

Women's Experiences with Prenatal Care: A Mixed-Methods Study Exploring the Influence of the Social Determinants of Health

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Abstract

Background & Purpose: Racial and ethnic disparities pervade birth outcomes in the United States and the state of Connecticut. While Connecticut's infant mortality rate is less than the national average, rates for the state's Black/African American and Hispanic/Latino communities exceed it. This study explored how prenatal care in Connecticut may be enhanced to address these disparities.

Methods: In spring 2013, seven focus groups and two semi-structured interviews were conducted (n=47). Participants also self-administered brief surveys. Recruited by local service providers, participants were 18 or older, pregnant and/or in the first year post-partum at the time. Most self-identified as non-white.

Results: Even when care was perceived as strong quality, participants perceived a lack of patientcenteredness. Participants knew the importance of prenatal care and actively prioritized it even when experiencing challenges accessing healthcare services or barriers to broader conditions needed to be healthy. Participants also reported experiencing discrimination in healthcare.

Conclusions & Implications: The women esteemed providers' clinical advice, but felt unheard in their prenatal care experiences and faced structural challenges which may be addressed by changing institutional policies and procedures.

Keywords

infant mortality; prenatal care; patient-centered care; social determinants of health; discrimination; health disparities

Cover Page Footnote

The focus groups were funded by the CT Department of Public Health (DPH) and approved by the UConn Human Subjects Review Board and the DPH Human Investigation Committee. The data used in this study were collected by the authors who assume full responsibility for analyses and interpretation of the data. We wish to thank the CT Department of Public Health, The March of Dimes, and all of the community partners who facilitated and/or participated in this study. We are also grateful to Cindy Nichols, MSW for her assistance with data entry and analyses. We are especially appreciative of the women who openly and generously shared their stories and their time.

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ABSTRACT

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INTRODUCTION

For over a century, infant mortality has been identified as a social problem and a critical indicator of overall population health (Giscombé & Lobel, 2005). Rates of infant mortality, like other health indicators, reflect pervasive disparities based on race and ethnicity (Williams & Mohammed, 2009). It is well established that women of color experience disparate rates in birth outcomes in comparison to their white counterparts, which in turn has cyclical implications for



child and adult morbidity and mortality (Dominguez, Dunkel-Schetter, Glynn, Hobel & Sandman, 2008; Rankin, David & Collins, 2011). This study primarily focused on the prenatal experiences of low-income, women of color, in Connecticut (CT). Primary considerations for the study centered on personal and structural barriers that women experienced in accessing care. Disparities in Health & Birth Outcomes

Nationally, the gravity of racial and ethnic health disparities is evidenced by African Americans and Latinos respectively having the highest rates of mortality in many leading causes of death including cancer, heart disease, stroke and hypertension, and infant mortality or death within the first year of life (Williams & Mohammed, 2009). Despite improvements in infant mortality rates (IMR), Black infants experience mortality and its major precursors: pre-term birth (PTB, <37 weeks gestation); and low birth weight (LBW, infant weight of <2500 grams at birth) at twice the rate of non-Hispanic White infants. Outcomes worsen for very low birth weight (VLBW, infant weight of <1500 grams at birth) and very pre-term births (<32 weeks gestation) with Black infants experiencing these conditions at three times the rate of White infants (Collins, David, Handler, Wall & Andes, 2004; Dominguez et al., 2008; Giscombe´& Lobel, 2005; Rankin, et al., 2011). Only 1% of births are VLBW, however, they account for more than 50% of infant deaths and 63% of the gap in mortality between Blacks and Whites (Collins et al, 2004).

In Connecticut, despite its status as the wealthiest state in the nation in terms of per capita income (U. S. Census Bureau, 2012), residents are not exempt from the pervasive racial health inequities which permeate the United States across the major causes of illness and death. The state's overall infant mortality rate decreased by 18% between 2000 and 2010 (March of Dimes, 2014), yet, no racial or ethnic group succeeded in meeting the Healthy People 2010 goal of 5% reported LBW (CT Department of Public Health (CT DPH), 2009). Further, while the state's overall IMR of 5.5 per 1,000 live births in 2009 was lower than both the national rate of 6.6 per 1,000 live births, and the Healthy People 2020 objective of 6.0 per 1,000 live births (March of Dimes, 2014), rates for its non-Hispanic Black/African American and Hispanic/Latino populations exceeded the national average. The IMR within the non-Hispanic Black/African American community and the Hispanic/Latino community was 11.9 and 7.1 per 1000 births respectively. The rate within the non-Hispanic White community was only 3.8 per 1,000 live births (KIDS COUNT Data Center, 2014). These statistics are important given that in Connecticut, a baby born with LBW is 30-times more likely to die within the first 28 days of life than a baby born with a higher birth weight (Mullen, 2012). Infants with LBW not only face an increased risk of death, but of illness and disability across their life course. Common challenges include developmental delays, cerebral palsy, respiratory, auditory and visual problems, cardiovascular disease, diabetes, and lowered academic achievement. Additionally, women who were LBW infants themselves have an elevated risk of having a child with LBW (CT DPH, 2013; Giscombé & Lobel, 2005).

The relationship between LBW and its negative impact on adult health exists independently of personal lifestyle choices such as smoking, alcohol consumption and diet (Giscombé & Lobel, 2005). It is true that many of the biological risk factors for PTB and LBW related to maternal health and behavior may be detected and controlled with adequate and early prenatal and preconception care. These include chronic diseases (e.g. diabetes, hypertension), folic acid intake, inadequate weight gain during pregnancy, and substance use (CDC, 2014). However, the factors contributing to PTB are multiple and complex, and there has been a general inability in the literature to identify the underlying causes of the exponential rate of LBW among



women of color. Two of the most widely used explanations for birth outcome disparities are: 1) differences in socioeconomic status and individual health behaviors, which fall under the rubric of the social determinants of health; and 2) differences in experiences of stress, particularly stress related to experiences of race-based discrimination (Collins, et al., 2004; Giscombe´& Lobel, 2005).

Because most studies investigated these phenomena in African-American women, the text which follows will primarily refer to women who are Black. However, it is important to keep in mind that Latinos, the current largest minority population in the United States, also experience elevated rates of PTB. Compared with non-Hispanic white women, the percentage of preterm births was 3–26 percent higher for Mexican, Central and South American, Cuban, and Puerto Rican women (MacDorman & Mathews, 2011). Puerto Ricans, a subset of the Latino population, suffer the most disproportionately from poor birth outcomes compared to other Latino groups (Bermudez-Milan et al., 2011).

Social Determinants of Health & Barriers to Care

The social determinants of health (SDOH) refer to the social and physical environmental contexts in which people live their daily lives and in large measure influence disparities in health outcomes (U.S. Department of Health and Human Services, 2010). These social determinants range from daily needs such as access to healthy food, interpersonal considerations including language and cultural familiarity, and extend to larger systemic and social issues including poverty, housing, transportation, access to social programs as well as the role of social norms including discrimination (Marmot, Friel, Bell, Houweling, Taylor, & Commission on Social Determinants of Health, 2008). Racial discrimination in the United States occurs and is propagated at the individual, institutional and larger societal levels, and has been well-documented in employment, housing and healthcare (Miller & Garran, 2008).

As a result of negative attitudes and beliefs based on race, people of color are overrepresented at the lower end of the economic spectrum and experience differential treatment and systematic denial of access to resources. Consequently, they have been repeatedly documented to experience disproportionately high incidence of mortality, illness, and other adverse health conditions as result of barriers related to these factors which affect daily life across a range of settings and institutions (Bermúdez-Millán et al., 2011; Marmot et al., 2008; Smedley, et al, 2003). Numerous barriers to receiving prenatal care have been identified in the literature, and may be classified as personal to each woman or structural, relating to larger societal factors and to characteristics of the clinical setting and provider (Phillippi, 2009). Utilization data, often the measure of access to care, is one-dimensional and does not translate into an understanding of the type of challenges the women experience, the interplay of these barriers, nor does it allow the greatest or most pressing challenges for pregnant women to be identified (Phillippi, 2009). Given the pervasiveness and often institutional nature of the problem, members of minority groups may or may not be aware of discriminatory behavior. However, recognition of such target status has been identified as promoting stress (William & Mohammed, 2009).

Personal factors which may impede care access include: lack of finances or insurance; ignorance about needing to obtain care as a result of being unaware of pregnancy status, contemplation of abortion or hiding of pregnancy status, or cultural or personal beliefs that care is unnecessary; fear of necessary medical procedures or of being reported for substance use; and the need for childcare (Phillippi, 2009). Structural barriers include the accessibility of the clinic



in terms of location, hours of operation, wait times and degree of child-friendliness; and a lack of a consistent care provider or poor quality of care. Women also indicated that staff's and clinicians' insensitive attitudes and a lack of linguistic and cultural congruence with their needs were barriers (Phillippi, 2009). It has also been determined that the structure of the current healthcare milieu, is not conducive to meeting the needs of people of color and families with low incomes (Connecticut Health Foundation, 2005). Healthcare providers, in the current managed care environment, are often under significant time constraints in order to contain costs. Further, the requisite paperwork and processes associated with healthcare visits entail high levels of complexity (Smedley et al., 2003).

These personal challenges and structural barriers can induce adverse psychological and physiological stress-response in the body, which in the case of pregnant women, correlates with PTB and LBW (Bermúdez-Millán et al., 2011; Williams & Mohammed, 2009). Giscombé and Lobel (2005) found that women who gave birth to VLBW infants reported higher rates of having experienced discrimination while pregnant, than women who gave birth to babies with normal birth weight; Collins and associates (2004) concluded that cumulative personal experiences of discrimination in African-American women is an independent risk factor for having a VLBW child; and Dominguez and associates (2008) note that racism affects health independent of other sources of stress, and that African Americans expectant mothers experience more such life events.

While problematic, identified barriers did not prevent most women from seeking and obtaining medical care at one stage or another in their prenatal experience. Women across a range of socio-demographic indicators not only cited similar barriers, but indicated their baby's health as the primary motivating factor in their decision to ultimately seek care (Phillipi, 2009). Rankin and associates (2011) deduced that effective, active coping behaviors in response to perceived discrimination had a moderating effect with regard to racial discrimination and may serve as a "buffer" between such experiences and poor birth outcomes (p. 370). Thus, by understanding both the challenges and strengths of women in Connecticut as they navigated the healthcare system during pregnancy, this research hoped to identify factors which promoted and challenged the pervasive racial disparities in birth outcomes that exist in the state.

METHODS

Data Collection

This study used a mixed-methods design, with a qualitative emphasis. The qualitative and quantitative components were implemented at the same session of data collection (Rubin & Babbie, 2014). A mixed-methods approach was particularly useful here since our research question called for "real-life contextual understandings, multi-level perspectives, and cultural influences" (Creswell, Klassen, Clark & Smith, 2011, p. 4). Focus groups were chosen because they allowed for synergy between group members in order to elicit insights regarding the particularly complex topic of racial discrimination (Padgett, 2008). Seven focus groups (n=45), two semi-structured interviews and surveys were used to explore the women's experiences with prenatal care (interviews were conducted in place of focus groups in areas with low recruitment for the study). The focus groups and interviews were facilitated by graduate social work students using a semi-structured interview guide (see Appendix A for the Focus Group Semi-Structured Discussion Guide). Topics addressed included participants' experiences with prenatal care providers, barriers to prenatal care, racism and discrimination and their effect on participants'



prenatal care experiences, culture and its influence on prenatal care decisions, risk and protective factors for pre-term birth, and recommendations for improving prenatal care and for informing the community about the importance of prenatal care.

In order to supplement qualitative findings, three survey instruments were also used in this study: the Demographic and Prenatal Care Survey; the Barriers to Prenatal Care Survey, and a Survey of Risk and Protective Factor for Preterm Births. The first included standard demographic questions as well as questions about pregnancy status, pre-term deliveries, use of fertility drugs, preparation for pregnancy, support with child care, site of prenatal care, dental care during pregnancy, health insurance during pregnancy and post-partum, and an abbreviated version of the Interpersonal Processes of Care Survey adapted to prenatal care (Wong, Korenbrot & Stewart, 2004). The Barriers to Prenatal Care Survey listed eight common barriers to care (transportation, work, lack of money, housing problems, lack of health insurance, and three difficulties associated with finding a prenatal care provider) and asked participants to indicate the extent to which each was a problem. The Survey of Risk and Protective Factors for Pre-Term Births was a listing of six risk factors (smoking, lack of folic acid, fertility treatment, uncontrolled diabetes, high blood pressure, and heart problems) and three protective factors (being healthy, eating healthy foods, and taking care of medical conditions). Participants indicated if they were aware of each of these factors.

Before the focus groups or semi-structured interviews began, all participants were screened and consented. They then self-administered the Demographic and Prenatal Care Survey. In order to protect confidentiality, data collection forms did not include participant names, but had a randomly assigned number which was also used to identify them during the focus group discussion. Participants self-administered the Barriers to Prenatal Care Survey and the Risk and Protective Factors for Preterm Births Survey during the focus group. These were integrated into the focus group methodology because they assessed patients' perspectives before the focus group component, as to not contaminate quantitative findings, and also prompted for personal reflection just prior to the relevant group discussion topics. In a sample of primarily low-income participants, many of whom may have struggled with literacy, this also allowed for the self-administered survey questions to be broken up and perhaps be more digestible to participants. Participants were given a gift card worth \$25 at the end of the focus group as an acknowledgement of their participation.

Human Subjects Review, Sample Recruitment, and Inclusion Criteria

Following approval by the University of Connecticut Human Subject Review Board as well as the Connecticut Department of Public Health Human Investigation Committee, participants were recruited via service providers from five regions (three urban and two suburban). Inclusion criteria were that the women were at least 18 years of age and pregnant at the time of the focus group and/or in the first year postpartum. Two of the urban regions specifically recruited from organizations that primarily served low-income, women of color, targeting women from different racial and ethnic backgrounds. Three focus groups were conducted in one of the urban areas with a total of 21 participants: one group comprised of low-income women who identified ethnically as Hispanic/Latina and who spoke Spanish primarily (this focus group was the only one which was conducted in Spanish); a second group comprised of low-income Hispanic and Black/African American; and a third mixed group of low-income Hispanic and Black/African American women. In another urban area, three focus groups were conducted with a total of 20 participants: one focus group was comprised of



low-income women who identified racially as Black/African American; the second of women who identified as ethnically as Hispanic/Latina, and the third of low-income women who identified as West Indian. One focus group was also conducted in a third urban area and had 4 participants who identified as White, Black, and/or Latina. One semi-structured interview was conducted in each of the two suburban areas - these two participants were White. Data analysis

The survey data were entered into an SPSS database, and descriptive and bivariate analyses conducted to describe the participants. A race/ethnicity variable was created by combining the responses to the ethnicity (if participant was Hispanic or Latina, or not) and self-reported race questions with the responses to questions about self-described ethnicity (particularly if Hispanic, Latina, or West Indian), and where the participant was born in order to clarify the race/ethnicity of those who either did not respond to the self-reported race question or who categorized themselves as "other." Focus groups and semi-structured interviews were audio taped and field notes written. The digitally recorded audio tapes were transcribed verbatim, and the Spanish transcript was then translated to English. Using NVivo version 10 software, the research team reviewed the transcripts, identified emerging themes, and developed codes and sub-codes. Following the identification of themes from each focus group, results were compared and contrasted in order to identify any similarities and/or differences between groups. Findings were triangulated among the three researchers as part of the thematic analysis, and discrepancies in analyses were discussed and consensus was reached between authors regarding final determination of codes and themes.

RESULTS

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Demographic and descriptive statistics

A total of 47 women participated in this project. The majority (91.5 % or 41) was from two urban areas. Fifteen of the women (31.9%) were pregnant at the time of the focus group, 30 (63.8%) were in their first year postpartum and two (4.3%) were pregnant at the time of the focus group and also had given birth in the preceding year.

By ethnicity, about a third self-identified as Hispanic or Latina. By self-reported race, just over half self-reported as Black or African American, a quarter self-reported as "Other" or did not report a racial category, and all but one of the remainder self-identified as White. Using the data from both the ethnicity and race variables to form one race/ethnicity variable allowed all the women to be categorized by race and/or ethnicity and allowed for discrepant data to be corrected. The one respondent who identified as Hawaiian/Pacific Islander was born in Jamaica, and thus was recategorized as West Indian.

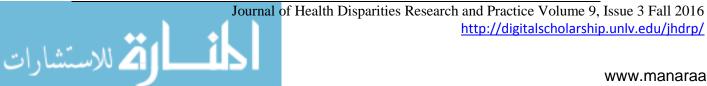
Most participants were born in the mainland U.S., and two were very young when they moved to the mainland. Six participants were 16 or older at the time of their move, whereas the other two were an infant and a toddler. Three participants did not speak English. The mean age was 28.8 years and the mean level of education was 12.3 years of school. The majority were single or divorced. Almost a third were working full or part time, and the remainder were not employed, or defined themselves as homemakers, students or self-described as retired. Just under half reported an annual family income of \$15,000 or less, just under a third had an annual family income between \$15,000 and \$50,000, one had a family income greater than \$50,001, and the remainder did not know. Almost all had children living with them, and about a quarter had previously had a preterm baby. Only one had received fertility treatments. About a quarter



received their prenatal care at community health centers, whereas the remainder were about equally divided between those who received care from hospital clinics, and those who received care from private medical offices. Three actively avoided the dentist, but more than a third did not or did not plan to have dental care during their pregnancy, a time period longer that the recommended six months for cleaning. Almost all had health insurance during their pregnancy whereas slightly fewer of those who were postpartum had health insurance. Most recalled having health insurance when they were children.

Table 1. Demographic Characteristics of Focus Group Participants					
	% (n) or				
Characteristic	Mean (SD)				
Hispanic or Latina (n=47)	38.3% (18)				
Race (self-reported; may choose more than one response) (n=47)					
Black or African American	48.9% (23)				
White	17.0% (8)				
Hawaiian/Pacific Islander*	2.1% (1)				
More than one race	4.3% (2)				
Other or unknown	27.7% (13)				
Race/Ethnicity Combined (n=47)					
West Indian	6.4% (3)				
Black or African American & Non-Hispanic	34.0% (16)				
Black or African American & West Indian	8.5% (4)				
Black or African American & American Indian/Alaskan Native	4.3% (2)				
Black or African American & Hispanic or Latina	6.4% (3)				
Hispanic or Latina & "Other" Race	23.4% (11)				
White & Hispanic or Latina	8.5% (4)				
White & Non-Hispanic	8.5% (4)				
Born in mainland US (n=47)	80.9% (38)				
# Years lived in Connecticut (n=45)	21.9 ± 9.8				
Only spoke Spanish (n=47)	6.4% (3)				
Age (n=45)	28.8 ± 6.7				
18-23	31.1% (14)				
24-34	42.2% (19)				
35 and older	26.7% (12)				
Highest level of education (n=44)	12.3 ± 1.6				
Eighth grade or less	2.3% (1)				
Some high school	20.4% (9)				
High school graduate	47.7% (21)				
Some post-high school	22.8% (10)				
College and/or post-college degree	6.8% (3)				
Marital status (n=46)					
Single, never been married (no partner)	63.0% (29)				
Divorced	2.2% (1)				
Married	21.7% (10)				
Partnered	13.0% (6)				

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Employment status (n=44)	
Employed for wages (full or part-time, or self-employed)	31.8% (14)
Not working	47.7% (21)
Homemaker	9.1% (4)
Student	9.1% (4)
Retired	2.3% (1)
Annual household income (n=44)	
< \$15,000	45.5% (20)
\$15,000 - \$25,000	22.7% (10)
\$25,001 - \$50,000	9.1% (4)
\geq \$50,001	2.3% (1)
Did not know	20.5% (9)
# of Children < 18 years of age living with participant (n=45)	
0	4.4% (2)
1-2	75.6% (34)
3 or more	20.0% (9)
Had a preterm birth (n=46)	23.9% (11)
Had taken fertility drugs or had a medical procedure to help get	2.1% (1)
pregnant (n=47)	
Did something to prepare for the pregnancy (question was	72.1% (31)
intended to be about preconceptonal preparation but the responses	
also describe actions taken during pregnancy) (n=43)	
Site of prenatal care (n=47)	
Community health center	23.4% (11)
Hospital clinic	34.0% (16)
Private medical office	38.3% (18)
Other	4.3% (2)
Dental care during pregnancy (n=41)	
Did not or will not go to dentist during pregnancy	39.0% (16)
Was purposefully	7.3% (3)
Had health insurance during pregnancy (n=47)	95.7% (45)
Had health insurance post-partum	86.2% (25)
Family had health insurance when participant was a child (n=46)	89.3% (42)

*Note: Participant who identified as Native Hawaiian reported that she was born in Jamaica. Thus she was reclassified as West Indian.

The Prenatal Scale Survey, which included a subset of the Wong et al.'s (2004) Interpersonal Processes of Prenatal Care tool, had a total of 18 items. For 16 of the 18 items, at least 76.6% (36) responded with either of the two most positive responses, indicating little variability and a generally high level of satisfaction with prenatal care. Only two items were not as positively endorsed. The first, was "How often did or do prenatal providers make decisions without taking your preferences or opinions into account?" which was reversed scored. About a third, (35.5%, n=16) experienced this sometimes, usually or always. The second was "How often did or do prenatal providers ask if you felt comfortable following advice that they gave you?" Similarly, 34.8% (16), said they never, rarely or sometimes experienced this.



Very few women endorsed any of the eight barriers to prenatal care. Five of the eight were endorsed as at least somewhat problematic by only 6.4% or less (3 or less) of the participants, whereas the other three were endorsed by 10.9% (5) to 14.9% (7) of the participants. The three items were as follows:

- 1. Have/had trouble getting rides or driving to my prenatal care appointments.
- 2. Had trouble getting to my prenatal care appointments because of food or money problems. [interpreted as financial problems]
- 8. Had trouble finding a prenatal care provider that I was comfortable with.

Table 2. Relevant Responses to the Prenatal Care Survey, Barriers to Care Survey, & Risk and Protective Factors for Preterm Birth Survey

Prenatal Care Survey		-				
On average during your pregnancy, how often did/do prenatal care providers (e.g. nurses, midwives, doctors)	Never	Rarely	Sometimes	Usually	Always	
8. Make decisions without taking your preferences/opinions into account? (n=45)	64.4 % (29)		35.5% (16)			
9. Ask if you felt comfortable following the advice that they gave you? (n=46)	34.8%	34.8% (16) 65.2% (30))		
Barriers to Prenatal Care Survey						
Indicate how much each of the following is a barrier for you?	at Big		Very Big Problem			
1.Have/had trouble getting rides or driving to my prenatal care appointments (n=46)	89.1% (41)			10.9% (5)		
3. Have/had trouble getting to my appointments because of food or money problems (n=47)	87.2% (41) 12.8% (6)		5)			
8. Have/had trouble finding a prenatal care provider that I was comfortable with (n=47)	85.1% (40)		14.9% (7)			
Risk and Protective Factors for Pre-	Ferm Birth	s Survey				
Risk Factors	Knew Was a Risk		E	Did Not Know Risk		
Lack of folic acid before pregnancy (n=47)	53.2% (25)			46.8% (22)		
Fertility treatments (n=47)	46.8% (22)		53.2% (25)			



On the Risk and Protective Factors for Preterm Births Survey, all but two women knew all of the protective factors, and most knew the risk factors. However, 46.8% (22) did not know that the lack of folic acid before pregnancy was a risk factor, and 53.2% (25) did not know that fertility treatments were a risk factor.

Bivariate analyses were conducted to assess for trends only; significance testing was not conducted given the small sample size. That said, two interesting trends were noted. The first pertains to the presumed inter-generational nature of the lack of insurance and the second to a possible relationship between having a preterm birth and being more aware of risk factors. Of the four participants who did not have health insurance as children, three also did not have postpartum insurance. Three of these four had health insurance while pregnant, and the fourth could not recall. Of those who had experienced PTB, 63.6% (7/11) identified ethnically as Latina (English and Spanish speaking). The relationship between PTB and knowledge of the importance of folic acid was stronger than that which was observed based on educational attainment: 40.0% (4/10) of those with less than a high school education, 42.9% (9/21) of those with a high school education, and 53.8% (7/13) of those with more than high school knew that the lack of folic acid was a risk factor. Of the 11 who had a PTB, 72.7% (8) were aware that the absence of folic acid was a risk factor whereas only 45.7% (16) of those who did not have a preterm birth (35) said they knew about folic acid.

Focus group findings

Thematic analysis of the focus groups and interviews revealed three main themes related to the participants' prenatal care experience: (1) Women identified concerns about the lack of patient-centered of care, particularly with regard to the administration of the healthcare system; (2) While women experienced challenges to accessing healthcare services as well as the broader conditions needed to live a healthy life, women also developed strategies to help mitigate such challenges. Almost universally, participants understood the importance of prenatal care, valued it, and actively worked to prioritize it in their lives, but some were unaware of certain risk factors for pre-term birth; (3) While women did not report experiencing racially-based discriminatory prenatal care, some did report experiencing other forms of discrimination in the course of their prenatal care. Although the focus of the study was prenatal care, the women also discussed their birth experiences, which further corroborated these findings.

Theme 1. The most significant finding in terms of its scope was that perceptions about the quality of the patient-centeredness of care varied widely among participants. Some reported receiving excellent treatment while others reported very negative experiences. Even when care was considered to be of strong quality, participants overwhelmingly perceived a lack of patient centeredness, with regard to both to healthcare administration systems and clinical care. This theme had several sub-themes as follows:

- a. more satisfaction with direct-care providers than office staff;
- b. preference for private doctors' offices versus community health center or hospital clinic (herein referred to as clinic-based settings);
- c. women's time was devalued;
- d. phone issues at clinic based setting;
- e. lack of continuity of care;
- f. lack of consideration for their personal preferences.



Participants reported more satisfaction with the treatment by direct-care providers than with that by office staff, although there was some variation.

- "I felt...like they [providers] were really involved in what I wanted."
- "My nurse has always checked if I need stuff for my diabetes. ...She be on track and get 'em for me....they're really helpful."
- "...they [providers] sucked, it was a horrible experience."
- In reference to office staff, one participant notes "*They be having an attitude. It seems like they carry their...issues...to work.*"

When women experienced poor treatment, some participants noted that they would advocate for themselves within the healthcare system, while others reported that they would simply try to ignore it. Several, but not all women who reported taking either approach, noted that treatment got better over time.

- "The situation with me not knowing I was pregnant until late made that certain ultrasound [technician] ... question me that much.... [It] made me feel like I was doing something wrong. She made me feel like I just want to leave. I did speak to my [provider] and she was like 'Don't worry about it. We are not going to send you to her again...'."
- "Like sometimes...they have their attitudes. I just ignored it... I didn't address it to nobody but eventually they change. Eventually...they got to see me, they changed."

Participants perceived large clinic systems to be less patient-centered than private doctors' offices; thus they expressed preferences for private offices as compared with hospital clinics or community health centers.

- "My doctor knew me cause it's only just him."
- "It was like family." [referring to providers private office]
- "I've been at the same doctor for like seven years but before I found that doctor I went to a local...community center and I felt like they're a mess. ...They're all over the place. They don't have no type of relation for you, it just feels they're just in there to get you in and out so that's why I, I stick with my private doctor and I don't go to community things."
- "Especially dealing with the hospital and it's just like real ugly; cause nobody actually knows you as a person...every time you dealing with one of the doctors you got to tell them all your information, all over again every time you go and that's crazy."
- Two women in one group saw the same provider in different settings and compared their different experiences. While the woman who saw the physician in the hospital clinic reported feeling "*unwelcomed*" and "*rushed*," the woman who saw him in his private office reported it as being "*a lot more comfortable, a lot more slowed down there*" and described the provider as being "*more relaxed*" in the private office setting.

Participants perceived that their time was devalued in the clinical encounter in two respects: they reported feeling rushed in their interactions with providers and some participants



also reported a double standard regarding timeliness. Participants highlighted the need for more time with their healthcare providers specifically to address individual concerns related to their pregnancy. Some women experienced being scheduled for appointments at the same time as other patients, with the same provider. Other participants reported waiting for scheduled appointments, often for 45 minutes or more, while noting that if they were 15 minutes late, they were forced to reschedule.

- "How do these doctors time these appointments? I don't know if they do fifteen minute time slots. I don't think that that's appropriate. You know like [in] pregnancy you come in with all kind of concerns like 'why is my back aching,' 'I was spotting a little bit last night,' whatever the case may be, and they have to fit you in in this small amount of time and sometimes the time is not a lot for you to address all your concerns."
- "You know how you prepare yourself to get to the appointment on time and they have you waiting for hours just to be seen....It's just that we have other things we need to do too. If the appointment was at 10 o'clock, we expect to be seen at 10 o'clock."

Telephone access to providers was a significant concern for some women who received care in clinic-based settings. Some women reported being put on hold for extended periods of time and others reported a lack of responsiveness on the part of staff.

- "Getting through was an issue. They put me on hold and I guess they forget. So on my end, it's frustrating, especially when you got a minute phone. So I can't hold so sometimes I tend to brush it off and like forget. So I just wait for them to call me, and you know give me an appointment."
- "They didn't know how to you know, speak to you on the phone...they was kinda nasty, snappy."
- "I generally had a hard time either getting through or just wouldn't end up getting the answers that I needed. I didn't call very often because the first few times I just couldn't get the right answers...I wouldn't get a call back generally unless it was about making an appointment."

Participants were very concerned about the lack of continuity of care providers. They noted this was often due to multiple providers rotating amongst patients in a practice setting, provider turnover, medical residencies, etc.

- "So...dealing with the hospital community, you never see the same person twice."
- "[At a community health center], they were switching me around with all these different doctors and I said, 'Look, can I just have one primary doctor?""
- "Having that comfortable relationship with a good provider is great to have because you can always go back and ask questions whenever needed."
- "If they had steady doctors, their doctors rotate like people change their underwear...."

Participants also reported a lack of consideration for personal preferences in care and provider prioritization of allopathic, clinical guidelines and business practices over women's self-knowledge of their bodies, concerns, priorities, and experience. Related to this, some women expressed difficulty finding a provider with whom they were comfortable. Some women,



particularly those reporting very negative prenatal and birth experiences, suggested that their clinical care providers could provide greater compassion and attentiveness. Participants were looking for more personalized, educational information about the pregnancy process which took into account their concerns and apprehensions. Participants also reported that their concerns and decisions about medication were not always taken seriously or responded to fully.

- "They kind of do rush you...like 'All right, we know what we're doing. We saw you and you're out of here. See you in four weeks.' And it's like I'm not gonna say they don't care about the mother, but I had issues in the beginning and it was like, blow them off. Like 'Well do this, do that and you'll be OK' and I'm like 'No...I never experienced this before. Somebody do something. Like this is not normal for me.'...They should be more into the mother, not just the fetus."
- "They want you to have a certain amount of what they want you to have for your...growing baby inside you and in the beginning I couldn't keep anything down. It doesn't matter how much you keep saying 'do this or do that'" so I just had to pretty much let them know I'm gonna do this until I'm not sick and then I'm gonna work on what you guys are asking me to do. I found myself almost lying sometimes ...just so I don't have to have that same conversation...every appointment."
- "When you're not doing exactly what they tell you...gaining a little too much weight at one time or not enough, you feel like you're doing something wrong. They're telling you it's necessary to do these things and that your child's health depends on all of this and it just puts so much pressure on you. It makes you feel like you're either doing it their way or you're doing it wrong."
- "[I'd like] a little more like compassion, time spent like actually getting to know the patients, and more information."
- "I'm uncomfortable taking pills and different things being pregnant...you're a doctor and you're saying 'take this and take that'" but...this is my baby. Is it really ok for my baby to be ingesting these things? And that's what made me feel uncomfortable...I got into a car accident and I was prescribed Percocet...and she's like 'oh, it's alright, as long as you don't have them all the time or get addicted'"...that didn't make me want to take them. I had the prescription and I rather stay in pain because I don't think it's safe enough."

While women were directly asked about their prenatal care experiences, participants interpreted the question to include birth experiences. Thus, several women also reported on their birthing experiences in the context of discussing their prenatal care. Data involving birth experiences revolved around the same concerns about patient-centeredness, including lack of personalization of care, deprioritizing patients' experiences, and devaluing of patients' time.

- "I give birth kind of quick once I get started. And I was ready, I was ten centimeters ready and waiting for the doctor and they were like 'hold off...hold her off as long as you can.' And it's like I could have gave birth in 15 minutes versus 45 minutes. So it just seems like it's kind of real routine to the people that are helping you give birth. It's really routine and it's like if something happens what do you guys...say then?"
- *"I don't mind them being in the room* [e.g. medical students and/or residents] *but everything is like twice. They had to check my cervix and the doctor checked me plus*



another guy....The lady that was there was like 'Oh my god, I feel sorry for you.' I'm not a doll. You can't do that. What the heck?"

• "...when I had that last child, I wanted to have a tubal ligation right after giving birth. And he basically informed me that he was too busy that day cause there were a lot of babies being born. So it was like, in, get my baby out, left me there with the birth, with the rest, after the birth stuff in there for like forty-five minutes. And I'm just stuck there and then he came back and didn't do the tubal ligation and told me to come back in eight weeks...that kind of threw me off and I never got the tubal ligation and now six years later I'm having another baby, and it's that same doctor."

Theme 2. In general, all women understood the importance of prenatal care and most everyone reported attending all or just about every prenatal appointment. Women actively planned to accommodate their prenatal care appointments into their lives, in terms of time management, transportation costs, etc. This position was almost universally expressed by the women, regardless of whether their prenatal experience was positive or negative. Women valued their medical provider's advice in regards to their baby's health.

- "If I had an upcoming appointment, I made sure I had you know [money for transportation], even if it was my last ten dollars, I knew I had to keep that and save that for my appointment to make it there. I had some challenges, but I just tried to prepare myself and know my schedule ahead of time."
- "Yeah I got prenatal care every single time, even with the doctors, I still made the visits. I still made sure that everything was fine." [This participant described her prenatal care experience as "horrible."]

The previously mentioned point that participants generally wanted to receive more pregnancy-related health education from their providers, was particularly the case as it related to risk factors and protective factors of preterm birth. For example, while they were aware that smoking during pregnancy could be problematic, they did not explicitly realize it was related to preterm birth. They also did not correlate fertility treatments or untreated, chronic health conditions as risk factors for preterm birth. They generally did not know about the role of folic acid.

• "You know when you get pregnant you need to have prenatal care but you don't pay attention to like 'oh let me start getting ready now for when I want to have a baby,' like as far as getting the daily folic acid."

Furthermore, most participants reported experiencing some economic, social, and/or environmental challenges to health and wellbeing, in other words, the social determinants of health (SDOH). While in some cases, these challenges affected the participants' access to prenatal care, the women emphasized that they did not prevent them from accessing prenatal care. These challenges primarily involved social services, money, transportation, and access to healthy food. Housing was also a challenge for some women. While many women were aware of social service and health programs available to them, those who were employed found the qualifying income threshold criteria too low. Likely as part of the women's overall commitment to their prenatal care, a major strategy which they emphasized was the importance of using social networks in helping them mitigate these challenges and access community-based resources.



Some participants also noted that the support they received from their "*social workers*" was invaluable in being able to navigate the social service system and barriers to accessing care.

- "Even if you have a ride you still need gas to get there....These are mandatory appointments that you have to go to so either way you're going to have to get there somehow whether it's asking for a ride or having just the gas money to make it there."
- "I'd take the bus a lot of times in certain situations when you don't even have the money to take the bus, and gets difficult."
- "It has been a problem for me because ...when it comes to eat for a week or use the money for gas to get a ride to the appointment, you gotta be able to eat, you gotta be able to feed yourself and if you have other children you would feed them too." "I just completely stopped taking [Medicare-sponsored transportation service] cause I couldn't stand the service anymore like the people were generally nice...just they were so tardy nobody was on time. I'd miss some of my appointments..."
- "There was an instance where the doctor was telling me like 'You should eat organic foods. You should eat, try to make things with organic stuff.' I was like 'Do you know what organic costs?' It's a lot of money!"
- "I've been pretty much house hopping for a year and a half now. It does get difficult because sometimes when you have something available it's in a different town and you have difficulty getting to your appointment somewhere else."
- "I know about the WIC program and stuff, but see, my thing is, I do work so everything as far as trying to get assistance—like okay you can't get it because uh 'you make too much' or so that was that's my problem even though I don't to me...I can't get any type of assistance because of the income...where [am] I supposed go and look for help?"
- "You shouldn't have to quit your job just to get assistance."
- "So I try to like tell people to the secret like find the offsite [application for Medicaid insurance coverage] and go through them because within twenty four hours you might not have a [insurance] card but you have your number which is just as good."

Financial access to healthcare was problematic for some participants. Participants were concerned about healthcare costs, knowing how to access Medicaid, multiple, logistical barriers to registering for public insurance through the State Department of Social Services, not being able to access prenatal care while waiting for coverage to begin, and not being accepted by providers due to being on public insurance. Also, for those women who were working, some found it challenging to balance work commitments with medical appointments.

- [In reference to receiving a hospital bill,] "*I was like that is way too expensive, especially for somebody who doesn't have that amount of money to pay...*" [Its important to make] "*sure that services are not only available but they are affordable for people who need them.*"
- "Sometimes if I didn't have a sick time I would have to lose pay or what have you, so I would you know they have Saturday's appointments or later office appointment...for me it was just getting an appointment that I can meet during my work schedule."



• "I've had three [Department of Social Services] case workers and never met one of them, never talked to one of them, never seen one of them. I have this one case worker that I call and I call and I call, cause right now I need help with like daycare and until I talk to my caseworker I can't get daycare so I call and I call and I call and I have yet to get to this person. I called to the point where like the mailbox is full. And...I've been down there and they say 'oh well you have to call because we don't know where your worker is at.'

Women with higher levels of education and working women had increased awareness of their rights and resources, as well as greater consciousness about how their life situations correlated with broad social and political structures. (Such awareness included for example: waiting at the Department of Social Services (DSS) too long to register for healthcare services; income thresholds on need-based programs being too low; and that healthcare should be a human right).

Theme 3. Finally, some women reported experiencing discrimination in their prenatal care on the bases of age, insurance type, and behavioral health history. Some felt disrespected, but no one described racially-based discrimination in the healthcare setting. Three of the six women who were not from the two primary urban areas shared the most egregious concerns about their provider's behavior. While the role of race is uncertain here, as all these women identified as White, the other factors could be identified as potential bases for discrimination in their cases. All three women were younger (early to mid-20s) and two were pregnant for the first time. One identified her past history of drug abuse as the source of the discrimination she experienced during her prenatal care. Other women expressed that it was not uncommon to be discriminated against based on the neighborhood or town where one lived. These women also resided in areas that seemed to be less well-resourced; thus, socioeconomic status and geography may have played a role as well.

- "In the hospital and [with] different healthcare providers, I did feel the discrimination, I did feel like I was less than because I had Husky" [e.g. Medicaid].
- "I almost used to feel like I almost had to wear a name tag that says I do work full time and I was trying to contribute to society but unfortunately I fall into the financial guidelines to where I'm eligible...You feel prejudiced, you feel like cause you getting DSS assistance that you're stupid, you're dumb, you're poor, you're uneducated and that's not the case. ...You always feel like you gotta prove that I'm not stupid, I'm not dumb."
- "I mean I was honest. I was like 'I was a drug user' [as it] was gonna affect how my baby grows, and when you tell people that, they don't want to see you."
- "Yeah, [city] has the reputation of not so nice girls that like to sleep around a lot, quite a lot of us get treated as such even though there's quite a few of us who do not."

DISCUSSION

Limitations

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Two methodological limitations of this project were: 1) the nature of the sample; and 2) discrepancies between participant response on the quantitative surveys and the discussion questions. The convenience sample was small and non-random by design; it primarily included urban women who were engaged in case management services. The participants were also all





able to attend focus groups or interviews that occurred during the day whereas women with more restrictive work and /or family situations may have been precluded from attending. Consequently, the findings, while informative, are applicable primarily to urban, low-income women of color *with* supportive social services.

The second limitation pertains to differences in how the women responded to the surveys and the discussion questions. Self-administered quantitative surveys were utilized to describe the sample and to help address the breadth of topics of interest to this project. Whereas overall the women reported general satisfaction with their prenatal care on both the survey and in the focus groups, there were some disparities between the survey and focus group responses regarding several items, e.g., knowledge of risk factors for preterm pregnancy, barriers to prenatal care, and some negative experiences with prenatal care. Approximately half of participants reported knowledge of folic acid and fertility treatment from the Risk Factors Survey; this was in contrast to the focus group findings, in which the vast majority of women reported a lack of knowledge regarding folic acid as well as the role of fertility treatments in preterm births. It is important to note that in this sample, almost a quarter of the women had previously had a preterm birth which may account for their heightened awareness of folic acid, but this does not account for the broader discrepancies in the qualitative versus quantitative data. Only one woman in this study had undergone any fertility treatments; thus most participants were unfamiliar with fertility treatments and had never fully contemplated their risk factors.

In the survey results, most women did not endorse the barriers to accessing prenatal care, yet in the focus groups, they noted many challenges to receiving services. As such, the term "barrier" may have been too strong. Even when women reported that money was not a barrier specific to prenatal care, they reported that money problems were a considerable concern for them. This apparent contradiction may be explained by the relationship between the extent and frequency to which these issues presented and the women's prioritization of their prenatal care. Their statements in this regard communicate determination and motivation to attend medical visits, obtain prenatal vitamins, and participate in other activities as necessary to promote prenatal health. While participants may have encountered many challenges, the women did not perceive them as barriers as they did, in the end, receive prenatal care.

Similarly, there was minimal endorsement of anything negative on the Prenatal Care Survey, yet substantial discussion of a variety of quality-related issues in the focus groups once the women were "warmed up." This suggests a general reluctance to respond negatively, at least initially and on self-administered "paper and pencil" surveys, and/or a problem with using a quantitative format for these women to address these topics. Furthermore, this discrepancy could be explained in part by the tendency of participants to rate services highly on satisfaction surveys, regardless of quality of care; the Prenatal Care Survey may in fact be a better indicator of how well the women's prenatal care met their initial expectations for care, as opposed to how well their needs were met (Royse, Thyer, & Padgett, 2010).

There was also some reluctance or perhaps confusion with two other questions. Many of the women who identified ethnically as Latina tended to endorse the "other" category in the racial identity question where they described themselves as "*Latina*," not a racial category. This finding in consistent with others which highlight the need for more valid mechanisms of racial and ethnic classification for Latinos (Ríos, Romero, & Ramírez, 2014; U.S. Commission on Civil Rights, 2009). Moreover, when asked what they did to prepare for the pregnancy, participants interpreted this to mean what they did during the pregnancy to prepare for birth. This



discrepancy may be because women did not receive adequate preconceptional care, which would have educated them on how to prepare for pregnancy. These findings suggest that a selfadministered survey alone is not ideal for this population. Future studies might consider an interview format instead. Nonetheless, the use of the two shorter surveys on barriers to care and risk and protective factors for preterm birth did seem to facilitate a deeper group discussion of challenges to prenatal care and knowledge of risk factors, even if the results of the two formats (survey and focus group) were somewhat disparate.

Implications

Healthcare Settings. Many women reported feeling unheard, disrespected, and as though the provider's clinical guidelines superseded the women's concerns or their own knowledge of their bodies, particularly when the women's concerns or experiences went against the providers' expectations that patients should always practice optimal healthy behavior. Examples of this were widespread, and included some women's reluctance to share their use of complementary and alternative medicine because they feared their providers do not understand it, and their challenges with taking prenatal vitamins and maintaining a healthy diet while managing morning sickness. Underlying participants' concerns was a desire for more patient-centered care.

"Patient-centeredness" is identified by the Institute of Medicine (IOM) as one of six aims in quality healthcare improvement. The IOM defines patient-centeredness as "providing care that is respectful of and responsive to individual patient preferences, needs, and values, and ensuring that patient values guide all clinical decisions" (Institute of Medicine, 2001). As part of a patientcentered approach, it is critical that providers offer patients not only the most current medical knowledge, but exercise sensitivity to the needs and experiences of individual patients with regard to their unique medical history and current care preferences or concerns. In so doing, patients and providers can be better partners in maintaining optimal prenatal health for women and improving birth outcomes. The IOM also recommends training to support the healthcare workforce in improving care provision and patient-centeredness (Institute of Medicine, 2001). Moreover, findings highlight that patient-centered care extends beyond the clinical encounter to include the systems in which healthcare is administered (e.g. process for scheduling appointments, timeliness of provider for scheduled appointments, continuity of care, etc.).

Findings in this study are consistent with previous findings that highlight poverty and poor quality of and access to the SDOH yield challenges in actualizing optimal prenatal health (Bermúdez-Millán et al., 2011; Phillipi, 2009). Thus, it is critical that the healthcare system better recognize how social and economic forces interact with biological factors to yield poor birth outcomes. Structural competency, as defined by Metzl (2012), "seeks to impart the ability to discern how a host of issues defined clinically as symptoms, attitudes, or diseases (e.g. depression, hypertension, obesity, smoking, medication 'non-compliance,' trauma, psychosis) also represent the downstream implications of upstream decisions about such matters as healthcare and food delivery systems, zoning laws, urban and rural infrastructure, [and] medicalization..." (p. 216). Enhanced medical models for structural change are needed, which may improve access to reliable and affordable transportation, assessable, healthy food, and improved processes to access state-administered welfare programs. Training in structural competency can also facilitate improved communication between providers, office staff, and patients, and help to debunk stereotypes and victim-blaming stigma. It is important that all employees of healthcare organizations attend such training.



Also consistent with Phillippi (2009), participants in this study experienced structural barriers to quality, prenatal care services. Healthcare organizations need to assess their policies regarding timeliness to ensure that patients are not required to wait prolonged periods of time either on the phone or for their appointments. Women reported being penalized when being tardy, but conversely were expected to wait indefinitely to access their providers. Further, health-related transportation options could be enhanced in terms of timeliness, reliability, and flexibility. In addition to significantly reducing the tardiness of pickups, women suggested that such a service needs to be real-time oriented, since often times transportation plans fall apart last minute and it can be very difficult to plan transportation days before an appointment.

Healthcare systems also need to be careful that their policies and bureaucratic procedures do not inadvertently punish patients. Patients may sometimes be labeled as non-compliant, problematic, or uncooperative for reasons that may be grounded in structural inadequacies. In one case, a participant explained that since she had a pre-paid cell phone with limited minutes, and since she often was required to remain on hold when calling her provider's office for indefinite amounts of time when trying to schedule appointments, she instead chose to wait for the office to call her to schedule periodic prenatal appointments, after she missed important target dates. Her motivation for doing this was to save valuable resources, but this behavior may be easily misconstrued as non-compliance. Thus, perceived non-compliance may actually be a consequence of coping with structural barriers.

Perhaps the lack of patient-centeredness in care may be linked to negative attitudes of healthcare staff toward women of color or low-income women, and by extension whether or not these attitudes - explicit or implicit - make for ambiguous encounters of discrimination in prenatal healthcare settings. If this is true, the subtle institutional nature of racism, may be addressed at least in part by healthcare facilities actively valuing diversity in terms of policies and procedures, as well as respecting the needs and expertise of patients with regard to their individual pregnancies. Thus, prenatal providers should be aware of and trained in antioppressive practice at both the individual and institutional levels, which may include both structural and cultural competence training. This is particularly critical in light of extant health disparity literature which holds that it is the experience of racism and discrimination across the life course which produces poor outcomes in the health of people of color (Williams & Mohammed, 2009). While discrimination in prenatal care was not a salient theme identified by the women in this study and did not seem to affect pregnancy outcomes, participants' poor experiences with care may have a cumulative effect, along with a number of factors disproportionately experienced by marginalized women. Participants noted other examples of how they were treated poorly in accessing prenatal care, yet they attributed this poor treatment to other dimensions of their identities (e.g. history of drug addiction, socioeconomic status). While these women did not report their experiences as barriers to accessing care, such triggering experiences may yield major obstacles for other women attempting to navigate otherwise challenging systems of prenatal care.

The importance of continuity of care was also highlighted by this study. The participants felt that preconceptionally, they were ill-informed about pregnancy and the ways in which to maximize their health prior to pregnancy. An example of this was that unless they had experienced a poor birth outcome with a previous child, most participants were ill informed about folic acid. Though most women experienced disjointed care, participants perceived the healthcare system holistically, often incorporating stories about their prenatal care, birthing



experiences, and children's pediatric care. In order to improve women's overall health, particularly that of low-income women and women of color, and to improve birth outcomes, a well-integrated system of care is needed for women over the life course, including preconceptional, prenatal, perinatal, and interconceptional care (Wise, 2008). If women had better integration of care, they may be more aware of pregnancy-related risk factors, and more engaged in said recommendations.

Future Research. In order to better assess the prenatal needs of CT women in general, further quantitative study is needed that includes a broader, larger and more representative sample. An interview-format of administering quantitative tools would also likely yield more valid and reliable information than self-administered surveys. Specifically, in order to prevent poor birth outcomes more effectively, it may be useful to better understand the specific experiences of those women who have lost an infant, have had babies with LBW and VLBW, preterm births, and/or who received prenatal care late or not at all. For such a study, a key informant approach would be warranted with a purposive sample. In order to address a limitation of this sampling strategy, it may be valuable to target women who were not as well connected to supportive services during pregnancy, or post-partum.

It is important to note that self-reported experiences with racial discrimination, particularly covert racism, is a difficult construct to measure. Since each individual only knows her own life experience, assumedly she has nothing to compare that experience to; thus a person may clearly recognize that she is being poorly treated without necessarily being able to identify that such mistreatment is covertly attributed to her race. Perhaps too, due to protective cognitive dissonance or denial, marginalized people may not consciously associate poor treatment with being racially discriminated against. In an attempt to mitigate these challenges in this study, a focus group format was chosen which could yield more of a consciousness-raising process and safety among participants. All but one focus group was homogeneous with regard to race or ethnicity. Nonetheless, participants did not report perceived racial discrimination in their healthcare. Additional, heterogeneous focus groups with participants of different races or ethnicities could potentially yield more critical consciousness about perceived differences in the quality of care and possible experiences with racial discrimination.

CONCLUSION

This study of the prenatal care experiences of low-income, women of color was informative. The findings in many respects, confirm existing literature with regard to women's personal and structural challenges to receiving care, as well as the women's primary motivating factor for pursuing and prioritizing care – the health of the child. The findings also add insight into the perspectives of patients who are part of demographic groups which suffer from health disparities, about their prenatal care experiences. Such insight may be critical for improving the prenatal experiences of such women and reducing disparities in birth outcomes.

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APPENDIX A: FOCUS GROUP SEMI-STRUCTRED DISCUSSION GUIDE

[Prior to the discussion, participants first self-administered the Demographic and Prenatal Care Survey.]

The survey you just completed asked you to describe yourself and explored your experiences with your prenatal care providers (doctors, nurses and midwives) and their staff. Now we'd like to further explore some particular aspects of the survey.

Think about your prenatal care experience with your prenatal care provider(s):

- Does or did your prenatal care provider(s) support you during your pregnancy? If so, in what ways? If not, why do you feel your prenatal care provider(s) did not support you? Do or did you feel like your pre-natal care providers know or knew you?
- 2) Does or did office staff (the people at the desk) support you during your pregnancy? If so, how? If not, why do you feel they did not support you?
- 3) Does or did anything prevent you from receiving the services that you needed? If so, what was it? [*Ask participants to complete the Barriers to Prenatal Care Survey.*]
- 4) Please think about racism and discrimination for a moment.
 - When you think about "racism," what comes to mind?
 - When you think about "discrimination," what comes to mind?
 - In what ways does or did racism and/or discrimination affect your prenatal care experience?
 - Have you ever avoided going for care during pregnancy because you felt you were being discriminated against? If so, please tell us more.
- 5) What if anything could have been done differently to improve the prenatal care that you received?
- 6) We'd like you to think about culture and discrimination. When you think about "culture," what's the first thing that comes to mind?
 - Do you think a woman's culture could affect her decisions about prenatal care? If so, how?
 - Do you think discrimination could affect a woman's decisions about going for prenatal care? If so, how?
- 7) Now we're going to do something a little different. We're going to show you a list of things thought to be related to pre-term births. Please take a few moments to think about them. Then, on the piece of paper that we're giving you, indicate if you knew about any of them. [*Participants self-administer The Survey of Risk and Protective Factors for Pre-Term Births.*]
 - What could be done so that more women would know about these risk and protective factors?
- 8) Finally, before we close the discussion, do you have any last thoughts about your pregnancy experience that you would like to share?

Thank you for sharing your thoughts and experiences with us.

