUP PARTICIPANT).

Lack of transportation was also a barrier to care. Women spoke about the challenges of Atlanta's limited public transportation and the need to have a car to get to each of their appointments. Even when they had a car, it could be difficult to find parking nearby which required women to walk far distances throughout their pregnancy.

Thus, some women saw little perceived benefit to attending all of their prenatal visits. One woman explained how she stopped going to her prenatal appointments when she felt they were more burdensome than beneficial and only went when she felt pressured to do so by her family:



To be honest, I stopped going to my appointments after I realized, [laughter] like I did my own WebMD research…I felt pressured to go, just to feel like I was doing something for my—when you really don't have to. It was just kind of like, all right, I need to be able to report back to my parents and all the other people that love me that my pregnancy is on schedule and everything's fine, so I went when I needed to go.
(WOMAN, FOCUS GROUP PARTICIPANT)

WOMEN'S EXPECTATIONS AND DESIRES

Women shared their expectations and desires for their birth, including how they wanted to be treated and what kinds of medical interventions they were willing to receive. Within these expectations, however, women shared some of the real fears they had and the impact of those fears on their health.

Nurturing Hospital Environments and Providers

Women discussed the importance of having a nurturing hospital environment with compassionate providers who would make them feel safe and valued. One woman explained how she and her partner ***"just wanted somewhere we knew people would be compassionate and caring"*** (WOMAN, FOCUS GROUP PARTICIPANT). Women wanted to give birth in an environment that welcomed and celebrated birth. Birth support workers felt that many of their clients wanted birth to be a spiritual experience but that hospital policies and practices inhibited such an experience. As one birth support worker said:

> ***They're people who are really about this bond, about this into their body, about being in relationship with this journey of pregnancy, having their baby, meeting their baby, breastfeeding their baby. Any interruption of this vision and dream is jolting, and it takes for a recalibration.*** (DOULA, FOCUS GROUP PARTICIPANT)

Birth support workers acknowledged that they often struggled to support women who had such expectations. They believed that part of their role was to help prepare women for the realities of a hospital environment where providers were overloaded and patients often had long wait times. One birth support worker spoke about managing such expectations in the following:

> ***Well, the expectation is for them to get service above and beyond, and for it to be all about them. When they don't get it, they get discouraged. Well, some of the things I talked to them about is "[Hospital X] have a lot of births, so you won't be the only person on the floor. It's several women that these nurses are working with, so you have to be kinda patient with the service that you get"*** (DOULA, FOCUS GROUP PARTICIPANT)

Natural Births with Minimal Interventions

Women expressed their desires to have natural births or births with limited medical interventions. They had specific ideas of what they wanted for their birth experience and developed birth plans which they were prepared to defend. This was particularly the case for women who were supported by doulas and birth support workers, and thus were even more aware of their options and rights during pregnancy and childbirth. One pregnant woman shared how she was preparing to go into labor ready to fight for what she wanted:

> ***I want [the baby] to come at her due date, but I've been trying to naturally prepare my body to have her. I did my birth plan, and I brought it to my midwives. I'm gonna bring it in cause I'm not playing games. If I have to do the C-section, do not do the down [vertical cut]. Give me the bikini cut. Don't use forceps, don't you mention epidural to me. I don't want an epidural at all. That's what I'm prepared for.*** (WOMAN, FOCUS GROUP PARTICIPANT)

These desires were often informed by women's own previous childbirth experiences or what they had heard from family and friends. Women who had previous traumatic childbirth experiences spoke about wanting to do things differently the next time around. For instance, one woman recounted:

> ***With my second birth, after having my first birth be a little bit traumatic, my second birth I wanted a doula, because I wanted a different experience, and I had read that that would help with just pain management and everything.*** (WOMAN, FOCUS GROUP PARTICIPANT)

Birth support workers also felt that the main reason women developed birth plans was to avoid repeating a negative experience. A birth support worker shared how this motivated one of her clients:

> ***She was very determined not to have the birth story that she had before. Her birth story was actually really fine...but she still left that birth feeling like there were things and decisions made that she didn't necessarily get a chance to make. She had things that she wanted to kinda do differently this time.*** (DOULA, FOCUS GROUP PARTICIPANT)

Fear of Adverse Outcomes and Death

Women had strong feelings about how they envisioned their childbirth, and one of the main reasons for this was their desire to control any possibility of a negative outcome. Women faced a lot of fear and anxiety over the possibility of a complication or cascade of medical interventions that could lead to death. Women described feeling stressed about having interventions like epidurals and C-sections which they felt could potentially spiral them into greater danger. One woman explained, ***"With my last doula I had, we talked about the crises of Black women dying. I told her that was one of the reasons why I wanted to avoid a C-section, because at first, I was afraid of—actually, I was afraid of dying"*** (WOMAN, FOCUS GROUP PARTICIPANT).

Women were acutely aware of their increased risk for maternal death and had been warned to avoid media coverage on maternal health as ***"they're just gonna scare you"*** (WOMAN, FOCUS GROUP

PARTICIPANT). For many women, this created a double bind whereby the very information they needed to navigate their care was causing them to feel more stress and anxiety. As one woman said, ***"I was having a lot of anxiety in my pregnancy because I had been reading so many articles about that. I want to be informed, but I had to stop reading them, because it was causing me to have some anxiety"*** (WOMAN, FOCUS GROUP PARTICIPANT). Both women and birth support workers believed this anxiety directly impacted women's physical, mental, and emotional wellbeing and had a direct correlation to the devastating maternal health outcomes Black women were facing.

DISRESPECTFUL AND ABUSIVE CARE (D&A)

The following section presents themes of women's experiences with D&A. As mentioned in the introduction, the goal of this study was not to confirm the global categories of D&A. However, women's descriptions of their experiences did align with many of the categories used globally. Specifically, women's experiences fell within the following themes: 1) harsh language; 2) ineffective communication; 3) lack of informed consent and confidentiality; 4) dismissal of concerns and pain; and 5) racism and discrimination.

Harsh Language

Women reported that providers spoke to them using harsh language and condescending tones, which made them feel dismissed and disrespected. They felt providers lacked basic bedside manners and professionalism, and that their language was at times rude and offensive. ***Women were told to "close your legs" when providers were not ready for women to push*** (DOULA, FOCUS GROUP PARTICIPANT) ***or were accused of being lazy after birth when they were not made aware of the health benefits of walking around*** (DOULA, FOCUS GROUP PARTICIPANT).

Women also described having their baby's or their own health outcome threatened during pregnancy and childbirth. Women felt this happened when providers wanted them to do something they either did not want to do or felt they did not have enough information about which to make an informed decision. One woman shared how she was spoken to harshly and told what was going to happen to her – rather than discussing with her what was going on and why she could not labor for longer.

> ***They said, "We'll give you two hours to dilate before we give you a C-section." Two hours. Nobody dilates to ten centimeters in two hours. Then they come in, and they pretty much gave me all this scare talk, like, "Your organs are starting to fail, and this is starting to go wrong, so you have to have a C-section."*** (WOMAN, FOCUS GROUP PARTICIPANT)

Births support workers confirmed that providers used rude and disrespectful language towards their patients. They felt providers were openly judgmental and condescending to women, especially laying blame upon women when they expressed labor pains as described in the following exchange between doulas in one of the focus groups:

RESPONDENT 2: ***I think it's very disrespectful to always assume that a person or a patient knows what's happening or what to expect. We're talking about just the language that's being used. "You know you don't have to holler like that," or, "You should know by now. You done had five babies." It's just—***

RESPONDENT 1: ***"You should have thought about that."***

RESPONDENT 2: ***Yes, that's a good one, too. They always tell her—***

RESPONDENT 3: ***"Before you laid down."***

RESPONDENT 2: ***"You should have thought about that before you got pregnant again." What are you talking about? Why are you talking to her like she's an object?***

Ineffective Communication

Women reported that providers did not clearly or fully communicate information about their medical care to them. Women often had to press their providers to give them enough information to understand what was happening to them or their babies. Some felt providers were purposely secretive with the information. One woman explained: ***"Not only was [the childbirth experience] process-y, it was process-y without explanation…I don't even wanna say secretive, but it was very, yeah, damn near secretive, [laughter] where they didn't wanna explain what was going on or how"*** (WOMAN, FOCUS GROUP PARTICIPANT).

Birth support workers felt women were often left wondering if they were being taken advantage of or if the miscommunication was a strategy to get women to quickly consent. One person said their clients often wondered ***"what good is me signing consent when I don't know what I'm signing? I don't understand it or anything. I think that's disrespectful. You taking advantage of the fact that I'm in this position right now"*** (DOULA, FOCUS GROUP PARTICIPANT).

Women also felt that if they did not probe their providers with questions or speak up about their care, providers assumed they were uneducated or someone to be taken advantage of. One woman captured this sentiment by saying, ***"When you don't know, they typically try to try you, to see how far can they get under your skin"*** (WOMAN, FOCUS GROUP PARTICIPANT). Others shared similar experiences of feeling like they were kept out of the loop or purposely ignored. In the following, a woman and focus group participant described how she had to ask whether her C-section was already in progress to the anesthesiologist:

> ***The doctor, I knew that he was a skilled surgeon, which is why I chose him, but his bedside manner was a little cold and kind of rough. In my birth plan, I said, "Please tell me what you're gonna do and when," but he didn't even tell me they had started. I asked the anesthesiologist, "Did he start?" He was like, "Yeah, you're already open." I was like, "What?" Cause you can't feel anything.*** (WOMAN, FOCUS GROUP PARTICIPANT)

The lack of communication caused women undue stress as they were often left to wonder what exactly was happening to them during labor. One woman reported that she felt fearful her providers were giving her incomplete information, and the way they interacted with her made her suspicious of their motives and unclear about her health status:

> ***I remember being in extreme pain and people asking me questions that seemed so urgent in their mind, like it was life or death, and I'm like, "Wait." They were asking me questions that made me feel like, okay, am I dying? Because how are you asking me to sign these papers? Am I signing my life away? Do y'all know something I don't know?*** (WOMAN, FOCUS GROUP PARTICIPANT)

Adding to this confusion was the fact that women often did not know who was in the room with them. Providers often did not introduce themselves or ask for permission to be in the room. This was particularly the case with residents and interns who women felt walked in and out of their rooms without consideration. As one woman said,

> ***There was a time where I was getting checked and my legs were spread open. The doctor, she was female, she was checking my cervix, actually, and this student just walks in. I'm looking at the doctor and looking at her, and the doctor's like, "Oh, can you leave?" I'm like, "You don't even knock."*** (WOMAN, FOCUS GROUP PARTICIPANT)

Lack of Informed Consent and Confidentiality

Women reported feeling ill-informed to fully consent and that providers did not preserve their rights to confidentiality. Women felt that they were manipulated into consenting or that procedures were completed without explanation, which led women to endure painful and rough procedures as they were not adequately warned. One woman explained how she didn't understand why they checked her cervical dilation so often, even asking the FGD moderator:

> ***Whatever they did—maybe you could tell me; I'm very curious how they do this—to measure the centimeters every five minutes. It was so painful…I think it hurt more than the contractions, and I kept saying, "Can they stop this? I don't want this. Whatever this is that you're inserting, it hurts. It's for what? I'm obviously progressing, right? Every time you do it, I've gone up a half-centimeter or a centimeter. I'm hearing you call out the numbers, even if you're not talking to me, but I hear y'all talking." I'm pretty much screaming every time I have a contraction, or every time they stick something up. I can hardly tell the difference. It's just pain, pain, pain…"*** (WOMAN, FOCUS GROUP PARTICIPANT)

The use of residents and interns was a particular source of discontent for women who felt that they "practice and play" on them as if they were guinea pigs (Woman, focus group participant). Women were never fully informed or asked to give permission on whether residents and interns could be

involved in their care. In the following exchange, a group of women in the focus group affirm one woman's experience with such an encounter:

RESPONDENT A: ***Why would you let somebody practice on me, and this is happening for real?***

RESPONDENT B: ***I'm so sorry.***

RESPONDENT C: ***They didn't ask you?***

RESPONDENT A: ***They didn't ask me.***

RESPONDENT D: ***No, they don't ask.***

RESPONDENT A: ***I found all of this out after the fact…Well, I had already pushed her out, they were just talking, and she was just going and showing her. I'm like, "Why are you showing her?" She's like, "Because she's practicing," and I'm like, "Why's she practicing on me? Something could seriously happen."***

Women expressed outrage at having their privacy violated during labor and childbirth. One woman explained her anger at being exposed after her childbirth:

> ***When I tore, they just took [the baby] out the room, and they were coming in and out of the room with the door wide open, and I was, "If y'all don't close the door—y'all got my legs wide open," and this is just not the—this is not the move. You can't do this.*** (WOMAN, FOCUS GROUP PARTICIPANT)

Dismissal of Concerns and Pain

Women described feeling that their concerns were dismissed and that their pain was ignored. Women reported that providers had complete disregard for their concerns, and many complained that they had to endure painful or rough procedures. One woman stated:

> ***They'll come and stick their hands in me every 10-15 minutes. That made me cuss all the nurses out. That hurts, for real…I was dilating and all of that. They switched the bed or whatever and went to check to checking me, sticking their hands up—I'm like, "No, that is very uncomfortable."*** (WOMAN, FOCUS GROUP PARTICIPANT)

Another woman described how she didn't even know that she could have received pain medication while receiving stitches:

> ***They didn't give me any pain medicine for my—getting my stitches or anything, so I was in there screaming while they were stitching me up, and I didn't know until recently that you were supposed to have pain medicine while you're getting stitches because I didn't tear with any of my other children.*** (WOMAN, FOCUS GROUP PARTICIPANT)

Birth support workers confirmed that women were often ignored and their complaints dismissed. A birth support worker shared how one of her clients was told she should have expected the pain:

> ***My last birth, it was two months ago, and she was in labor, first baby, 34 years old. She was very***

nervous, just very nervous about giving birth, and about delivery, just the whole process. When she got there, she was treated almost like she should have known what to expect. When I got the phone call, she was just like, "Could you please come down here? Because they're making me"—she was saying her nurse, "is making me feel like I should not be in this kinda pain, or I should have expected this." (DOULA, FOCUS GROUP PARTICIPANT)

Racism and Discrimination

Women reported experiencing pervasive forms of racism and discrimination throughout their pregnancy and childbirth. Providers judged them harshly and made assumptions about them because they were Black. Women felt that providers played into prevailing stereotypes of Black women and lumped them all together, as described by the following woman:

I felt like [the provider] just lumped, "Oh, you're Black. You're overweight. You eat fried chicken every day and don't take care of yourself." I think that's—she just assumed that and assumed that I just need to—I don't know…That was probably her perception, but it just came across as disrespect. (WOMAN, FOCUS GROUP PARTICIPANT)

Women were discriminated against based on a range of factors, including socioeconomic status, age, and marital status. Discrimination based on insurance coverage was a prominent topic of discussion among both women and birth support workers. ***Women felt that if they had public insurance, they were "not a priority"*** (WOMAN, FOCUS GROUP DISCUSSION) and had to endure longer wait times, judgment, and condescending behaviors by providers. This sentiment was echoed by birth support workers who perceived insurance status and class as a major source of bias and a driver of poor treatment. In the following, a birth support worker shared how providers "class" low-income patients and make them feel inferior:

Class means a whole lot because according to where you get your prenatal care, they already class you because you live in a certain neighborhood…They class you already just by where you get your prenatal care, and what side of town you live on, and where you deliver at. It is a thing. Even when you're going to [Clinic Q], the nurses and the providers, they even make the patient feel like they're less than cause this is where you come—you gotta come here to get these services. (DOULA, FOCUS GROUP PARTICIPANT)

Women also reported being discriminated against based on their age and marital status. Young women felt mistreated by the assumptions and judgments providers made about them. One woman shared:

I think it is a big part of being Black and young, cause I'm only 19. My boyfriend, he's been to every appointment, he's on all my paperwork, I'm on all his paperwork, so when you come in, they'll be like, "Oh, is this the [father]"—yes, it is, or the way that they come. You guys know what I mean? They'll be like, "Oh, is your partner in here?" I'm like, "He's sitting right there. He's been here the last six hours that I was." That's him. (WOMAN, FOCUS GROUP PARTICIPANT)

Some young women expressed deep distrust of providers who they felt took advantage of their presumed inexperience. As one woman said, "[providers] feel like the younger crowd—they don't know so they'll go for anything. You know what I'm saying? If you don't speak up, then they will basically try to experiment on you" (Woman, focus group participant). Birth support workers spoke about the barrage of mistreatment Black women endured in a system seeped in institutionalized racism:

> ***When you're Black, already there's so much inherent medical racism. There's so much in the way that we're trained. There's so many assumptions that are made on what got you pregnant. How many other kids do you have? How many abortions have you had? Who's this person with you? Is that the father? Who's that over here?***
> (DOULA, FOCUS GROUP PARTICIPANT)

While this led many of the women to seek out health care providers who were Black, racial concordance did not always mitigate the mistreatment women felt. Rather, some women felt Black providers and other providers of color were equally disrespectful, which in fact made them feel even worse as described by one woman in the focus group:

> ***I think it was even more [disappointed] that it was coming from a person of color. I wish that—I think that made it even more insulting, because in this environment, I would appreciate being taken—anytime you wanna feel like an individual, but especially with someone of your kind. You know we're not all the same, so I don't expect to have to educate you on that, whereas with a white person or another race, I might have to say, "Hey, I know this is your client, but this—we're not all the same."***
> (WOMAN, FOCUS GROUP DISCUSSION)

POSITIVE EXPERIENCES

As can be expected, women had a wide range of experiences during childbirth, not all of which were negative. In fact, what made women's experiences so complicated was that those "beautiful moments" with their providers could swiftly transition to treatment that women perceived to be disrespectful and abusive. However, women tried to articulate what they did appreciate about their experiences, and women often went out of their way to acknowledge such moments.

Women appreciated clear communication from their providers. They reported more trust when providers introduced themselves and explained what was happening to them throughout their pregnancy and childbirth in a way they could understand. As one birth support worker said, women had positive experiences when providers ***"came in, introduced themselves, talked about what—how they saw things going, where they were"*** (DOULA, FOCUS GROUP PARTICIPANT). In the following, a focus group participant described how her doctor's explanation of her need for an unplanned C-section enabled her to trust her doctor and feel at peace with the decision:

The doctor came in. He said, "This is why I think you should have a C-section. There could be cord prolapse, cause you're already in labor. You're four centimeters, and you have so much fluid." I had excess fluid this time, too. "If I try to turn the baby, it could break your water and it could turn into an emergency situation. Instead, I think the safest choice is just to go ahead and give you a C-section now. We can take our time. Your baby's transverse, so there's nothing that I can do at this point." I was okay with it. I accepted it. It was a very calm, quiet surgery…It's not what I expected to happen, but I really trust my doctor.
(WOMAN, FOCUS GROUP PARTICIPANT)

Women also reported more positive experiences when providers respected their birth plans and involved them in shared decision-making. ***Just having a provider simply ask patients "what do you think"*** (DOULA, FOCUS GROUP PARTICIPANT) ***had a huge impact for women.*** They appreciated being listened to and asked for their preferences, as well as being allowed to practice their preferences such as labor positions and having support persons present.

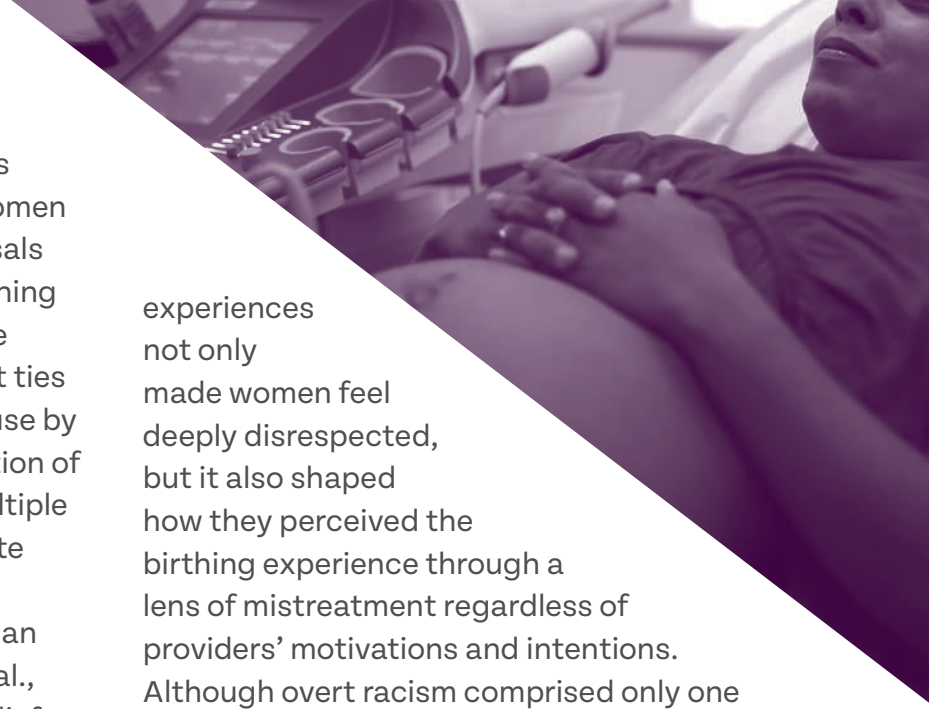
DISCUSSION

This qualitative study explored Black women's and birth workers' experiences during pregnancy and childbirth and their perceptions of mistreatment. Our study found that women hoped to give birth in caring environments with empathetic providers with whom they had built a trusting relationship over the course of their pregnancy. Rather, as other studies have shown (Attanasio & Kozhimannil, 2015; Declercq et. al., 2013; McLemore et. al., 2018), our data show that women faced widespread mistreatment before, during, and after childbirth. **Specifically, women experienced 1) harsh language; 2) ineffective communication; 3) lack of informed consent and confidentiality; 4) dismissal of concerns and pain; and 5) racism and discrimination.**

Overall, the many forms of abuse experienced by women in our study were inextricably linked to their status as Black women. The women in our study spoke at length about the verbal abuse they suffered from providers who used condescending language, threats, and ineffective communication as a means to blame and belittle them. They felt that providers purposely withheld information from them, leading women to be mistrustful and suspicious of their providers' intentions. Women felt that providers judged them more harshly and made racist assumptions about them because they were Black. They felt that providers were more willing to overtly express their biases and treat them poorly on account of those biases, such as being dismissed and ignored. Women reported that health care providers were more likely to use harsh, scolding, and threatening language as other research has documented (Beck, 2016; Maina et. al., 2018; Vedam et. al., 2019).

Overall, the many forms of abuse experienced by women in our study were inextricably linked to their status as Black women. Women felt that providers judged them more harshly and made racist assumptions about them because they were Black.

Lack of consent and dismissals of pain were also frequently reported by women in our study. Research confirms healthcare providers are less likely to obtain informed consent for medical procedures from Black patients (Rosenthal &



Lobel, 2011; Vedam et. al., 2019), which was observed by the doulas we interviewed. Women in our study also reported frequent dismissals of their anxiety or pain throughout the birthing experience. Viewing Black patients as more pain-tolerant and less deserving of consent ties directly to a history of subjugation and abuse by the medical system and a cultural devaluation of Black bodies (Rosenthal & Lobel, 2011). Multiple studies of healthcare providers demonstrate racial bias in the perception of pain and treatment for pain in Black patients (Hoffman et. al., 2016; Maina et. al., 2018; Meints et. al., 2019). These biases are associated with beliefs about the biologic differences between Black and White people, which date back to slavery (Hoffman et. al., 2016). Whether intentional or not, these actions by healthcare providers reinforce the notion that Black women are inferior and less deserving of care compared to their white counterparts.

Women in our study were acutely aware that their experiences with D&A manifested from a medical system which continually devalued their lives because of their race. Women were also blamed for the profound physical and mental impact that such devaluation had on them. Such experiences not only made women feel deeply disrespected, but it also shaped how they perceived the birthing experience through a lens of mistreatment regardless of providers' motivations and intentions. Although overt racism comprised only one of the themes generated from the focus group discussions, aspects of all five themes stem directly from racial prejudice and discrimination towards Black people. Racism has been shown to take many forms in patient-provider interactions during pregnancy for Black women, which include dismissing patients' beliefs and providing sub-standard care to Black compared to white mothers (Rosenthal & Lobel, 2011). Overall, the negative experiences of Black women during their birthing process are directly tied to both implicit and explicit racial bias of healthcare providers (Altman et. al., 2019; Saluja & Bryant, 2021).

Women in our study were acutely aware that their experiences with D&A manifested from a medical system which continually devalued their lives because of their race.

Research has shown that perceived experiences with racial discrimination and prior negative experiences heavily impact patients' mistrust of the health care system (Martin et. al., 2013; Peters et. al., 2014; Shepherd et. al. 2018). Black patients report much higher levels of distrust in the healthcare system than their white counterparts (Armstrong et. al., 2008; Armstrong et. al., 2013, Boulware, 2003). Negative experiences with racial discrimination have also been shown to impact patients' fears of conventional healthcare services as well as their perceptions of the quality of care they received (Shepherd et. al., 2018). For

many, including the women we interviewed, these experiences reinforced past negative encounters with the health care system and increased the desire to minimize interactions with facility-based health care services for future pregnancies. Given that Black women are nearly three times more likely to die from a pregnancy-related cause than white women, these data are particularly disheartening (Petersen et. al., 2019). In order for health care systems and providers to earn the trust of Black patients, there must be concerted efforts to acknowledge and eliminate the role of racism as the risk factor to poor maternal health outcomes.

There are ways in which women's experiences can be improved – and not all of them require fundamental health systems reconfigurations. Consistent with previous research (Bennett et. al., 2006; Brown, 2009; Martin et. al., 2013; Lori et. al., 2010;), participants in our study expressed improved trust and satisfaction with their healthcare providers when providers explained what was happening, involved women in the decision-making process, and were empathetic to women's needs. The use of basic communication skills by providers (e.g. introducing themselves to patients and their families, making eye contact, explaining medical procedures before they were done) had positive effects for the participants in our study. Listening to and valuing the lived experiences of Black women by providers also has the power to transform the quality of maternity care in this country. Thus, interventions aimed at improving effective communication, promoting respectful and compassionate interactions and reducing implicit bias have the potential to improve trust and satisfaction and work towards an equitable and respectful experience.

LIMITATIONS

A main limitation of the study is the generalizability of the findings. We conducted the research with a relatively small sample of Black women and birth support workers in Atlanta, GA. We partnered with community-based organizations working on Black maternal health and rights to recruit eligible participants, and this may have led to a sample of women who were more acutely aware of the current state of Black maternal health which could have influenced their responses in the focus group. Additionally, while we conducted focus group discussions with experienced community-based moderators using a topic guide, this may have resulted in researcher bias with some issues being discussed at greater length than others. Additional research on this issue is required to determine whether these findings translate to other populations of women in other areas of the United States.

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CONCLUSION

This study sought to understand Black women's experiences during pregnancy and childbirth and their perceptions of disrespect and abuse during facility-based childbirth. We found that women not only experienced mistreatment but that much of the mistreatment was driven by the pervasive nature of racism in health care. While many of the women reported individual acts of mistreatment, all the participants in our study highlighted the broader impact of a maternal health care system and culture that consistently marginalized and devalued the lives of Black women. While this study did not look to link mistreatment with outcomes, our findings support the need to recognize the role of racism in maternity care and serves as a call to action to address the root causes of the health disparities that exist for Black women.

We found that women not only experienced mistreatment but that much of the mistreatment was driven by the pervasive nature of racism in health care.

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BMMA

BLACK MAMAS MATTER ALLIANCE

THE BLACK MAMAS MATTER ALLIANCE (BMMA) is a national network of Black women-led organizations and multi-disciplinary professionals who work to ensure that all Black Mamas have the rights, respect, and resources to thrive before, during, and after pregnancy. BMMA honors the work and historical contributions of Black women's leadership within their communities and values the need to amplify this work on a national scale. For this reason, BMMA does not have chapters. The alliance is composed of existing organizations and individuals whose work is deeply rooted in reproductive justice, birth justice, and the human rights framework.

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