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Using Focus Groups to Understand Racial Disparities in Infant Mortality

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Introduction

Infant mortality, the death of a child before 12 months of age, is a significant and devastating public health problem in the United States that disproportionately affects Black children. The burden of this racial health disparity is distributed unevenly across the country, even at the county and city level. Michigan has the 2nd highest Black infant death rate in the US with 13.1 infant deaths per 1000 live births (CDC, 2015).

Within Michigan, Kalamazoo County has the 4th highest Black infant death rate with an approximately 4:1 ratio between Black and white infant deaths. In response, a community initiative (Cradle Kalamazoo) was created to reduce these devastating racial health disparities. As part of that initiative, we sought to understand to understand the phenomena from the perspective of community stakeholders.

Methods

We conducted focus groups with: low income at-risk women in the community, women who had direct experience with infant mortality, and health and social services providers who work with families during the perinatal period. A total of ten focus groups, with 59 individuals, were conducted: Two focus groups (n = 12) recruited at-risk women from a domestic violence shelter and from local home visiting services. Three focus groups consisted of community members who had experience with infant mortality (n =25), and five were health professionals (n = 22) of various racial/ethnic and gender identities. Focus groups were recorded, transcribed, and qualitatively coded using principles of grounded theory.

Results: Community

Many of the community members who attended the focus groups were willing to share their thoughts and beliefs about the causes of infant mortality among Black infants. The main themes they discussed were safe sleep, maternal health behaviors, concerns about healthcare, and finally stressors faced by pregnant women and mothers.

Selected quotes from community members are provided below.

Safe sleep

Inaccurate beliefs about safe sleep:

“It’s the way their esophagus and for when they throw up, like if they spit up, cause if they’re on their back they can choke.”

Conflicting information from providers about safe sleep:

“Now they sell these rocker sleepers in the store now, the hospital told me it was fine for the baby to sleep in there but my nurse that comes in said that it’s not okay.”

Difficulty engaging in safe sleep:

“I think that’s what is probably really dangerous. It’s that the baby wants to be up and you’re like I really need to sleep.”

Maternal health behavior

Perception of invulnerability to risk:

“I’ve got 4 kids, um my first one, I didn’t smoke, his dad smoked, and I know this is bad, I picked up my first cigarette when I was 7 months pregnant with my second child, and they’re healthy, smart, beautiful... they have no complications at all. I smoked with my child and it was fine.”

“My babies just sleep in the bed with me. I haven’t had a problem, this is my fifth baby.”

Misinformation about the effects of maternal health behavior on child development:

“There haven’t been no studies showing that marijuana has like a bad effect.”

“I feel that everybody is different and that is one of the unfortunate things. Someone can smoke and have problems and someone can smoke and no problems.”

Healthcare

Negative feelings about prenatal care appointments/feeling like concerns were dismissed

“I hate when they do those appointments when you come in there, you sit down for a long time and they come in and all they do is listen to the baby heartbeat and then you leave.”

“... at mine all they say is that I was fat and come to find out I was preeclampsia and gained 100 pounds.”

“But they try to make it seem like there was nothing wrong with me and I’m like hey.. I’m in pain something’s wrong... And I kept going in and kept going in, and they, Oh, there’s nothing we can do, and then come to find out it’s blood in my baby’s placenta.”

Distrust of the medical system/perceived racism and classism

“What if there is somebody back in the lab that says oh you know, I don’t want the population to grow in this race?”

“Or because low income, they trying to profile us, you know on our income, they don’t care.”

Frustration with lack of follow-up from home visitors

“...And then she never brings it...I don’t know, she might be keeping it for herself or something. So.. cause she always told me she was going to come and bring it and I never see her. And then when she come back and I remind her...And she’s like oh yeah, I’m going to get it to you. And then you don’t see it.”

Results: Providers

Providers expressed beliefs about the causes of infant mortality as being systemic and multifaceted. Many healthcare providers shared a common perception that both racism and toxic stress play a role in infant mortality. Finally, they reported a sense of perplexity and a growing belief about shared responsibility for Black infant mortality. Selected quotes are provided below.

Systemic

“It’s almost like how we kept trying to pull up out of the swirling cycle there... its almost daunting just to think about it because its not about one factor or another it is so huge and systemic.”

“That’s what makes it so challenging is because you can’t say ‘Oh, I can fix this and that will fix it.’”

Toxic Stress and Racism

“I truly believe that it comes back to racism and the stress with racism. Waking up everyday and thinking that you’re a certain color and how that impacts you going into a place to receive services or how you’re treated or the trust for your doctor or the trust of the people giving services to your baby.”

“I’ve had a lot of trauma in my life but I don’t know what its like to be a person of color. There just are no breaks from it, and I think their stress and chronic trauma is there and perpetuates, it’s just compounding everything.”

Grappling with “Why”

“Well, you look at the Kalamazoo community, and the supports are there...A lot of them seem to be connected...But it seems like it’s there, yet we still have this huge disparity between ethnic and racial groups and that’s just—it’s hard to fathom why.”

“It sometimes feels like as healthcare providers we’re missing something. It feels like there must be a way to do it better. Because the data is irrefutable.”

“That’s the hard part. That’s the puzzle, because we feel like we are giving the same level of care and the same chances and the additional resources and the programs. So why are we still failing? Where are we losing these babies?”

Discussion

Both community members and health professionals highlighted the role of systemic racism in black infant mortality. Based on these data, we recommend coordinated and strengthened efforts by organizations that provide healthcare to pregnant women to increase providers’ cultural competency. Organizations may benefit from anti-racism training for administrators and providers, as well as continuous monitoring and quality improvement informed by client data (i.e., clients’ perceptions of services). Another potential solution may be hospital-based advocates for Black and low-income women to help ensure that they receive the services they need and deserve.

