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Authors

McLemore, Monica R

Altman, Molly R

Cooper, Norlissa

et al.

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Health care experiences of pregnant, birthing and postnatal women of color at risk for preterm birth

Monica R. McLemore^{a,*}, Molly R. Altman^b, Norlissa Cooper^c, Shanell Williams^b, Larry Rand^d, Linda Franck^e

^a Family Health Care Nursing Department, University of California, 2 Koret Way, N431H, San Francisco, CA, 94143, United States

^b UCSF Preterm Birth Initiative, 3333 California Street, Suite 285, San Francisco, CA, 94118, United States

^c Department of Social and Behavioral Sciences, Health Policy, University of California, 3333 California Street, San Francisco, CA, 94118, United States

^d Marc and Lynne Benioff Endowed Chair in Maternal Fetal Medicine, Director of Perinatal Services, Fetal Treatment Center, University of California, Dept. of Ob/Gyn and Surgery, Divisions of Perinatology and Pediatric Surgery, 550 16th Street, Box #0132, San Francisco, CA, 94143-0132, United States

^e Department of Family Health Care Nursing, Jack and Elaine Koehn Endowed Chair in Pediatric Nursing, University of California, 2 Koret Way, N411F, Box 0606, San Francisco, CA, 94143, United States

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ABSTRACT

Background: Chronic stress is a known risk factor for preterm birth, yet little is known about how healthcare experiences add to or mitigate perceived stress. In this study, we described the pregnancy-related healthcare experiences of 54 women of color from Fresno, Oakland, and San Francisco, California, with social and/or medical risk factors for preterm birth.

Methods: This study was a secondary analysis of focus group data generated as part of a larger project focused on patient and community involvement in preterm birth research. English and Spanish speaking women, age 18 or greater with social and/or medical risk factors for preterm birth participated in two focus groups, six weeks apart. Data from the first focus groups are included in this analysis.

Results: Five themes emerged from thematic analysis of the transcripts. Participants described *disrespect* during healthcare encounters, including experiences of racism and discrimination; *stressful interactions* with all levels of staff; *unmet information needs*; and *inconsistent social support*. Despite these adverse experiences, women felt *confidence in parenting and newborn care*. Participant recommendations for healthcare systems improvement included: greater attention to birth plans, better communication among multiple healthcare providers, more careful listening to patients during clinical encounters, increased support for social programs such as California's Black Infant Health, and less reliance on past carceral history and/or child protective services involvement.

Discussion: The women in this study perceived their prenatal healthcare as a largely disrespectful and stressful experience. Our findings add to the growing literature that women of color experience discrimination, racism and disrespect in healthcare encounters and that they believe this affects their health and that of their infants.

1. Introduction

Preterm Birth (PTB) is defined as birth occurring prior to 37 weeks of gestation (Behrman and Butler, 2007). It is estimated that 1 in 9 infants in the US are born too early and these infants are at risk of mortality and neonatal morbidity, with the risk inversely related to gestational age (Manuck et al., 2016). The causes of PTB remain poorly understood (Behrman and Butler, 2007). Epidemiologic evidence suggests preventable socio-behavioral risk factors for PTB, including: substance use (i.e., alcohol, illegal drugs, tobacco) (Bryant et al., 2010), stress and pregnancy-related anxiety (Hogue and Bremner, 2005; Rich-

Edwards and Grizzard, 2005), poor nutrition (Hennessey et al., 2009), late entry to prenatal care (Bryant et al., 2010; Gennaro et al., 2008), and unintended pregnancy (Behrman and Butler, 2007). Non-Hispanic Black women in the US are 50% more likely to experience PTB than white women (Martin et al., 2014). Additionally, in 2014 the PTB rate for Black women was estimated to be 13.23% and 9.03% in Hispanic women (Martin et al., 2014). Despite attempts to elucidate the causes of this health-related disparity, PTB remains a complex medical-social condition where little progress has been made over recent decades to reduce rates or improve outcomes. Research that more fully engages the people most affected by PTB may lead to breakthroughs in addressing

* Corresponding author.

E-mail addresses: monica.mclemore@ucsf.edu (M.R. McLemore), molly.altman@ucsf.edu (M.R. Altman), norlissa.cooper@ucsf.edu (N. Cooper), shanell.williams@ucsf.edu (S. Williams), Larry.Rand@ucsf.edu (L. Rand), linda.franck@ucsf.edu (L. Franck).

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this stubborn epidemic, as has been demonstrated with other conditions such as HIV (Agency for Healthcare Research and Quality, 2016; Kogan et al., 1994).

2. Definitions

It is important to provide clarity in language when discussing PTB, given that the social determinants that contribute to PTB are described in different language than purely medical risk. For example, in this paper we use PTB to mean births that are not medically indicated (i.e., multiple gestation, cesarean section or induction of labor for maternal or fetal reasons) prior to 37 weeks gestation. Additionally, it is essential to define both medical and social risk for PTB. Social risk for PTB encompasses one or more of the social determinants described in the literature associated with the condition, such as unstable housing (Behrman and Butler, 2007), food insecurity (Hennessey et al., 2009), exposure to stress and/or stressors (Hogue and Bremner, 2005; Rich-Edwards and Grizzard, 2005; Gennaro et al., 2008). Whereas medical risk factors for PTB include infections during pregnancy (Behrman and Butler, 2007; Manuck et al., 2016), a prior history of PTB (Behrman and Butler, 2007), preterm labor (Behrman and Butler, 2007), and a history of previous poor birth outcomes (Behrman and Butler, 2007; Bryant et al., 2010).

When citing previously published literature, we are attentive to using the words the authors use to describe their sample. However, for the purposes of this paper, women of color specifically refer to self-identified Black, Hispanic, Latina, or mixed-race individuals with of the aforementioned categories being their self-identified primary racial identity.

3. Background and significance

Several studies have documented the healthcare-related disparities and poor birth outcomes for women of color (Bryant et al., 2010; Gennaro et al., 2008; Agency for Healthcare Research and Quality, 2016; Kogan et al., 1994; Smedley et al., 2002; Braveman et al., 2015; Giurgescu et al., 2011). However, few studies have addressed the factors that contribute to these disparities. It is hypothesized that women of color experience longer lifetime exposure to chronic stress, which may lead to fluctuations in allostatic load (wear and tear) and contribute to the higher risk of PTB for these women (Braveman et al., 2015; Giurgescu et al., 2011). Other investigators have suggested that women of color experience discrimination, racism and disrespect in healthcare encounters and that this affects the health of women and their infants (Rankin et al., 2011; Tucker Edmonds et al., 2015; Ertel et al., 2012; Pullen et al., 2014; Nuru-Jeter et al., 2009; Dominguez et al., 2008; Slaughter-Acey et al., 2016). A recent study (Slaughter-Acey et al., 2016) found significant associations between racial microaggressions and PTB in women who had mild to moderate, but not severe, depressive symptoms, but did not find a significant association between PTB and overall perceived stress. These findings suggest that racial microaggressions could be an independent as well as potentiating risk factor for PTB in women of color.

Interpersonal care, such as communication between physicians and patients and social concordance has been shown to be a significant aspect of quality care (Smedley et al., 2002; Dehlendorf et al., 2016; Thornton et al., 2011). Although suggestive, the existing limited literature is insufficient to characterize how prenatal care is often experienced by women of color and to fully understand if and how such encounters add to or mitigate perceived stress and affect risk for PTB. Few studies have been conducted to understand the experience of healthcare encounters for people of color as distinct from their health seeking behaviors, in the context of experiencing racism and discrimination (Braveman et al., 2015; Giurgescu et al., 2011; Rankin et al., 2011; Tucker Edmonds et al., 2015; Ertel et al., 2012; Pullen et al., 2014; Nuru-Jeter et al., 2009; Dominguez et al., 2008; Slaughter-

Acey et al., 2016). It has been shown that Black women are less likely to get clinical advice and support to decrease smoking and alcohol use during pregnancy (Kogan et al., 1994). Additionally, Black women are less likely to receive antenatal steroids, tocolytic medications, and are more likely to have a birth by cesarean section (Paul et al., 2006). More specifically, whether or not women of color seek care and what factors impact those decisions are distinct from understanding their experiences of their healthcare encounters, which has been shown to impact patients' perceptions of the quality of the care they receive (Dehlendorf et al., 2016; Thornton et al., 2011).

Another important dimension of the healthcare encounter, as Shim and colleagues (2010, 2013 and 2016) have shown, is cultural health capital – defined as the cultural skills, attitudes, behaviors and interactional styles that are exchanged, leveraged and valued during clinical interactions. Cultural capital of the provider and the patient impact the perceptions of quality care and, more importantly, can facilitate or impede authentic engagement between patients and their healthcare providers (Chang et al., 2016; Dubbin et al., 2013; Shim, 2010). Lastly, our recent work (Dubbin et al., 2017) has shown that African-Americans perceive categories of illness, such as coronary heart disease and diabetes, as products of ongoing racial and socio-structural dynamics that create and maintain health burdens, as opposed to lifestyle diseases where the ultimate culprits are their personal health behaviors and lack of healthy choices. A tension between the effectiveness of personal health behaviors and living with illness was described by African-Americans when communicating with their healthcare providers about their care.

Given these complex factors and their potential profound impact on healthcare and outcomes, a greater understanding is needed of healthcare experiences of women of color who are at medical and/or social risk for PTB to guide the development of interventions to improve this crucial aspect of healthcare delivery. Therefore, the aim of this analysis was to describe the pregnancy-related (e.g., prenatal, birth, and postpartum) healthcare experiences of women of color at medical and/or social risk for PTB.

4. Methods

4.1. Setting and sample

This study was a secondary analysis of focus group data generated as part of a larger project focused on patient and community involvement in PTB research. In the parent study, women at medical and/or social risk for PTB were invited to identify and prioritize research questions that were important to them for the purpose of influencing local and national research funding agendas (Franck et al., 2017a). Women from Fresno, Oakland, and San Francisco who were age 18 or greater, English speaking, English and/or Spanish Speaking in Fresno, with medical and/or social risk factors for PTB from community-based programs in each of the cities were invited to participate. These geographies were chosen because of the high PTB rates for women of color. In Fresno, the overall PTB rate for all races/ethnicities in 2012 was 11.7%, in Oakland, 9.6% and 9.0 in San Francisco. However, in Fresno the rate for Black women is 17.6% and 11.8% for Hispanic women; in Oakland the rate for Black women is 12.7% and 9.8% for Hispanic women; and in San Francisco the rate for Black women is 14.8% and 10.1% for Hispanic women.

In order to meet eligibility these agencies needed to serve pregnant self-identified Black and/or Hispanic women, or any pregnant woman seeking social services, and provide some programming such as prenatal, childbirth preparation, post-partum or parenting classes. Additionally, the agencies needed to have capacity for childcare and transportation support for participants, and willingness to host both focus group sessions. In total, seven focus groups were conducted, two each in Oakland and San Francisco, and three in Fresno with a total of 54 participants. One group of Spanish-speaking women was conducted

in Fresno given their proportions ($n = 60\%$) in the population of pregnant people in the city. Spanish speaking focus groups were not conducted in Oakland or San Francisco because they represent a significantly smaller proportion of pregnant people and those at medical and/or social risk for PTB in those geographies.

Women participated in two audio-recorded, 2-h, focus groups, six-weeks apart, facilitated by the first and last authors. In the first session, women discussed their healthcare experiences and generated a list of uncertainties about health and/or healthcare specific to their current or recent pregnancy that, through group work, they reframed as researchable questions. In the second session, women reviewed the question list and prioritized those questions and broad topic areas of most importance, reflecting on the impact that having answers to such questions might have had on their own prenatal healthcare experiences (Franck et al., 2017a). Both of the Spanish speaking focus groups were conducted in Spanish using three native Spanish speakers who served as facilitators. Additionally, all materials including the transcript were translated and reviewed by the team who conducted the focus groups, translated into English and reviewed by a fourth Spanish speaking medical interpreter.

Given the similarities in demographics, questions generated, and healthcare seeking experiences of the women served in all geographies, the data from all sites were pooled. Participants were provided gift cards as remuneration for their time. Food and on-site childcare were provided by partner agencies where the focus groups occurred.

4.2. Ethical considerations

This study was reviewed and deemed exempt from human subjects protection procedures by the University of California, San Francisco Committee on Human Research # 15–15698. This exemption is important because the community partners maintained all contact with participants including demographic and detailed case management information. This intentional distinction between the service agency who held all identifying information and personal demographics and the research team who did not collect any of this information in writing, provided participants the opportunity to openly discuss their providers, hospitals, and health service agencies without fear of retaliation. This also allowed community partners to maintain their relationships and connections with participants in the study and to assist the study team in tailoring the interview guide and focus group questions to be familiar participants as they were aligned with the institutions' practices.

4.3. Data collection

Focus group interview guides were developed in partnership with community partner staff. An iterative process was used to develop the guide, in accordance with the main principles and methodology for patient and public engagement produced by the UK James Lind Alliance (James Lind Alliance Guidebook, 2004) and with specific reference to the methodology for research prioritization for PTB (Duley et al., 2015). The same interview guide was used at all sites and included brief introductions of all participants after a grounding exercise specific to each site. Next, participants described their healthcare seeking experiences during pregnancy. The rest of the interview guide focused on the generation and identification of research questions that women had specific to their pregnancy care. Data for this analysis were generated in the first focus group from responses to the questions that asked participants to introduce themselves and describe their general healthcare experiences and then their pregnancy, birth, and postpartum experiences. Field notes were taken at each group by a member of the research team. Given the exemption from human subjects protections, these notes provided the research team with important demographic information to describe the research participants. The notes also provided context for the general flow of the focus group and any significant events that occurred during the focus group. For example, newborns,

infants, and children were present at all focus groups however, some had as few as two children, others as many as nine.

Next, probing questions were used to encourage participants to elaborate on their reflections about their experiences, such as: what, if anything, they would change about those experiences, what care they did not receive but wish they had or wanted more of, or what they liked best. Additional insights regarding the themes were derived from discussion throughout the first focus group sessions. The second transcripts were not included in this analysis since the focus was specific to the ranking and prioritization of the research questions generated by the groups.

4.4. Analysis

Focus groups were audio recorded and transcribed verbatim. All authors have training in qualitative data analyses and participated in the thematic analysis (Braun and Clarke, 2006) to code the transcripts and develop themes related to healthcare as experienced by the women during prenatal care. Briefly, thematic analysis includes several phases: Familiarize yourself with your data (first and second author), generate initial codes (first and second author), search for themes (team), review themes (team), define and name themes (team); and produce the report (team; 31). The first and second authors listened to the recordings and reviewed the transcripts for accuracy. Next, the first and second authors independently conducted line-by-line coding on all of the first focus group transcripts, which contained sharing of personal experiences, from all of the groups.

After initial codes were developed, they were discussed and then section-by-section coding was completed by two of the authors. An iterative process was used to determine the salient quotes from the data. Disagreements between reviewers were resolved by discussion amongst the whole research team. Finally, a second iterative process was used within the team to refine the themes and choose the quotes that could be included as exemplars. Once the exemplars were identified, several members of the team drafted the first manuscript and a final iterative process was initiated to complete the report.

5. Results

Demographic characteristics extracted from the field notes and transcripts of the participants by site are shown in Table 1. The 54 participants ranged in age from 20 to 44 and among them had 122 children, of whom 111 were living and 45 were born preterm; of those, only 41 were still alive at the time of the focus groups. Within this sample of women at medical and/or social risk for PTB, this corresponds to a 37% PTB rate (41 babies born preterm/111 living children) which is significantly higher than the rates for all ethnicities in the three geographies.

Five themes emerged from participants' descriptions of their prenatal and perinatal healthcare experiences: disrespect, stressful interactions, inconsistent social support, unmet information needs, and confidence in parenting and newborn care. Each theme is described below with exemplar quotes that illustrate the essence of each theme.

5.1. Disrespect

Focus group participants described *disrespect* during their encounters with healthcare institutions and providers. Disrespect was described as feeling dismissed and treated rudely because of their race, marital status, knowledge, education, being low-income, or having public insurance. Nearly all of the participants described disrespect in their narratives and several gave detailed descriptions. One participant said:

But I have a bone to pick with them. I had decided at eight months to be clean and sober; my son, like I said, he was a natural baby. I

Table 1
Demographics of focus group participants.

Number of Participants By Geography					
	Number of Participants in Focus Group 1	Self-identified Race/Ethnicity	Number of Reported Pregnancies	Number of Reported Living Children	Number of Reported Preterm Births
Fresno					
Black Infant Health	8	Black	17	16	4
Every Neighborhood Partnership	7	Hispanic/Latina	16	12	7
Holistic Cultural and Wellness	11	Hispanic/Latina	27	21	14
Oakland					
Best Babies Zone	7	Black – 3 Hispanic/Latina – 3	12	12	4
Black Wellness Council	7	Mixed – 1 Black – 6 Mixed – 1	9	9	4
San Francisco					
Black Infant Health	8	Black	26	26	7
Homeless Prenatal Program	6	Black – 5 Mixed – 1	15	15	5
TOTAL	54	Black – 22 Hispanic/Latina – 21 Mixed – 3	122	111	45

didn't want any medicine. The nurse was very disrespectful. She kept asking me did I want fentanyl and did I want morphine? When I came up there, I was up there with a lady who was in a recovery program with me. And she didn't really know what to do. So, my nurse kept coming in – in the process of her pushing these drugs on me. And she kind of snapped off on her and told her like, “Stop offering her that.”

Specific to race, almost all participants attributed disrespectful language and conversations with staff as a common experience they have throughout their day to day lives, and were not surprised that healthcare teams and systems perpetuated those experiences, one participant said:

“And I also wonder how much of the advice or – yeah, advice they give you is based on our race because I was Hispanic and I was a teenager and I got pregnant, the nurse assumed I was going to be pregnant a whole lot of times and she suggested right away I should get rid of my child without asking me if I wanted to or not. So, is it based on my race? Is it based because I'm already high-risk of dropping out of high school because all that was told to me? So, they were already determining what I was going to do with and setting limits on me just because of my race. How much of that is influenced on my race? I think all of it.”

Most of the women described situations where they did not believe their wishes were respected. In addition, many described feeling ignored or that they were receiving care that was different and of a lower caliber than women of other races/ethnicity or with private insurance. A participant described a situation where she watched another woman in the emergency department receive different treatment:

I also think like if you're on Medi-Cal or you're a certain race versus private insurance it makes a difference because I've watched the same doctor. He was nice to this little white couple, but a single black woman coming in, even though the father came with me, it was like I did feel like the treatment was different. And it's like I do feel like if we don't have private insurance they do treat us differently. They cut costs, cut edges, or don't tell us everything at some of these hospitals.

Other participants cited their race, ethnicity or language spoken as the cause of the disrespectful treatment. One participant who identified as Hispanic and an immigrant said:

She [NICU nurse] was super, super rude at that time. I understand that they are tired, super busy and whatever. But I felt super sad at that time because it was super stressful, confused. Everything was shocking for me because I didn't expect that situation at that time. And actually I was very obedient, was opposite of you because it wasn't a new system for me. I was a foreigner at that time. And they told me, “Go home.” And I went home. And that time when my daughter passed away I felt super, super guilty and bad with myself because I didn't stay longer with her [participant's daughter].

5.2. Stressful interactions

Participants described *stressful interactions* with all levels of staff throughout their prenatal care and birth experiences. Participants described stressful interactions such as: healthcare encounters regarding medical co-morbidities requiring treatment during pregnancy, lack of staff empathy with the difficulties associated with multiple and frequent appointments, lab testing, and unsatisfactory encounters with trainees. Others discussed being singled out or “red flagged” due to past involvement with the criminal justice system or proximity to partners who had committed crimes. One participant summed it up this way:

They had me going to everything, but there was this disconnect. I was going to the hospital every other day. I was going to the emergency room. I had spotting. I would tell the resident. I would call in and tell them my blood pressure is through the roof. They would send me to emergency. Emergency would send me home. It was stressful. I think the fact that they kept running me around made it more stressful. In the end the medicine wasn't working...And I'm off work now. And now they don't want to send me back to psychology, but I didn't feel supported. I was going through depression—everything. It was just I didn't feel like I was being heard at all.

Another participant shared this experience:

Then from [hospital 1] I didn't get any service all night and then they were really like treating me so bad that I left there in a cab and went to [hospital 2]. And the whole time nobody is telling me why I'm bleeding, what's going on. I'm a bleeding mother and they're like just—they're not educating me about the stress. I believe it was stress that was causing me to bleed. And then I had a really bad day. I had two shots of vodka and some beer and a cigarette, which is better

than jumping off a bridge or—so, I was like just trying to do my best because when you get bad days you just cope the best way you can.

A third participant shared the stress of uncoordinated services, stressful interactions with healthcare providers, staff and social services agencies as a public insurance healthcare recipient after a lifetime with private healthcare insurance:

Yeah, just – I'm more of a natural, like I gave birth natural. I didn't have any medicine or anything, so the different ways in which I could decrease the stress in my life and that was very stressful. I had no job. I had to go to court and do all kinds of stuff. I didn't get my unemployment. I had to go on welfare. I had no experience with that. That was stressful having to go down to the county and dealing with all this kind of stuff. It was like a culture shock. It was just weird. I don't know. It was very disturbing to me and my family ostracized me too because I'm the only unwed person in the family, so my brother's not speaking to me. It was just—stress.

Another participant followed up on this point and told a long story about the bleeding symptoms she experienced and the impact it had on her ability to work during pregnancy:

It was really unbelievable because I think I had high risk all the way through, but just being at work and—I would be at work and I would be spotting or I would go to the bathroom and I'd be like...Every thought was like, "Okay, this next time I go to the bathroom it's going to be either freaking miscarriage or it's over, right?" And then when I would take a couple of days off or go home and just lay there with my feet up, no spotting, no bleeding. I show up for work and it's in my head like, "Am I going to have to leave or are they going to say this today?" And I'd go to the bathroom, bleeding. And then so it finally got to the point where I was almost asking like, "Okay, just give me my cheque. Let me go ahead because I just want to go home and have my baby because being here, ya'll are stressing me out and I'm going to have a miscarriage or something." And I noticed it, like the back and forth just in your head thing about possibly having to leave early today or if I go to the bathroom and feel sick in five minutes think I'm going to leave and you're going to lose your job, you know? It was super stressful.

5.3. Inconsistent social support

Some participants described their experiences of being single or *without consistent social support* and described the negative impact that this had on their pregnancy-related care. As also illustrated in the quote above, participants reported that the lack of social support caused them to feel stigmatized, and increased their stress. Sometimes, this led them to ignore physical signs of distress including preterm labor because they had no one else to help them provide for their families. Engagement (or lack thereof) of the father of the baby was one of the most frequently discussed situations where the participants felt a lack of social support that negatively affected their pregnancy. One participant said:

And so I spoke with a social worker while I was pregnant. I'm a single mother and I was really stressed out. Me and the father were not getting along and there was this period of time during my pregnancy where I had no idea where he was, if he was safe, if he was okay. And so it was also from violence and so much going on in my neighborhood. And so I went to the social worker just to talk about being stressed out, about having to work and only have my income and not really knowing if the other parent would help. My daughter's father is not helping right now. And so I was just very stressed out, you know? How am I going to pay bills? How am I going to save? How am I going to be able to do all these things by myself?

Another participant described the positive impact that peer support

groups played in her life.

I was going to say, programs like Black Infant Health that was my saving grace because it was like if I wasn't among those women to sit down and just have that because I was going to the groups at [hospital 2]. It's like a bunch of, you know, white women or whatever and they had their husband. I was fortunate I had the dad, but still it was like to be around sisters, you know, to have that. And it felt like they talked to me about things that had to do with my body, the ethnicity issues, whatever it was, they connected to me as a black woman and understanding that sometimes my needs are different from somebody else's.

When discussing social support, many participants correctly identified policies and procedures that limited or did not allow for family members to support the birthing person. An example of this was relayed by this participant:

There's not too much we can do to stop it [labor]" But they tried to put me like in an area where it was like completely sterile, completely clean because they wanted to be sure that she was ready to come. And then I think I was maybe two days away from being 30 weeks. They were like, "If we can get you to 30 weeks, we'll be happy." And I'm like, "Oh, okay." So, I just sat there in this clean room which nobody could come visit me except for the doctors, not my children at home, not my support. I could only pick up the phone and talk to people. And then once the labor actually started it was like, "Well, there's going to be a bunch of people in the room [clinical staff], so you can only have three people in the room. And that's too many." And I was like, "Okay." So, it was my mom, my cousin, and my daughter's father.

5.4. Unmet information needs

All of the women who participated in each city described unmet information needs, particularly related to procedures, clinical tests, and rationale of activities from the clinical staff. A particularly poignant example of this was told by one participant:

When I was 5 months pregnant, about 20 weeks, my entire body got itchy. I used to scratch so much I'd pull up pieces of skin and flesh and everything. And the doctor would change the medication. He'd give me one and it wouldn't go away, so the next week he'd give me another one, and the next he'd give me another. Until I couldn't take it anymore—I lasted like 2 months like that and he never sent me to get any tests done to find the reason for the itchiness—so I came over here to the hospital on my own and the doctor told me that I had an infection that only one in 10,000 women got, that it was an infection in my liver. They'd damaged my liver they told me.

Another participant who had already had a premature baby said this:

Questions, yes. My situation wasn't like the other women who have shared, but my babies came at eight months and I'm not sure why. They didn't tell me why, but I was always left with the question that if I were to want more babies, would they all be preterm? Because the ones I had were back-to-back, they're 10 months apart, and I want two more children. But I ask myself, will the other two also be preterm? How can I know?

Another participant who wanted to attempt a vaginal birth after cesarean made this comment:

Is it normal – okay, with my first child, I had her at 19 and they told me that when I had my first C-section, I didn't dilate. Then all of a sudden, it went from I couldn't have her (my second child) by vaginal, so they told me that I had to have a C-section. So, then when I got pregnant with my second child, they told me that I couldn't have

her vaginal either. And I'm like how did you just tell me? Did you check to see if I can – so is it normal that the doctors just automatically tell you that you can't have your baby vaginally after a first C-section?

5.5. Perceived competence and confidence in parenting and newborn care

Participants perceived *competence and confidence* in their ability to provide care to their newborn baby across a wide range of parenting skills, including nutrition, emergency responses, and balancing other daily obligations. Participants specifically discussed the unique experiences of parenting a premature baby with confidence, but without competence. One participant discussed her ability to care for her baby who was born at 6 ½ months and weighed 14 ounces:

He just—sometimes he Bradys [becomes Bradycardic], but I know what to do when that happens and Bradys is when he stops breathing. I sleep with him right with me. You know he has a bassinets and a crib and he doesn't sleep in any of that because I want to make sure my son is okay, so he sleeps right with me and if he stops breathing I know exactly what to do to—

Unfortunately, this parent was not fully informed about the hazard of co-sleeping and did not have information about safe sleeping. She continued to discuss her gaps in knowledge and confusion about from whom she was supposed to receive that information.

Another participant who was a mother of premature twins was confident enough in her skills that she was able to identify and seek out other parents with babies in the neonatal intensive care unit and share her experience:

I think a good place [for support] would be like in the nursery like because there's so many parents in there that are going through stuff. And nine times out of ten nobody talks to them. It's like I see another lady with twins and her twins and I'm like, “Oh, don't worry. Everything is going to be okay. Like my daughter was on this machine. My daughter was on that machine. My daughters were in the same position that your babies were in. It's going to be okay. Try not to stress so much. Maybe you should take time to go home.”

Another participant who had a premature baby shared this story about the need to support their children, but not “baby” them:

And you could also ask maybe the question why do some parents baby their preemie? They shouldn't have to baby them because then it's teaching them that they have to be babied versus finding those strong whatever thing that they need to thrive on. They're like, oh, I can do it for myself type thing because I think that's what helps my daughter. She would fall because she would see her sisters running and she would want to run. And when she got an Achilles tendon transfer on both her legs done, now she's able to run and try to skip. She hasn't started like jumping, like jump rope or nothing, but she is jumping and other things that she couldn't do before

5.6. Women's recommendations for systems improvements

Participants offered specific recommendations about how healthcare systems can be improved to provide more respectful care, which included: greater attention to birth plans, listening to patients during clinical encounters.

Participants saw birth plans as a way to use their voice during their birthing experiences particularly when they perceived that the staff would control when and how their social support could be present during birth. Half of the participants felt that the birth plan would protect them from stressful interactions with staff, however, when describing birth plans, one participant said:

“I thought that should be just a part of the questioning when you

come in. Like that should be something that they ask as you're being admitted; do you have a birth plan? What is your plan for just the labor in general? [Not having drugs] That was like number one on my birth plan, which told me you didn't read that. And I kept asking them. And especially like if you're not able to advocate for yourself or your other people in the room are not— if you don't have an advocate, because labor is a lot of work, and you may be tired. You may fall asleep. Something may happen, and so that piece of paper is supposed to serve as your voice along with the rest of your people. But it's like I took the time to make this birth plan. We printed it out for you. We brought copies. We didn't ask you to do anything with it but read it. And they did not or they said, “Oh, well. You know? Yeah, that was a nice idea.” There were a couple of people – no, I'm thinking maybe one person looked over it.”

Another participant discussed the intersection of poverty, debt, inability to seek timely care, and medical risk and the difficulties of entering prenatal care:

“I mean, I was at high-risk. My size apparently had a lot to do with it. With the twins, I gained 50 pounds. I did not know I was pregnant and when I started getting medical help, I was put down to the lowest because I came in at 18 weeks and they were trying to figure out what was wrong with me. I'm explaining to them I had trouble at the other clinic because my primary health clinic did not want to see me because I had a debt with them. So, for me, it was hard to find a place where I can go and find medical help because of various situations that are not just there. I did not have insurance. I did not qualify for MediCal. So, that leaves me nowhere. So, I was referred by the Emergency Department to Clinic A. When they did finally take me, because they realized I was – through my calculations, I was at 18 weeks, I come in and they're trying to figure out what's wrong with you? Dietician had me in tears because I was 12 pounds overweight and I was – so, here I am, trying to be happy because I'm pregnant again, right?”

5.7. Recommendations for how providers can be better in the clinical encounter

All of the participants discussed strategies to improve the communication by healthcare providers. Specifically, participants charged health and social services agencies to develop better communication among and between multiple caregivers when women are classified as high medical and/or social risk, put less reliance on previous case files and child protective services (CPS) involvement, and allow more people “who look like them” to work in healthcare. Participants provided several examples of feeling disconnected from their clinical team, specifically their nurses and physicians:

“I know for me, the whole labor process was very impersonal. I just felt like the nurses were just there to protect the hospital and watch monitors. So, that was kind of off. I didn't know who was going to be delivering the baby. So, I didn't have a set doctor. I had MediCal, so I just was seeing a different physician, like I didn't have a set one. So, that was a little not comforting because you didn't know who was going to be there, but I would just say mostly it was the whole labor process just not really feeling connected with the staff.”

Another participant said:

Well, for one, I just feel like – I don't know. I know everyone's not like that, but when you have MediCal and come into the doctor's office or if they're seeing primarily MediCal, they just already have this stereotype already on you and I just got – a lot of times I felt like the doctors kind of talk down to me as if I didn't have a clue as to what was going on.

Building on that comment, another participant added:

Some people think that you don't understand things. We are intelligent people and you feel like somebody doesn't understand it, well maybe can you put it in different words? If you think I don't understand this model, can you find another way to present it? Or before you think I don't understand it, let me be able to analyze it and ask you questions. Or give it to me and let me tell you about it.

Another participant said “Trust us, especially recognize we're the experts in our own bodies. I ask her, “Have you ever been pregnant?” “No, but I've been a doctor for two years.” I said, “Uh-huh...thank you.” No, I'm not a doctor but I have a body and I've done this before.”

Many of the participants in this study had some type of carceral involvement – either their own incarceration, with children in custody of CPS and/or men involved in the pregnancy who were or had been incarcerated. Additionally, some participants had experiences with substance use treatment. Given this reality, many participants spoke about being afraid of being reported by their healthcare team – particularly if they were already carceral involved. One marginally housed/homeless participant summed up these intersections:

“So, we'd always go and stay across the street right there by Western Union, right behind where the farmers market is across the street, right across the street. That's where we slept. And then the clinic was really nice and it got to a point where we were just like we're so hungry or whatever. They let us stay at the waiting room. They would bring us some food or whatever. We'd try to hide underneath the chair, but I mean they all knew, but they just felt bad. I mean I wish—but I mean my whole thing was I have three CPS cases with them over there and I thought that going there again I'm going to definitely for sure be red flagged, but –I think healthcare provider is real important to somebody who wants to have their baby. Do you know what I'm saying? I'm not saying I'm a bad mom or whatever. I'm just saying that where my life was and my realization of what life is going to be about or how life is, it could have gone either way. But to me, I was thinking more like, well, let me just try to stay alive for the next day versus there is no future –I'm barely making it to the next day.

6. Discussion

This analysis is the first to our knowledge to describe the birth, prenatal, and postpartum healthcare experiences of women of color at medical and/or social risk for PTB. The themes of disrespect, stressful interactions, inconsistent social support, and confidence and competence in newborn care as well as the specific recommendations for improving relations between prenatal providers and patients suggested by the study participants provide direction for further research and quality of care improvement initiatives.

The women in this study perceived their prenatal healthcare as a largely disrespectful and stressful experience. Our findings add to the growing literature that women of color experience discrimination, racism and disrespect in healthcare encounters and that they believe this affects their health and that of their infants (Rankin et al., 2011; Ertel et al., 2012; Pullen et al., 2014; Nuru-Jeter et al., 2009; Dominguez et al., 2008). The specific examples of how structural factors such as history of carceral involvement, unstable housing, and poverty, that intersect with the themes of inconsistent social support, single marital status and the use of public insurance contribute to women of color's perceptions of disrespectful healthcare seeking experiences during across pregnancy are discussed. These complex findings suggest that future research and intervention should focus on listening to pregnant people rather than solely on the interpersonal interactions between patients and providers (Dehlendorf et al., 2016; Thornton et al., 2011). Participants stated they would participate in additional focus groups and suggested that new research methods were necessary that include the voices of pregnant people. Additionally, the women in this study

suggested that healthcare service providers needed different ways to capture a pregnant person's experiences seeking care to understand how “complex” it is to be poor, a person of color, a parent, and other identities held by the participants. Similarly, the participants discussed the need for providers who “look like them” and understand the cultural exchanges that occur during their healthcare seeking experiences.

There is theoretical discourse, but limited direct evidence, linking the pathways and mechanisms for stress related to discrimination, racism or disrespect in healthcare to negative health outcomes such as PTB (Slaughter-Acey et al., 2016; Congdon et al., 2016; Geronimus et al., 2015). Given the consistency of the limited reports of its pervasiveness and profound potential impact, further research is urgently needed that incorporates the perspectives of women of color to address disrespect in health service delivery and reduce the perceived stress associated with pregnancy related care for all women. Additionally, an intersectional lens could be helpful in discerning how to understand the relationship of marital status, income status, levels of education that potentially contribute to feeling disrespected.

An additional consideration is that our participants were drawn from community-based organizations whose missions are to provide social support and other social resources to childbearing families. Even with these supports, participants described experiences of stress, disrespect and inconsistent social support. Previous research has shown structural factors such as social support during the prenatal and postpartum periods (Rosenthal et al., 2015), group prenatal care (Ickovics et al., 2011), familism (Campos et al., 2014), and religious and/or spiritual connection (Cheadle et al., 2015) have a significant impact on maternal stress and mediate the stress experienced by women of color when seeking pregnancy-related care. Our findings expand this work by providing data from women seeking social support services that more or different structural solutions are warranted to improve healthcare experiences, particularly the stress of multiple appointments, increased monitoring and care for other children when women are categorized as high risk during pregnancy.

A positive and surprising finding of our analysis is that many of the women felt competent and confident to care for their babies. Studies of parental experiences of caring for babies at home, particularly after NICU discharge highlight parental feelings of lack of confidence and competence in caring for preterm infants (Franck et al., 2017b; Holditch-Davis et al., 2009; Kurth et al., 2016; Murdoch and Franck, 2012; Leahy-Warren et al., 2012). Moreover, stress, poor social support or poor provider support are associated with parental feelings of inadequacy in child caregiving (Holditch-Davis et al., 2009; Kurth et al., 2016; Murdoch and Franck, 2012; Leahy-Warren et al., 2012). Further research is needed to understand the genesis of parenting competence and confidence in the context of otherwise stressful patient-provider interactions experienced in pregnancy care.

Similar to the work of Tucker Edmonds et al., 2015, our findings show that there are health systems factors that negatively affect women of color's healthcare experiences. Specifically, the lack of connection participants felt to their providers, the role of trainees in their care provision and the participants' perceptions of a lack of caring or respect from their providers of care were also identified in our findings. Future work should test and evaluate patient-driven recommendations on improvement of care such as greater attention to birth plans and active listening from the healthcare team.

Generalizability of the findings from this study is limited by its small sample size and geographic and healthcare context. Further research is needed to determine if the themes generated by the participants in this study will be different or similar to those from other low income groups and women of color in other regions of the United States. Additional focus groups and other developmental work eliciting experiences of pregnancy-related care are warranted. Ideally, future work would also include the perspectives of providers, members of the healthcare team, advocacy groups and others involved in the support and provision of pregnancy-related care. Strengths of this study include a sample

comprised exclusively of women of color at either medical or social risk for PTB, both pregnant and postpartum women, women with multiple births who had experienced PTB and those who did not.

In summary, women of color with socio-demographic risk factors for PTB described disrespect, stressful interactions, and inconsistent social support during the prenatal and perinatal period. However, they expressed strong confidence in being able to care for their newborn babies, even if born preterm. They recommended improvements for the healthcare system, particularly with respect to provider-patient communication. Women in this study identified both individual and structural factors that contributed to their perceptions of their experiences. These findings are important and can potentially contribute to the development of patient-centered interventions that can improve care for women of color at socio-demographic or medical risk for PTB.

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Monica R. McLemore PhD, MPH, RN is an Assistant Professor in the Family Health Care Nursing Department, and a clinician-scientist at Advancing New Standards in Reproductive Health, a program of the Bixby Center for Global Reproductive Health, all at the University of California, San Francisco. She also serves as Associate Director for Community Engaged Research for the Preterm Birth Initiative-California.

Molly Altman PhD, CNM, MPH, is a certified nurse-midwife and a postdoctoral fellow with the Preterm Birth Initiative at the University of California, San Francisco. Her current work focuses on exploring the impact of provider interactions within the pregnancy and birth experiences of low-income women of color.

Norlissa Cooper MSN, RN is a Registered Nurse at San Francisco General Hospital. She holds a Masters of Science with a concentration in Nursing Education from Georgetown University. She is pursuing a Doctoral Degree in Nursing with a concentration in Health Policy at the University of California, San Francisco. She currently sits on the Executive

Board of the Service Employee International Union Local 1021 as the Nursing Industry Chair.

Shanell Williams is the Community Engagement Specialist for the UCSF Preterm Birth Initiative – California. She is an elected trustee of the City College of San Francisco and a San Francisco native. She is working to complete her bachelor's degree in political science.

Larry Rand MD is a perinatologist at the University of California, San Francisco (UCSF) where he serves as Director of Perinatal Services at the UCSF Fetal Treatment Center and holds the Marc and Lynne Benioff Endowed Chair in Maternal Fetal Medicine. He is the Principal Investigator of the California Preterm Birth Initiative (PTBi), a place-based, transdisciplinary, and community-partnered research effort that aims to better understand local contextual influences of social determinants on reproductive biology and the interventions to mitigate their risk. The multi-year initiative is jointly funded by Marc and Lynne Benioff and the Bill and Melinda Gates Foundation.

Linda Franck, RN, PhD Franck is a Professor in the Department of Family Health Care Nursing and holds the Jack and Elaine Koehn Endowed Chair in Pediatric Nursing at the University of California, San Francisco (UCSF) School of Nursing. She is the Co-Principal Investigator – California, for the UCSF Preterm Birth Initiative (PTBi).