Information and power: Women of color's experiences interacting with health care providers in pregnancy and birth

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ABSTRACT

Rationale: Preterm birth and other poor birth outcomes disproportionately affect women of color. Emerging evidence suggests that socially-driven issues such as disrespect, abuse, and discrimination within the health care system influence how people of color experience care during pregnancy, birth, and postpartum, which contributes to poorer outcomes for the mother and baby.
Objective: As recommended by community partners, we explored how interactions with providers were perceived and understood in the context of seeking care for pregnancy and birth.
Method: For this constructivist grounded theory study, we recruited 22 self-identified women of color 18 years of age or older and who were between six weeks and one year postpartum. Women participated in interviews exploring their experiences, which were audiorecorded and transcribed. Data were analyzed using dimensional analysis and situational analysis methods.
Results: The concepts of information and power surfaced in analysis, in which providers have control over the information they share and "package" information to exert power over women's ability to participate in decision-making. An established relationship with providers and acknowledged levels of privilege or marginalization influenced how information was shared. Contextual factors included provider bias and judgment towards their patients, health care system structural issues, and the overall power dynamic between patient and provider.
Conclusions: Women of color's experiences during pregnancy and birth were influenced by how they were treated by providers, particularly in how information was shared and withheld. The providers' control over information led to a power dynamic that diminished women's ability to maintain autonomy and make health care decisions for themselves and their children. This study provides insight and impetus for change in how providers share information, utilize informed consent, and provide respectful care to women of color during pregnancy and birth care.

1. Introduction

Preterm birth and other poor birth outcomes disproportionately affect women of color. Black women, in particular, have a two-fold higher risk of preterm birth as compared to White women (March of Dimes, 2014). Socially determined factors such as racism and discrimination across the life course adversely affect women and their pregnancies (Alhusen et al., 2016; Alio et al., 2010; Bower et al., 2018; Dominguez, 2011; Mehra et al., 2017; Nuru-Jeter et al., 2009;

Slaughter-Acey et al., 2013). The use of stereotypes by health care providers and patient perceptions of these stereotypes affect the experience of care quality for those in marginalized groups (Calabrese et al., 2014; Rosenthal and Lobel, 2016; Shavers et al., 2012). In particular, implicit bias represents a large driver in perceptions of inequitable care (Maina et al., 2018; Tajeu et al., 2018). Efforts to mitigate implicit bias and judgment have been reported (Burgess et al., 2017; Van Ryn, 2016). Yet, a deeper understanding is needed to understand factors and influences within the health care interaction that

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may further contribute to these disparities.

The association between care experiences and outcomes has theoretical basis across multiple socioecological pathways with individual, community, and societal impact (Bronfenbrenner, 1994). Toxic stress related to adverse life experiences and racism affects reproductive outcomes such as unintended pregnancy, pregnancy risk, and preterm birth (Braveman et al., 2017; Hall et al., 2019). At the community level, social and environmental factors such as residential segregation and subsequent poorer living conditions, income inequity, and educational disparities have a cumulative effect on risk for adverse outcomes (Burris and Hacker, 2017; Mehra et al., 2017). At the societal level, structural racism is associated with poor birth outcomes (Wallace et al., 2015, 2017), demonstrating the need to examine the influence of both system forces and individual-level interactions on outcomes for women of color.

Patient-provider interactions can be seen as a structural component of health care systems influencing how patients experience care. While often perceived as being dyadic and free of structural influence, how providers relate to and influence care is a product of the systems set in place to support or hinder the care that is provided (Scott et al., 2019). Interactions between patient and provider serve as an essential conduit for women feeling supported in their care experience, and, given the powerful impact these structural factors have on how care is received, exploration of these interactions is needed to recognize larger influences from a historically racist and patriarchal system (Washington, 2006). Reproductive justice, an intersectional health equity framework developed by women of color with the premise that all people should "have the economic, social, and political power and resources to make healthy decisions about our bodies, sexuality and reproduction for ourselves, our families and our communities in all areas of our lives", is a helpful way to frame these interactions within a larger structural construct (Asian Communities for Reproductive Justice, 2005; Black Mamas Matter Alliance, 2018a).

Socially-driven issues such as disrespect, abuse, and discrimination within the health care system play a significant role in how women of color access and experience care during pregnancy, birth, and postpartum, which contributes to adverse outcomes for mother and baby (Attanasio and Kozhimannil, 2015; McLemore et al., 2018; Ruiz et al., 2014; Salm Ward et al., 2013). Women of color have described care interactions with health care providers that are disrespectful and include feelings of powerlessness and loss of autonomy and self-determination (Harrison et al., 2017; McLemore et al., 2018). Many women of color feel powerless to make decisions and desire a more active role in their care (Ebert et al., 2014). Attention to quality communication and trust-building have been shown to improve perceptions of care for Black women during pregnancy (Cuevas et al., 2016).

In a previous study, women of color in San Francisco were recruited as community partners and were asked to bring forth research questions that they felt were important to their community as part of a community-engaged research prioritization project (Franck et al., 2018; McLemore et al., 2018). These women identified a research priority to explore how disrespectful interactions with providers influence birth outcomes. Therefore, the purpose of this study was to explore how women of color make meaning of their experiences interacting with health care providers, focusing on respectful and disrespectful care experiences. We aimed to explore how these interactions were perceived and understood in the context of seeking care for pregnancy and birth.

We note that some pregnant and birthing people do not identify with the terms woman, women, or mother. We use these terms in this article to represent the study sample because all included participants identified with these terms, although the experiences represented by this study are not meant to be exclusive to female-identified pregnant and birthing people.

2. Method

Data were collected between September 2015 and December 2017 using constructivist grounded theory methodologies informed by Charmaz (2014), Clarke (2003), and Schatzman (1991). In brief, constructivist grounded theory acknowledges the subjective and involved nature of the researcher in relation to the participant—not as an objective observer but as an active partner in the interaction. With that subjectivity comes strong requirements for ongoing reflexivity and interrogation of positionality from the researchers to expose and account for the multiple ways in which assumptions and extant knowledge inform the research process (Charmaz, 2014; Clarke, 2003; Schatzman, 1991).

Five researchers, with extensive expertise in qualitative methodologies, reproductive healthcare, vulnerable communities, racism and discrimination, and community engaged research, including four identifying as women, four currently practicing as nurses or nurse-midwives, and two women of color, comprised the study team. Our initial assumptions included: 1) how patients are treated influences not only their experience but also their outcomes; 2) racism and discrimination exist and are prevalent in health care interactions; 3) people come to health care encounters with experiences that can either help or hinder their ability to trust the care they receive; and 4) providers have an opportunity to provide care that builds trust and respect. These assumptions positioned the initial research question within a social justice lens and were continually checked against knowledge gained from participant experience.

Participants were recruited through a community-based organization offering health and wellness services to low income women and families in San Francisco. Participants were invited to enroll if they were 18 years of age or older, were between six weeks and one year postpartum, and self-identified as a person of color. A purposive sample of 22 women was obtained through the organization with some snowball effect (i.e., participants invited others to contact the researchers if they were interested in the study). Later in the study, theoretical sampling (purposive sampling and/or re-examination of existing data based on ongoing analysis and developing theory or concepts) was performed to saturate concepts of common experience (Charmaz, 2014; Schatzman, 1991).

After meeting inclusion criteria, women were invited to participate in an open-ended, semi-structured interview with one of the investigators to discuss experiences in pregnancy, birth, and postpartum. All interviews were conducted in a private room at the community-based organization from which participants were recruited. The lead author (White-identified nurse-midwife and researcher) and the second author (Black-identified student nurse-midwife) conducted audio-recorded interviews lasting 30–120 min. Investigators used prompts to elicit participant experiences, but the participants were free to direct the interview to topics that were important to them. Recordings were professionally transcribed verbatim for analysis.

We analyzed transcripts using dimensional analysis (Schatzman, 1991) in which codes or dimensions of experience were identified within data that help define the overall experience of interaction for the participants. Dimensional analysis uses a natural analytic approach, whereby investigators organize codes within a matrix of understanding that includes an overall perspective and related context, conditions, processes, and consequences (Kools et al., 1996; Schatzman, 1991). As multiple dimensions are identified during analysis, "auditions" are conducted to determine the most salient dimension, or perspective. The perspective is chosen based on the concepts with the most explanatory power within the observed interactions, in this case between patient and provider (Kools et al., 1996). Once a perspective is determined, other important dimensions are assessed for their fit within the four categories of context, conditions, process, and consequences of that perspective (Kools et al., 1996). We used situational mapping throughout analysis to highlight concepts (or situations) that influence

the relationships between dimensions, particularly issues of power and critical discourse (Clarke, 2003). Multiple perspectives may be identified in the course of dimensional analysis, with several salient dimensions representing distinctly different analyses reported upon separately. This study reports the perspective with the best fit as a theoretical framework to describe the experiences of women in their interactions with providers during pregnancy and birth.

Strategies for maintaining rigor and reflexivity throughout analysis included journaling, writing memos on individual interviews and dominant dimensions, triangulation of dominant themes, and frequent meetings with team members for analysis development (Charmaz, 2014). Salient dimensions were iteratively auditioned at different stages of analysis by two members of the research team, with theoretical sampling occurring to fill gaps in knowledge and to reach theoretical saturation.

Human subjects approval was obtained from the University of California, San Francisco's Human Research Protection Program. All participants gave informed consent and received a $50 gift card for their participation. Data were managed and analyzed in accordance with University privacy and security standards.

3. Results

Twenty-two self-identified women of color enrolled in the study and were interviewed (see Table 1). Of these participants, eight identified as African American or Black (non-Hispanic), four as Latina or Hispanic, one as Native American, three as Asian (two as Chinese and one as Thai), and six as multi-racial (two Black/Hispanic, one Black/Samoan, one Black/Filipino, one White/Hispanic, and one Native American/White). Participants' ages ranged from 23 to 39 (median 32). As a group, the participants had a total of 55 birth experiences, 57 children born, and 56 living children. Interviews occurred between six weeks and 11 months postpartum (median four months postpartum). Participants received care across multiple clinics and birthed in both public and private hospital settings throughout the San Francisco Bay area, representing diverse experiences in healthcare provider interactions.

3.1. Dominant perspective: power and privilege in patient-provider information exchange

Participants described wanting complete, truthful, and comprehensive information about their care and options available to them. Yet, they felt that the quality and amount of information received from providers was dependent on how providers saw them as individuals. Participants perceived that information was **packaged** in such a way as to allow or hinder their ability to make decisions around their own care in pregnancy and birth. Thus, information that providers shared could either empower or disempower women in their sense of autonomy and self-determination, which then influenced their ability to have control over their experience.

Factors influencing how information was provided included

Table 1
Participant demographic and other information (*N* = 22).

Participant feature	Statistics
Mean age in years (range)	32 (23–39)
Race/ethnicity (number of women)	
African American/Black	8
Asian	3
Hispanic/Latina	4
Native American	1
Multiple races/ethnicities	6
Average months since birth for interview (range)	4 (1.5–11)
Total births represented	55
Total preterm births represented	13

whether participants had an established relationship (or were able to build one) with their providers, and if they had visible or acknowledged sources of privilege (such as education) that deflected existing biases or stereotypes about her ability to make healthy decisions for herself and her baby. Further, contextual factors such as power, interpersonal racism and judgment, and structural factors in the health care system also influenced how providers chose to share information (see Fig. 1).

3.1.1. "Packaging" of information

Participants shared stories of when they felt good about their interactions with providers; others shared examples of when interactions were not as successful. Failures in information exchange usually centered upon lack of information, biased or incomplete information, and the perception of "packaging" of information to direct the interaction in ways perceived to benefit the provider. The term "packaging" was chosen by the investigators to describe the process by which participants perceived providers to be intentionally or inadvertently using information sharing as a mechanism for controlling interactions with and influencing decision-making of patients. Acts of withholding information, providing partial information, or providing misleading information were often perceived by participants to reflect the provider's assumptions around the patient's ability to make "good" decisions on their own behalf and therefore influenced patients' autonomy and self-determination. Women of color in this study understood when information was offered in a truthful, unbiased, and comprehensive way; they also detected and described being directed toward or removed from certain decisions through information "packaging" in their interactions.

Participants described impactful actions by providers that influenced their perception of trust in the information they received. One participant shared how important it was for providers to sit down and explain things clearly—

> "If you have a question they sit down with you like you sit down right now with me. They sit down. They explain you. They ask if you understand. So, you know? So, it's good. Yeah, it's good" (6).

Having information communicated in clear, complete, yet understandable language was meaningful for participants as they navigated uncertain and sometimes scary experiences in pregnancy and birth.

Participants wanted information about their care and an avenue for shared decision-making with their provider. Clear explanations of risks and benefits of various options for care were important for maintaining autonomy and self-determination for participants and their babies. One participant who experienced a preterm birth shared her desire to have her providers clearly describe all risks and provide all relevant information in order for her to make decisions around her care—

> "I would really have to have a doctor that was like, "Okay, look. I see that you had a baby premature. I see that—you know, really sit down and discuss what the risks are, have a plan of action for being high [risk] pregnancy. "These are what we're going to do. If we see, this, this, this, this is what we're going to do. If you see this, this, this, this is what's going to happen" (2).

Besides wanting complete and unbiased information around risks, this participant also describes a desire to feel fully informed of the processes she could expect, further building trust that her provider would be there and care for her fully in the context of being high-risk.

Lack of information exchange, or incomplete information, caused several participants to feel uncertain and confused, fearful, left out of decision making, and disrespected and violated, all leading to the feeling of not being valued or cared about. One participant shared her experience during a postpartum hemorrhage in which she received no information about what was happening to her and was treated as if she was not a person who was part of the situation and deserving of information—
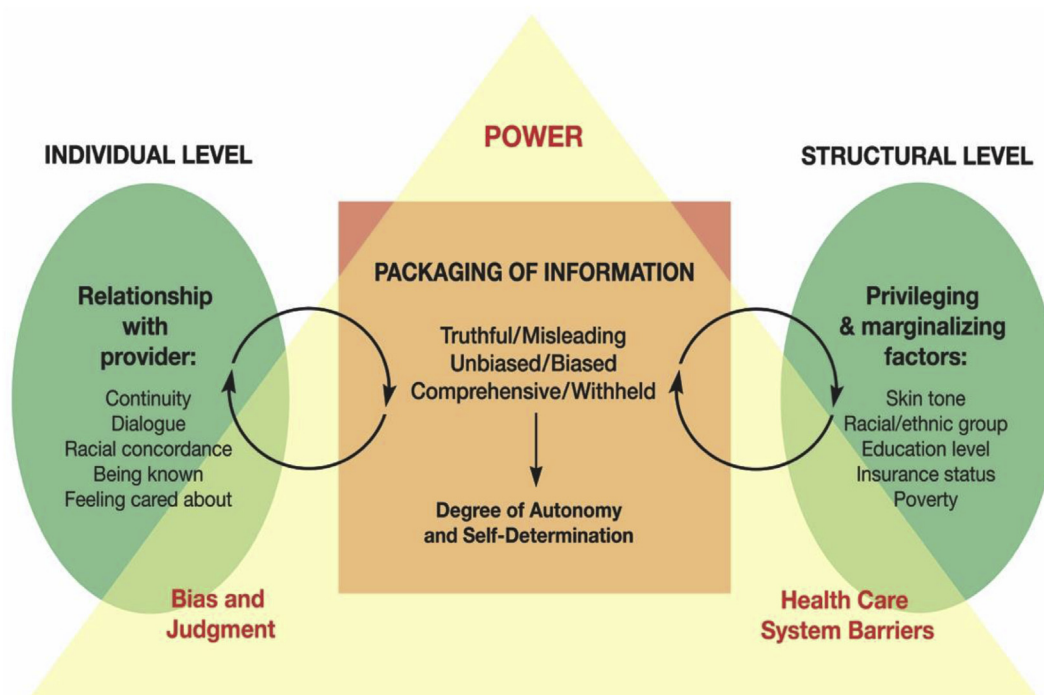
Fig. 1. Conceptual framework for information packaging.

"I don't know if it was like a—like a time-pressed issue or if it was like—I don't know what it was, but they—because no one explained anything. […] It was—it was scary because I didn't know what was happening, and, I mean, it was obvious that it was a serious issue because of, like, the look on everyone's face and, like, how—how no one was even talking to me. They were just talking to each other, and they were, like, you know, like I said, just reaching in me. And I'm like, okay, why is this happening? Like, can someone just tell me a little bit about what's going on, please. Yeah. A brief explanation would have been helpful at that time" (8).

The lack of information at the time of the intervention was perceived as a lack of respect for bodily autonomy, which put the participant in a position of not having the information or resources to actively be a part of her care, removing her power of self-determination.

Another participant shared her experience of being ignored when she wanted to know what happened during her traumatic birth experience. During an obstetric emergency in which her uterus ruptured during labor, she was rushed to a cesarean birth, and the baby was transferred to the neonatal intensive care unit at another hospital. She described pleading for information that was never disclosed—

"But nobody, not [the hospital], not [the second hospital], nobody told me anything about [what happened]. They never told me about it. All they told me was that the uterus erupted and there was complications. That's why I didn't understand … I was like, "What is that?" […] they still weren't telling me anything. They felt that—they said they wanted me to get better and they didn't want to cause more stress upon my recovery" (3).

Providers were in control of information that these women desired and deserved to know, yet it was not provided. Participants interpreted the lack of information exchange, whether intentional or unintentional, as a signal of not being cared about or valued as a person deserving of knowledge.

The use of information packaging to direct women towards provider recommendations was evident in words, such as "forced," "harassed," and "bullied," illustrating the effect that these conversations had on participants' perceptions of care and treatment.

"And so I met with one doctor, and she actually tried to forcing me to get all these tests that I wasn't into and that I—some of them I were and some of them I just wasn't into. […] "I'm like, okay, so why are you trying to force me to get—you're harassing me and bulling me to try to make me get that—these type of things that I don't want." (4).

Other times, participants shared experiences where providers criticized their ability and suitability to parent due to having questions and wanting more information—

"I told him that I wanted to do a little bit more research and that I wasn't going to get him vaccinated at that moment. And he was like, "Well, I thought that you cared about your children. But if that's not the case, then feel free to go." It was like, "Really?" That's not okay" (17).

Participants perceived these types of exchanges as disrespectful, coercive, and judgmental, and not taking the woman's perspective, experience, and right to autonomy into consideration.

3.2. Conditions that influenced the information exchange

Two important conditions influenced how participants perceived the information that they received from providers: Having an established relationship with their provider, and the visible or acknowledged sources of privilege and marginalization that participants brought with her into their interactions with providers.

3.2.1. Establishing relationships leads to better information exchange

One of the most important aspects of having or building relationships with providers was opportunity for ongoing conversation and knowledge exchange. Having consistent providers allowed for continued dialogue, removed the need to repeat information about a person's medical or social history, and reduced the risk of feeling judged. One participant shared—

"The service was cool. I saw the same doctors and nurses to where I

built the relationship with them all the way up until the day that I was scheduled to have the baby, which was good" (21).

Having an established relationship with a provider played a large role in participants feeling listened to, supported, and cared about in the context of their care. They wanted their provider to know their story and remember what was shared previously so as to not force them to recount their history over and over. Participants shared a loyalty to their providers in exchange for investing energy into building a relationship—

"But you try to be loyal to your provider because you think that they know your history" (2).

Being known and cared about by providers was key to establishing trusting relationships, which then allowed space for partnership in decision-making and positive information exchange.

Unfortunately, many participants experienced fragmented care through their pregnancy and birth. The lack of consistency served as a barrier for relationship building with providers, limiting trust and connection—

"… I never had like the same midwife. So, I didn't really get a chance to build a relationship too much with whoever was seeing me, because I was seeing so many different people. It was like, just another number, not very personalized I guess" (16).

Lack of continuity in providers contributed to a feeling of disconnect and fragmentation of care, which then put participants in the position of needing to continually advocate for what they needed, defend against bias and judgment, and provide information over and over again in order to get quality care.

Several participants brought up a desire to have providers of the same racial and ethnic background providing care. Racial congruence served as a catalyst for building trustful relationships between patient and provider, and further established connections and shared understanding.

"It makes a big difference when you have a doctor or a midwife that's the same race as you. It makes a huge difference" (24).

One participant shared her hierarchy of preference for providers of color—

"I prefer black above all. I always ask for specifically a black woman. But if that can't be found then the next thing is a woman of color. And if that can't be found then the next thing is a man of color, yeah (laughs)" (17).

She also shared why she felt strongly about having her care during pregnancy and birth be with providers of color—

"Like I just wanted my child to be born like around other black people. I didn't want them—because I was already going to be in a hospital. And it was already going to be a part of an institution. I just wanted there to be like community there. And so it was great to have [them] like a part of the process" (17).

Being supported by those who understand the struggles of being a person of color, are aware of and impacted by structural racism, and who are able to provide a sense of community in an otherwise sterile environment were all important to women of color in their desire for connection and relationship with their providers. This desired relationship in turn influenced the ability for there to be effective and compassionate information exchange and shared decision-making during care encounters.

The role of privilege in information exchange. Participants had varying degrees of either privileging or marginalizing factors within their lives and received different treatment by providers. Privilege in this context was defined as elements of status that enabled and increased social standing; marginalization was defined as those elements that decreased

social standing and ability to flourish (Hall and Carlson, 2016).

Participants with social privilege such as lighter skin or higher education perceived these factors to influence the quality of the care they received. One participant shared how she felt her light skin influenced providers' assumptions that she was White and therefore neither impoverished or in need of support services (i.e., food supplementation, financial support, discounted childcare) —

"It could be in a good way or a bad way, you know? Like either way I think—I've experienced a lot of times where I've been put, you know, kind of in this like privileged white girl category where it's like, "Oh, because you have white skin or maybe your kid is wearing some like [designer] onesie that like you must have money. And you must not need these services or whatever." You know? Like I feel like in good ways and bad ways. It could benefit me or it could not benefit me, but I do think that there are judgements and biases that have been put on me, yeah" (18).

For this participant, being misidentified as White and having money likely positively influenced the care she received, but also limited her receiving guidance about support services from her providers.

Education as a source of privilege was specifically highlighted by one participant as what influenced a change in care for her during pregnancy. For purposes of describing this dimension in depth, her story will be highlighted as an exemplar that represented a pervasive concept across the dataset but was not as clearly stated (or recognized) by other participants. Her story reflects a feeling of difference in care due to having a higher education degree, as well as her perceptions of how providers see her and others like her—

"But I think an interesting thing is, though, that I always received a different response once people realized that I went to UC Berkeley. Like somehow it comes up and then they treat me differently, which is really interesting because it feels unfair because what if I hadn't, you know?" (17).

For this participant, the change in provider behavior and treatment was obvious after they found out about her educational background, which seemed to lessen assumed stereotypes (i.e., 'crazy Black woman') that she perceived from them—

"Would I have been a different person, you know? Like what about people who haven't had any sort of college education? They deserve to be treated fairly, but I always noticed that it piques the interest of the health care professionals that I have some sort of education. They're like, "Oh, maybe she's not a crazy Black woman," or something, you know? […] it just makes me feel weird because, one, I feel like I'm accessing on like a certain type of privilege. And I feel like a part of me does it on purpose because I know that they're going to treat me better after I say that, which makes me feel a little bit bad because I am accessing privilege" (17).

The participant then shared her perspectives on why she feels providers treat people differently based on race and education—

"[Providers think Black women are] uneducated I think probably. Yeah, definitely. I think that once they figure out that I've had some education they're just more friendly, more—they see me more, you know? It's like I'm not just […] another random person to just push along, you know? I have something there that they feel is valuable enough for me to be especially respected I suppose as opposed to others, yeah" (17).

Her college education from a prestigious university created value which raised her status among providers and therefore improved her care. She also felt her educational status made providers more comfortable talking with her—

"Like, for example, they see me there with like multiple children and like I think they're more likely to go out of their way to do things for

me after they hear that, yeah. Or even just like being more friendly in conversation, being more like comfortable with me, talking more and not just talking about like medical stuff. Like talking about themselves. Like they seem more comfortable I think" (17).

She specifically called out how she feels providers likely judge and stereotype Black women and how being educated challenges those stereotypes—

"I don't know, but I think that potentially it's probably like they would consider me more tame in a lot of ways than their general understanding of like some stereotypes about Black women. Or maybe even that I may understand where they're coming from more because they have education. […] Maybe they feel like they don't have to talk down if they think that I can understand them I guess" (17).

Not only did her education modify the stereotypes that women experience daily, but it created a connection with her providers that allowed for relationship building, in turn leading to more individualized care.

3.2.2. Marginalization and its influence on information exchange

Explicitly calling out perceptions of marginalization was prevalent across many transcripts, often in the form of identifying bias and judgment from providers in the care participants received. Many participants noted differences in care due to racism, classism (poverty), education, and public insurance. One participant's summary of her perception of stereotypes highlights her feelings of marginalization—

"I think race and status. Her dad didn't go to the shorter appointments with me because they were like 15 minutes and he was coming from a different city. So, wouldn't that make sense to come—but he was at all the big, big appointments. So, I think not seeing—it felt more like stereotyping. You know, like another black female without a husband or someone. It just kind of made me feel that way, like I was just another number, just somebody you just kind of sent along" (2).

Another participant shared her experience with a provider bringing up abortion during her first visit with no hint of that being what she wanted and wondered if her status at the margins contributed to why her provider mentioned it—

"I remember when I got tested for the pregnancy and found out I was pregnant they mentioned I still had a few weeks left to get an abortion. And I was like, "Huh." And I couldn't figure out whether it was just because of—or if this is something they say to everyone, but it felt like they said it because of maybe the fact that I appeared single. I don't want to necessarily say for sure that it was because I was black, but maybe because I didn't have good health insurance. I was on government assistance. Too poor to have a kid, or whatever" (16).

Even in the absence of overt displays of bias from providers, participants often felt subject to stereotyping that perpetuated feelings of marginalization. The intersections of poverty and race were also noted in these exemplars describing judgment from providers.

3.3. Contextual factors influencing patient-provider interactions

Participant experiences around information exchange all occurred within the context of larger issues within society including provider bias and judgment, structural factors within the health care system, and power leveraged by providers.

3.3.1. Bias and judgment

Using a racial equity lens, we included the impact of bias and judgment within the dimension of information sharing as part of the

context in which these interactions occurred. Participants, particularly those with multiple marginalizing factors at play such as poverty, homelessness, or substance use, related that bias and judgment from providers influenced care that was given and how they experienced care. Most participants perceived their care as being of poorer quality than care that is provided to those with more privileged status—

"So, yeah, but the whole like racial profiling thing, like I just feel like I didn't get my needs met, you know, like oh, so I'm over here. Oh, like I just feel—didn't feel as important as the next person" (20).

Another participant shared noticing differential treatment due to her race—

"When we were in the appointments I would tell them about my concerns. And they were just like, oh, okay; yeah, yeah, yeah. And then sending me off because you want to hurry up and get through this appointment. But the people after me, you know, you're nice and sweet to them. I saw a difference in care" (2).

Regardless of intent, participants internalized their perceptions of poor care as a reflection of judgment against them by their providers, which therefore influenced the information exchange between patient and provider.

3.3.2. Health care system barriers

As part of how participants experienced their interactions with providers, there were structural components of the health care system that impacted participants' ability to access information and use information to make decisions about their care, such as access to insurance, difficulty in accessing services, fragmented care coordination, short visits, inconsistent providers, and lack of diversity and concordance in health care providers.

Many participants in our study described difficulties in accessing quality care, which therefore influenced how, when, and where they interacted with providers. Challenges in securing public insurance was a prominent theme. As a consequence of struggling to get access to insurance coverage, participants often opted to avoid care, partially due to fear of judgment and fear of being turned away. One participant shared her blunt observation of what it means to be poor and seek health care—

"If you're poor and you don't have no money, you ain't going to the hospital, for what; for them to kick you out?" (3).

Additionally, participants had to engage with fragmented service delivery that often required them to travel to different locations and providers in separate appointments. Considering that many of the participants in this study relied on public transportation and had other burdens of poverty (e.g., multiple jobs, little financial, emotional, and community support, need for ancillary services such as food stamps, WIC), fragmentation of care was a barrier to access.

Internal clinic structural issues such as long wait times followed by short appointments adversely affected participants' abilities to communicate effectively and feel heard and respected in their interactions with providers. Participants shared requests for some leniency in being late to appointments given how much they were juggling and how difficult it could be to get to appointments (e.g., due to transportation, childcare, location)—

"So, it's like, you know, you need to have some kind of consideration if I'm a little late, you know. I'm carrying a full load here and I need to have time. I might not be able to be there right on time" (1).

Participants also noted the irony in how clinics were unforgiving about patients being late, yet chronically ran behind schedule forcing them to wait for long periods of time.

"And you know what else they should do at these hospitals? If I'm five minutes late for my appointment they tell me, "Oh, you have to

reschedule." Or you have to pay a fee or something, but when I come on time I sit in the lobby for 45 minutes. What the hell? Like shouldn't you guys be rescheduling or paying me a fee, right (laughs)? Why do I have to wait and I'm on time, but if I'm late you can't see me? That's crazy." (9).

Seemingly minor factors such as making a patient wait for an appointment were shown to have a large impact on the trust and respect that these participants felt from their health care providers.

3.3.3. Power in context

As described by participants in this study, the "packaging" of information represented an assumption that the provider knows more about what is right for the patient than the patient herself. Examples of power were evident in their stories—

"So, why not communicate with me your concerns while you have me in the office instead of going behind my back and chattering all my mental—all my providers, the nurse, all of them, the social workers, all communicate with each other. They're a team. So, if one knows, they all know. So, if they would just tell me if I was a part of the team (laughs), which I'm not—they […] want to have this paternal relationship with me when they should be working with me, not thinking they're doing something in my best interest" (12).

The less regard a provider had for a patient ("difficult," "unpopular," "undesirable"), the more information packaging appeared to have occurred, and ultimately more power or control was exerted within the patient-provider relationship (Sinivaara et al., 2004).

4. Discussion

Women of color in this study described experiences that highlighted the influence of power and privilege in how information was packaged in provider-patient interactions. Information was often presented in such a way that decreased the women's abilities to be involved and actively participate in health care decisions. Factors such as level of privilege or marginalization and ability to build relationships with providers played a significant role in how information was provided. Lastly, contextual elements such as bias and judgment and system-level factors set the stage for these interactions to be interpreted by the women involved, in an often very negative light (see Fig. 1).

These findings are similar to what has previously been reported in the literature around experience of discriminatory care during pregnancy and childbirth for women of color (Cuevas et al., 2016; Harrison et al., 2017; Oparah et al., 2016; Salm Ward et al., 2013), how perceptions of discrimination affect patient-provider communication (Attanasio and Hardeman, 2019; Hall et al., 2015; Hausmann et al., 2011), and associations between racial discrimination and poor birth outcomes (Alhusen et al., 2016; Alio et al., 2010; Davis, 2019). The phenomenon of participants noting unequal interactions based on race and background has been seen in other contexts, such as with vaccination recommendations (Fenton et al., 2018). Participants in this study provided a lens on patients' understandings of how inherent biases and overt judgments influence the way providers provide care, share information, and treat their patients. Our study adds to the growing body of research documenting patients' desire for relationships with providers (Sword et al., 2012), and the disappointment, feelings of powerlessness, and frustration in the health care system when this desire is not met (Sheridan et al., 2015).

Participants shared perceptions of stereotyping by providers, such as the assumption that Black pregnant women are single, poor, and uneducated, which have been documented in other studies (Cuevas et al., 2016; Rosenthal and Lobel, 2016). The way stereotypes played out for these participants was similar to previous studies examining stereotypes in other health care contexts as well (Calabrese et al., 2014). Further, stereotypes that 'blame the mother' for her poor

outcomes reinforce a false assumption of personal responsibility rather than address systemic causes for health disparities (Scott et al., 2019). These stereotypes, viewed through an intersectional lens in which differing levels of oppression and discrimination impact participants across multiple layers of identity, reinforce the need for understanding structural influences in the patient-provider interaction, rather than focusing on perceived personal impacts (Rosenthal, 2016; Davis, 2019). The concept of stereotype threat, or women feeling a need to present themselves a certain way in order to avoid stereotypes, was also evident in this study and supported in the literature (Abdou and Fingerhut, 2014).

This study was conducted with low-income women of color representing intersecting marginalizing factors, but these experiences are not unique to those who are poor. The intersectional paradox demonstrates that high socioeconomic status does not mitigate risk for poor health outcomes among Black populations (Braveman et al., 2015; Bowleg, 2012; Davis, 2019; Jackson and Williams, 2006). While this study describes some changes in provider behavior and treatment of those with disclosed privilege (such as education), the fact that these women were initially treated poorly still stands. These results may, however, provide insight as to how provider interactions could play out for those with other intersecting marginalizing identities.

The idea of power influencing how providers interact with patients is an important concept to consider within this context. Medical paternalism relies on a belief that "the provider knows best" and is best suited to make health care decisions for their patients (Aggarwal et al., 2014; Tzeng et al., 2015). Through this power dynamic, women are not treated as equal partners in care but rather as persons assumed to be dependent on their provider to make decisions in their best interest. Providers acknowledge that this power differential exists and will persist as patients are seeking expertise and knowledge in order to receive care (Nimmon and Stenfors-Hayes, 2016). Also important in this conversation around power is the concept of "informed consent". Providing consent should be a way for women to be active participants in their care; yet, informed consent can be a poor representation of a patient's free will and often presents an illusion of autonomy rather than the real thing (Dixon-Woods et al., 2006). Given the context in which women, in particular, are asked to provide informed consent, the providers have power over how information is shared and in what situation women understand their options.

The concept of privilege influencing interactions with providers seems to be novel and not represented in the current literature. There are similar ideas to what this study highlights, particularly the concept of cultural health capital: "how broad social inequalities operate in patient-provider interactions and shape the content and tone of health care encounters" (Shim, 2010). Cultural health capital (CHC), as described by Shim (2010), includes the cultural and social skills and abilities that a person possesses that influence health care interactions, including language, non-verbal communication, dress, or style of interaction. While not discretely identifiable as education, race, and socioeconomic status, CHC encompasses various aspects of each privilege source and likely contributes to operationalization of privilege in the interactive setting of health care. As level of privilege within the information exchange in our study seemed to more fully focus on discrete aspects of privilege and marginalization based on race, education, and socioeconomic status, we maintain the current language around privilege but considered CHC as a potential additional concept in how these stories are understood (Shim, 2010).

When situating this study within the current literature around patient-provider interactions, the concept of information "packaging" by providers as influenced by level of relationship and acknowledged privilege and marginalization, is new and provides depth of understanding not described elsewhere. Putting the responsibility on providers to be aware of how they provide information within the patient-provider interaction, as well as understanding of positionality when working with patients who live and exist within marginalized

communities and structures, is a key finding that warrants further investigation and action.

4.1. Strengths and limitations

This study benefited from a wealth of data from a diverse sample, representing a large number of discrete pregnancy and birth experiences across many health care settings. Limitations to the current study include geographic restriction to one city and recruitment of participants from one community organization. As data were collected retrospectively, there is the potential for recall bias from the participants telling their stories, which may have heightened recall from the negative interactions as compared to positive ones. Lastly, while the research team's clinical expertise as health care providers (nurses and nurse-midwives) may have enriched the data and analysis, it also may have influenced findings through positionality as providers. Similarly, given the racial identities of the interviewers, racial concordance/discordance may have influenced the depth of experience shared by some participants. Investigators continually used reflection strategies such as memoing, journaling, and team discussions to interrogate positionality throughout the analysis process.

As with most qualitative research, these findings are not meant to be considered generalizable, but they are expected to be transferrable. The context in which these interactions occur (bias/judgment, health care structure issues, and power) are omnipresent throughout U.S. based health care and therefore predictably influence how providers interact with women of color in many locales and settings.

4.2. Implications

This study provides direct implications for care delivery improvement. Provider education around person-centered care, training around how to meet explicit needs for patients such as being heard and cared about, and implicit bias training are theoretically important to improve the care experience for people of color but have not been successful without structural commitment and demand for change (FitzGerald et al., 2019; Maina et al., 2018). Suggestions for change at the individual level should include provider- and staff-focused education and training around person-centered and respectful care and implicit bias. Change at the institutional level should include organizational commitment to upholding a respectful, supportive environment of care, creating flexible schedules for appointments, provision of peer advocates and doulas, and diversification of the provider workforce (Davis, 2019; Sheridan et al., 2015). Larger systemic actions should include institutional re-examination of the organization of care including insurance and support services, action to dismantle oppressive structures that enable structural racism and discrimination, and policy action to better support persons seeking reproductive care (Came and Griffith, 2018). Lastly, to achieve goals embedded in the reproductive justice and intersectionality frameworks, we recommend partnering with communities of color to build new equitable systems of care that address the needs of the community (Black Mamas Matter Alliance, 2018b; Oparah et al., 2016; Rosenthal, 2016).

5. Conclusions

Women of color's experiences in health care during pregnancy and birth are influenced not only by their own previous health care experiences and their lived experience but also by how they are treated by providers, particularly in how information is shared and withheld. When women receive information that is incomplete, biased, or misleading, it diminishes their ability to maintain autonomy and make health care decisions for themselves and their children. While consideration of health literacy and tailoring information for patients to make it understandable are important, there is a difference between providing information in understandable language and packaging

information based on biases and assumptions. When providers package information differentially for women based on racial or classist assumptions of knowledge, education, or ability, they are providing discriminatory care. Yet, women should not be put in the position to have to present themselves in a certain light in order to receive respectful care, nor should they have to circumnavigate incorrect or biased information—the responsibility should be on the provider to give complete, truthful, and unbiased information in order to give women of color the chance to make decisions on their own behalf, and ultimately provide equitable care.

Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.socscimed.2019.112491.

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