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# Using Focus Groups to Understand Racial Disparities in Infant Mortality



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# Introduction



- Infant mortality is a significant public health problem in the U.S.
  - 23,440 infants died in 2013 (6 per 1,000 live births)
- Significant racial disparity
  - Nationally, African American infants are 2 times as likely to die than are white infants
  - The disparity in Kalamazoo is significantly higher
    - ratio of 4.5:1
- Cradle Kalamazoo - local initiative to reduce racial disparities in infant mortality
  - Need to include the voices of at-risk women

# Study Aims

- Gather data on perspectives of community members and health professionals about:
  - the causes of infant mortality in our community
  - ways to reduce racial disparities in infant mortality



# Methods

- Ten focus groups, 59 total individuals
  - Two focus groups ( $n = 12$ ) recruited at-risk women from the YWCA 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.
- Participants drew upon their experiences to describe the scope and nature of the problem, including its determinants and consequences, and made recommendations for action.

# Community Member Results: Primary Themes

- Safe sleep
  - Inaccurate beliefs
  - Conflicting information from providers
  - Difficulty engaging in safe sleep
- Maternal health behavior
  - Perception of invulnerability to risk
  - Misinformation about the effects of maternal behavior on child health
- Healthcare
  - Concerns about anti-nausea medication
  - Negative feelings about prenatal care appointments
  - Distrust of medical system and perceived racism and classism
- Stressors
  - Financial
  - Children
  - Unplanned/unwanted pregnancies

# Negative feelings about prenatal care appointments

- “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.”
- Feeling judged by providers/ providers were rude
- “And, every time, ‘oh, you’ve gained a lot of weight. You understand that it is only 32 pounds in the average birth?’ I didn’t want to go anymore, they need to be more positive instead of saying that.”
- “... at mine all they say is that I was fat and come to find out I was preeclampsia and gained 100 pounds.”



# Negative feelings about prenatal care appointments (cont'd)

- Providers missing/dismissing medical complications
  - “No I’m just saying like cause I had a doctor through my first trimester and I was in pain, a lot of pain, and she was just telling me that it was, it was just my uterus or something... Yeah contracting and stretching and I was like no something is really wrong and then I found out that in my second trimester that I had blood in my baby’s placenta and they called it placenta previa or something like that”



# Distrust of medical system and perceived racism

- Perception that there is hidden racism in the medical system
  - Concerns about efforts at population control and that doctors may intentionally try to make you sick
    - “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?”
  - “Why [are] black people the only people that get sickle-cell?”



# Themes from Health Professionals



# Causes - “It’s Not Just One Thing”

## The causes are 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.”
- “Almost without fail, they have been abused as children, um, sexually, emotionally, and physically. And it’s just constant. But it’s not always sexual, sometimes it will be emotional, and ‘Well, I got hit so I’ll go here,’ and it just goes on and on and on. It’s the only interactions they have had with men and how their moms have interacted with them their entire lives, and it’s just what they are used to, and I think that plays a huge piece of what we see...”  
“That’s what makes it so challenging is because you can’t say ‘Oh, I can fix this and that will fix it.’”
- “...it was compound stress. It wasn’t just that one thing.”
- “Safe sleep is a result of other things. It’s a stem of the root of the cause.”

# Causes: 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 remember talking one time to a quite large African American male . . . .and I said to him, you know, I was talking to him about trauma, you know just the symptoms of trauma and the experience, and he said ‘Trauma? You’re talking to me about trauma? My whole life has been nothing but trauma. For me, I’m used to trauma, that’s my norm’ .”
- “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’s hard, you know, how do you tell what factors lead up to why a child dies? I would say it’s got to be different in every one, and again it’s why does it seem to happen in this group so much more than in another? What’s different about them aside from the color of their skin?”
- “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.”
- “Except when the statistics come out, we find out it’s four times the number of black babies that are dying than white babies. How is that happening?”
- “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?”
- “What’s wrong? What are we missing?”

# Conclusions



- Both community members and health professionals highlighted the role of systemic racism in black infant mortality
- Community members expressed
  - Some dissatisfaction with their prenatal care experiences
  - A perception of the presence of systemic racism and classism that influenced their health care experiences
- Providers expressed
  - The causes of infant mortality are systemic and multifaceted
  - Racism and toxic stress play a role in infant mortality
  - A sense of being perplexed about the solution to black infant mortality



# Thank You



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Participants of YWCA and Infant Mortality focus groups

YWCA Kalamazoo

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Cradle Kalamazoo

<http://cradlekalamazoo.com>