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

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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

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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 mircoaggressions 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