Birthing While Black: The Maternal Health Experiences in Kansas

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Abstract

The state of maternal health and infant mortality in the United States is far worse than 33 developed countries (CDCP NCHS, 2018). Black mothers and infants die at twice the rate in comparison to mothers and infants of other races (CDC, 2020). Infant mortality is the death of a child before the age of one. The Sisters and Brothers for Healthy Infants Initiative focuses on education, community engagement, elevating the voices of Black mothers and fathers, and a community birthday party to celebrate Black infants first birthday. This signature event is known as Celebrate Day 366, a day to share information Black infant mortality, co-parenting, and fatherhood, conduct a community conversation on birth equity, and celebrate Black babies first birthday. This paper reflects the results from a panel discussion of community members and stakeholders in Kansas sharing their experiences with maternal and infant mortality. The Health Equity Framework four main components (systems of power, relationships and networks, individual factors, physiological pathways, that are integral to the inequities in maternal health and infant mortality was used to guide our research analysis (Peterson, et. al 2020). As a part of the qualitative content analysis, five themes emerged: 1) stress during pregnancy; 2) advocacy; 3) innovation of technology not equating to health equity; 4) realization of inferior care; and 5) racism and stereotypes. The themes reflected similar lived experiences amongst Black mothers, fathers, and physicians surrounding maternal health and infant mortality inequities. The results of the CD366 panel discussion highlight the importance of exploring how, if at all, Black mothers and fathers, are benefiting from the birthing experience.

Keywords

Community Engagement; Infant Health; Maternal Health; Prenatal Care

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ABSTRACT

The state of maternal health and infant mortality in the United States is far worse than 33 developed countries (CDCP NCHS, 2018). Black mothers and infants die at twice the rate in comparison to mothers and infants of other races (CDC, 2020). Infant mortality is the death of a child before the age of one. The Sisters and Brothers for Healthy Infants Initiative focuses on education, community engagement, elevating the voices of Black mothers and fathers, and a community birthday party to celebrate Black infants first birthday. This signature event is known as Celebrate Day 366, a day to share information Black infant mortality, co-parenting, and fatherhood, conduct a community conversation on birth equity, and celebrate Black babies first birthday. This paper reflects the results from a panel discussion of community members and stakeholders in Kansas sharing their experiences with maternal and infant mortality. The Health Equity Framework four main components (systems of power, relationships and networks, individual factors, physiological pathways, that are integral to the inequities in maternal health and infant mortality was used to guide our research analysis (Peterson, et. al 2020). As a part of the qualitative content analysis, five themes emerged: 1) stress during pregnancy; 2) advocacy; 3) innovation of technology not equating to health equity; 4) realization of inferior care; and 5) racism and stereotypes. The themes reflected similar lived experiences amongst Black mothers, fathers, and physicians surrounding maternal health and infant mortality inequities. The results of the CD366 panel discussion highlight the importance of exploring how, if at all, Black mothers and fathers, are benefiting from the birthing experience.

Keywords: Community Engagement, Infant Health, Maternal Health, Prenatal Care

INTRODUCTION

In the US, babies are dying at a rate of 5.9 per 1,000 live births (CDC, 2018). Infant mortality is the death of an infant before their first birthday (CDC, 2020). In the United States, infant mortality rates are the highest compared to other developed countries (CDCP NCHS, 2018). The United States is 33rd of 36 countries within the OECD (CDCP NCHS, 2014). Other developed countries have an average of 3.9 deaths per 1,000 live births; even the states with the lowest infant mortality in the United States, New Hampshire and Vermont, still rank higher than 25 other countries (CDCP NCHS, 2014). It is evident there is an infant mortality crisis within the United States.

All babies are not dying or experiencing birth the same way. The infant mortality rate for Black infants is 10.8 per 1,000 births, while it is 4,9, 4.6, and 3.6 per 1,000 births for Hispanic, Non-Hispanic White, and Asian infants, respectively (CDC, 2020). Similarly, to other health inequities in the United States, Black infants experience disproportionate poor outcomes. The infant mortality rate for Black infants is 2.3 times higher than the IMR rate for White Infants (MH HHS, 2021). Black infants are four times more likely to die compared to White infants due to complications of low birth weight (MH HHS, 2021). Even more concerning, In Kansas, the infant mortality rate is highest for Black infants (11.9), compared to whites (5.7) and Asian/Pacific Islanders (3.1) (March of Dimes, 2019).

According to a Kaiser Family Foundation analysis of CDC Wonder Data, 14% of infants die in under an hour post birth, while 26% die between 1 -23 hours post birth, 13% die 1-6 days post birth, 13% die 7-27 days, and the highest percentage of infants, 34%, die 28-364 days after birth (Peterson-KFF, 2017). The health disparity gap for birth outcomes is not isolated to infants. For Black women particularly, the maternal mortality rates are astoundingly higher than those of other races. For pre-term birth, the rates of Black mothers and White mothers shows an astounding disparity of 14.39% and 9.26%, respectively (Peterson-KFF, 2017).

Without discounting the incredible impact social determinants of health (SDOH) have on adverse health outcomes, concerning pre- and post-natal care, structural racism is a driver of poor health outcomes (Taylor JK, 2020). Surrounding poor maternal and infant health due to less culturally competent care, less access to qualified services, historical mistreatment in the healthcare system (Taylor JK, 2020). The Sisters and Brothers for Healthy Infants Initiative (SBHI) was created in collaboration with local graduate chapters of historically Black fraternities and sororities (known as the Divine 9). This initiative was formed to create a consensus among organizations with the like mindedness of addressing the infant mortality disparity in the State of Kansas. Members of local graduate chapters of Historically Black Fraternities and Sororities convened to leverage their presence in the community to engage other community members and advocates in bringing awareness to the infant mortality crisis.

The main goal of the coalition is to establish awareness surrounding Black maternal and infant health disparities and elevate the voice of Black mothers and fathers, SBHI hosts an annual weekend event to celebrate Black babies' first birthday. Known as Celebrate Day 366, the celebration is held in the community and provides information and creates awareness of Black infant mortality. To engage the community, a panel was organized to share individual and collective perspectives on the state of Black babies and parents in the state of Kansas. The panel unpacked how **stress, racial discrimination**, and **inequities give way to poor maternal and infant health and mortality outcomes**. This panel consisted of mothers, fathers, physicians, and advocates with the aim of **sharing firsthand experiences** of those having babies, **personal stories**

of infant death, and **ideas on what is needed to build a network of advocates**. This publication expands on the research process used to analyze the concepts explored during the panel discussion and findings related to maternal health and infant mortality.

Health Equity Framework

The Health Equity Framework defines "health equity" as having the *personal agency* and *fair access to resources and opportunities* needed to achieve the best possible physical, emotional, and social well-being." (Peterson et. al,l, 2020). The health equity framework considers outcomes from a population perspective, not individual perspective (Peterson et. al, 2020). The four tenets of the framework are centered around personal agency in the healthcare experience (Peterson et. al, 2020). The tenets are as follows: 1) Systems of Power, 2) Relationships and Networks 3) Physiological Pathways and 4) Individual Factors (Peterson, et. al., 2020). Our research directly connects to the Health Equity Framework as it elevates the firsthand systemic, physiological, and individual Birthing experiences of Black physicians, mothers, and fathers.

The Black experience is not a monolith and while it is essential to examine population specific trends, the health equity framework also provides room to acknowledge individual factors. Individual factors are defined as a person's response to social, economic, and environmental conditions that promote health equity through attitudes, skills, and behaviors that enable their personal and communities' health." (Peterson et. al, 2020). Finally, maternal health and infant mortality is a result of the strength of physiological pathways, so it was an essential component to consider in our research. Physiological pathways are factors that promote health equity when a person's physical, cognitive, and psychological abilities are maximized. (Peterson et. al, 2020). As part of the health equity framework, the theme of stress falls into the physiological pathways tenant-requiring more attention on how to alleviate stressful events for African American mothers during pregnancy.

METHODS

This panel included thirteen participants who were mothers, fathers, physicians, and advocates who have experiences related to both positive and negative birthing outcomes. Eighty-eight community members attended the panel discussion. Though normally held in person, the ZOOM video platform was used as a response to the COVID-19 pandemic, and the use of this platform is further discussed upon conclusion. To reach the objective of sharing experiences and ideas to build advocacy, each person on the panel had an equal opportunity to answer a set of semi-structured questions in two breakout sessions. The first sessions included a parental discussion of mothers and fathers to share birth experiences and advocacy. The second discussion focused on Black paternal experiences dismantling stereotypes, and highlighting paternal advocacy. The panel discussions were a collaborative opportunity to hear from an array of voices in the community which uncovered alarming similar experiences surrounding maternal, paternal, and infant health and infant mortality.

Panelist Discussion Guide
1. To help our audience understand concerns of the state or Black mother and fathers in Sedgwick County, in your own opinion, share with us what infant mortality means to you and how it affects the community?

2. Considering black women and infants are 3 to 4 times more likely to die during birth in Kansas regardless of socioeconomic status and education and, what concerns did you have during your child's birth?
3. How do you feel about the Black women are strong stereotype? What can we do as a community to protect Black women?
4. In your opinion, what do you suspect the long-term impact of higher rates of Black maternal and infant mortality and racial discrimination will be on our communities?
5. In your opinion, how do you feel these disparities have impacted Black fathers? (do you feel you are able to advocate for your wife/children's mothers, sisters, and friends?) (How tough has it been to protect your children from systemic racism?)
6. How does the way the world view black men impact the way you raise your sons and daughters? What can the community do to better support, Black fathers?
7. In your opinion, what do you suspect the long-term impact of higher rates of Black maternal and infant mortality and racial discrimination will be on our communities?

Analysis

The panel discussion was led by a facilitator (SS) and was recorded on a Zoom meeting platform. Once recorded, the recordings for panel discussions experiences were hand transcribed by study staff to ensure accuracy. After transcription, the research team independently used content analysis to code and create themes from the discussion. Transcripts were coded by three researchers. The team used an iterative process, and conducted initial open coding of the transcripts, followed by a team discussion of our initial codes and findings. A code book was created to help with the second round of axial coding. During the second round of coding, five major themes emerged from the data during a discussion where consensus was reached an agreement of findings occurred.

RESULTS

Five themes were present throughout the discussion; 1) stress during pregnancy; 2) advocacy; 3) innovation of technology not equating to health equity, 4) realization of inferior care; and 5) racism and stereotypes. Themes were derived from using content analysis to conduct extensive coding of panelists reflections and discussion during the event.

For the stress during pregnancy theme, the perspectives of mothers and fathers were particularly integral to theme development. Participants described *Stress during pregnancy* as a physical, mental, or emotional feeling of strain, discomfort, and disruption during the prenatal period. One participant stated the following regarding the stress of COVID-19 during pregnancy, "So as a Black woman as it is, and as a Black pregnant woman, … we just carry a different burden. And so, we may hear those vaccinations are safe, there may be data to prove it, but we just still have that fear." Another participant stated, "…it's already fear associated with it [pregnancy] because you the woman has to get through the pregnancy with low stress, nourishment, and you have to go out into society to where people stereotype you as a Black women..." Stress in a variety of forms is detrimental to fetal development and maternal health. A Black mother on the panel talked about the toxicity of stress. This panelist stated, "Yeah, it just, it really does seem never-ending and it's so much added stress on top of what we already have [being pregnant and societal pressures]...". Stress is also felt by the partner or father, "…it was a wakeup call having a daughter

that was in the NICU for 30 days. I was faced with the reality that I could be raising my daughter by myself if my wife didn't make it,"

The theme of advocacy emerged from many of the statements made by the panelist in their descriptions of fighting to get the best care for themselves, their wives/partner, and their patients. This theme includes the importance of both self—advocacy and advocacy for others. We define as identified advocacy as physical, mental, and emotional support that from a party external to the birthing person and/or infant. Birthing persons can only self-advocate to a certain extent for themselves and their infant during the pre-birth, birthing, and post-birth experience. This was supported by our physician panelist who stated the following about her patients, "…training-wise something that I do have to think about is, moving forward as a physician is potentially, like if something like this happens again, like how can I be like a spokesperson for like my future patients or like learn from some of the mistakes that happened early on in the pandemic that, so they're not repeated in the future." Other panelists talked about the importance of a support person in the room, the impact this can have on their care, "... having that support system that will speak for us when maybe we don't have the words to say or we haven't even thought about something that far ahead would really help us feel more comfortable, maybe not be so isolated." While another panelist, who recently gave birth talked about the importance of doulas, particularly given the new COVID-19 restrictions, "I really feel like having that support person, doulas are very needed, especially because they are the ones that are able to go into the hospital, they don't count as your one person now."

The third theme that emerged was innovation of technology not equating to health equity. Panelists noted disappointment that innovation, usage, and access of technology has not produced positive results for Black maternal or infant mortality. Participants reflected on their concern with the increased use of modern technology to improve health outcomes, but lingering dismal maternal and birth outcomes for Blacks. One panelist mentioned the importance of modern technology to communicate with patients, ".... It kind of just puts in the, like we did a lot of telehealth this year and it puts the importance of like listening to your patient and actually hearing what they have to say because you can't see, you can't see what's wrong, so it's like really just listening and understanding what's wrong." (OB/Gyn Physician Panelist).

The fourth theme, "realization of inferior care" acknowledges the weight birthing people and their family members experience as a result of inequities in the birthing experience. One panelist stated, "As a Black woman who gave birth to a Black daughter, I had a horrible experience, and I'm from the healthcare community so I would have expected differently, right, but terrible experience." Similar experiences were related by panelists who were not in the medical profession, "just treat me the same... I know we're different because of color, race, culture, whatever, but just, we just want to be treated fairly and treated the same as everybody else," The fathers on the panel also shared their concerns about their wives care, "but when our women, when your wife is going into surgery or going to the hospital and she's pregnant, you want her to get the same attention or the same service, or whatever you want to call it, as, as their White counterpart." Another father stated, "You know, you don't want, I don't want my wife to go in there and she says she's in pain and you put her pain level at a level three where someone else says they're in pain and you put it at a level seven or eight." Panelists also talked about the differences in care, noting some friends have more medical team support depending on where they live, "she lives in Denver, and so she was mentioning how in their healthcare system they have home health nurses that come to visit

pregnant women weekly outside of their monthly rotational appointments." Stating this additional level of care should be standard.

The final theme that emerged is racism and stereotypes. Many of the panelists expressed their concern and experiences in dealing with racism in general, these experiences are ever present even when seeking healthcare. One father stated, "being a Black man and being a Black husband, and the stereotype is that we're bigger, stronger, faster, we can deal with more pain, we can deal with whatever life brings us, and unfortunately we have, we have dealt with things that were unfair." One of the panelists wanted to dispel historical stereotypes mentioning a study they read on the high involvement of Black fathers in their children's lives, "First thing, you know, is that according to a study by the Centers for Disease Control, Black fathers were the most involved with children no matter if they live with them or not..."

DISCUSSION

Infant mortality is an indicator of the health of a community and our nation. The disparate Black infant mortality rate in the United States is an indicator of a lack of well-being not only for a special community of people, but for the nation. Our study takes a glance at the issues driving infant mortality rates and poor maternal outcomes from the perspective of the physician, patient, and fathers/partners. Overwhelmingly, our findings indicate Black men and women going through pregnancy experience obstacles to equitable healthcare. Five major themes emerged from the Celebrate Day 366 panel discussion: stress during pregnancy; 2) advocacy; 3) innovation of technology not producing results, 4) realization of inferior care; and 5) racism and stereotypes. These major themes were marked with individual experiences in the healthcare system, not only from patients but providers who took part in the panel discussion.

Stress is one of the first themes we uncovered from the panel discussions. This fits within the healthy equity framework for the impact stress can have physiologically. Pregnancy is a natural time of stress. However, there is an added layer of stress the panelist expressed because of their race/ethnicity and their interactions with their healthcare team.

It is well documented that physiological stress can lead to chronic health problems as well as poor birth outcomes (Jackson, 2005). Geronimus (1992) has established the weathering hypothesis, which clearly details the impact stress can have on the body for African Americans. For many Black women, this stress is often tied to discrimination and racism (Jackson, 2005). Other studies have found the impact of stress during pregnancy can lead to low birth weight, premature birth, compromised immune systems for both the mother and baby (Dominguez, 2008 and Taylor, 2020). Stress was felt by our panelists, both mothers and fathers, in terms of their physiological stress, emotional health, and overall well-being. While similar studies have documented pregnancy as a stressful life event, our findings provide a new perspective for Black women and provides insight to where we need to further intervene. Without intervention, maternal and infant health inequities will continue to rise resulting in more infants born at low birth weight, premature, and health consequences for the mother. To improve birth equity, this is an area to intervene in before deleterious results occur.

The realization of inferior and disparity care can be burdensome and a harsh reality to face amidst a plethora of emerging new experiences. Especially when health care staff are tasked with the responsibility of care above all else. Many of our panelists spoke of their experiences and the perception of receiving inferior care or at least biased care. Similar findings were found in Wang,

Glazer, Sofaer, Balbierz, & Howell (2021) who found Black and Latina women felt unheard during their pregnancy care and felt they experienced bias.

The theme on innovation of technology not producing results addresses the assumption that maternal health and infant mortality outcomes should be improving as our society obtains more technological advances. Not only is that assumption dispelled by the startling statistic that the United States ranks 33rd of 36 developed countries, but it can also be addressed by the qualitative evidence found throughout the CD366 panel discussion (CDCP NCHS, 2014). However, this theme ties to a larger issue around receiving inferior care and systems of power which is part of the health equity framework. If there are advances in treatment and technology to improve maternal outcomes and birth outcomes and the disparities still exist, then the issue is equity. Having perceived limited access to health care advances that can improve or save lives has become an issue of advocacy which emerged within the panel discussion.

Advocacy is one of the most critical themes our work uncovered. The issue of advocacy ties indirectly to the other four themes. Previous literature called for technology to be an asset is supporting women and infants to reduce poor health outcomes related to maternal stress. (Gortmaker et. al, 1997)_The reasoning for this is clear, patients who can successfully advocate for themselves within the healthcare system may experience less stress, while benefiting from more advanced care, even when faced with systemic racism.

Self-advocacy also requires substantial health education and/or literacy, which may not always be available in an equitable way. A study that evaluated health literacy for low-income mothers of infants revealed that 72% of their n=186 participants had low health literacy, which positively correlated with with education, household income, language, social support, parenting self-efficacy, and early parenting practices. (Lee, 2018). For this reason, advocacy from additional sources is critical to the pregnancy and birthing experience. Additional sources may include family, friends, doulas/birthing supporters, or critical birth care staff. The inability to be your own advocate can result in compounded stress. Panel participants told anecdotal stories of their experiences being ignored in a healthcare setting regardless of their education or social status. The inability to have their voice and health concerns heard by their healthcare team was a common occurrence among panelists who were patients, including those with a medical background (OB/GYN). Fathers who participated on the panel also indicated their personal struggle to advocate for their wives/partners during childbirth. _Being an advocate for your own care does require some personal agency, which is another tenant of the health equity framework.

There is evidence in the literature of the benefit of parental involvement in birth (Alio, (Kornosky,et al., 2010). They found father absent births were more likely associated with premature or low-birth weight births. The risk of prematurity and low-birth weight were even greater for Black women when the father is absent. Our research contradicts the literature that partner support is not significant for prenatal and maternal health and experiences of Black women (Straughen et al, 2013). Our panelist discussion provided important perspectives on paternal involvement during pregnancy and the birthing process. Fathers on our panel were concerned about the stigmatization that often accompanies Black men and how they experience this in the health care system and at the prenatal appointments. However, they also talked about how important it is for them to be involved in the process. Black fathers in our panel really embraced the final tenet of the health equity model which is the relationships and networks of support. While one of our final major themes is centered on stereotypes, it is important to acknowledge and create spaces for Black fathers to continue to be advocates in the birthing process, have a presence to

maintain good birth outcomes and cultivate their involvement to help improve health equity in this area.

Finally, the fifth theme "racism and stereotypes" draws the connection between health equity and racial injustice. There is a consensus in the literature that racism and discrimination is a determinant for poor birth outcomes for Black women and infants. Dominguez, Dunkel-Schetter, Glynn, Hobel, and Sandman (2008), proved there is a direct correlation between discrimination and infant birth weight. Racism can also be a driver for infant mortality risk because of the connection with stress and access to culturally competent care. Statistics show most Black people living within the United States expect their experiences with the healthcare system to be met or impacted by covert or overt racism (Nong, 2020). Our panelist confirmed this reality by sharing their birth experiences stories. The literature shows this reality is present for many Black birth persons. (Taylor, 2020) Like other races, Black birthing people only have personal or shared accounts to prepare for the journey to motherhood and labor process. However, unlike their counterparts, care interactions are cluttered with racism, often rooted in stereotypical biases. The literature, along with our research, substantiates that racism is leading to maternal stress and further perpetuating disparate health outcomes. Our research calls for additional support, resources, and engagement with providers to improve maternal and infant health outcomes.

Limitations

Our panel discussion was set in a virtual format due to COVID-19. Even with this limitation for direct in-person interaction amongst the panelist and audience, the authors believe we have captured a rich set of data on our derived themes. In addition, our work examines disparate Black maternal and birth outcomes and intentionally elevates the voices of the father on these issues. While this panel is a start to that process, we wanted to understand the impact of paternal presence on birth outcomes for Black women and infants. For future work, we will recruit a greater number of fathers to increase our knowledge in this area. Finally, there are always limitations to a study, particularly when collecting individual perspectives. While we cannot generalize to all Black women and fathers who experience negative birth outcomes, this does provide a snapshot in time of specific experiences and a path to follow to learn more from this population.

CONCLUSION

The healthy equity framework can help inform future work on areas of birth equity for Black mothers, fathers, and infants. The findings of our study are a continuation of some established issues in the literature. However, the information we have learned from Black fathers in this study is important. Using the health equity framework to consider ways to intervene or enhance the scope of the current work will be important to execute With modern advances in health care, Black women and infants are not benefitting. We also learned from our panelists the importance of providers including Black fathers in the pregnancy and birthing process. The importance of advocacy was a strong theme through this paper. Future work in this area within the medical field, research, and community practice needs to figure out how to best intervene on the issues that continually require patients to self-advocate when circumstances do not allow them to advocate. Finally, the issue of racism, stereotypes, and systemic racism is lingering. Improved training in culturally competent care by providers and health care systems is needed, birth equity training to reduce bias and racism, and an equitable care model is needed.

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