Using Focus Groups to Identify Ways to Reduce Infant Mortality in Kalamazoo

Leah Dries, Ariel Berman, & Amy Damashek
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

• Local initiative to reduce racial disparities in infant mortality
  ▫ Need to include the voices of at-risk women
Present Study

- Conducted focus groups with at-risk women in Kalamazoo to hear
  - their thoughts about ways to reduce infant mortality
  - reactions to the Steering Committee’s goals
Methods

• Participants in the focus groups included residents of the YWCA Kalamazoo domestic violence shelter, as well as women enrolled in home visiting services.

• Both focus groups were held at the YWCA Kalamazoo.
  ▫ Focus groups lasted 90 minutes.

• Focus group participants each received a $25 gift card.

• Groups were audiorecorded and transcribed.
Demographics

- 13 participants in total
  - 6 participated in the YWCA focus group
  - 7 participated in the home-visiting focus group

Racial Identity

<table>
<thead>
<tr>
<th></th>
<th>African-American</th>
<th>Biracial/Multiracial</th>
<th>Caucasian</th>
<th>Other</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>8</td>
<td>1</td>
<td>3</td>
<td>1</td>
</tr>
</tbody>
</table>

Highest Level of Education Achieved

<table>
<thead>
<tr>
<th></th>
<th>Some H.S.</th>
<th>H.S. Graduate</th>
<th>Some College</th>
<th>College Graduate</th>
<th>Other</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1</td>
<td>6</td>
<td>4</td>
<td>1</td>
<td>1</td>
</tr>
</tbody>
</table>
Employment

- Unemployed
- Employed Part-Time
- Employed Full-Time
- Disabled - not employed
- Home-maker
- Other
Gross Annual Income

- 8 of the 13 participants reported a combined household income of less than $5,000

- The remaining 5 participants reported a combined household income of between $25,000 and $54,999 annually
Focus Group Questions

1. How do you think we can reduce infant mortality in Kalamazoo, especially among black infants?
   a) How can health care staff (e.g., hospital staff, doctors’ offices) help?
   b) How can social agencies help?
   c) What other agencies or groups can help?

2. What are some ways that we can better support pregnant women and those who have just given birth?
   a) How can health care staff (e.g., hospital staff, doctors’ offices) help?
   b) How can social agencies help?
   c) What other agencies or groups can help?
3. Representatives from several groups in Kalamazoo have been meeting to try to figure out how to reduce rates of infant mortality in Kalamazoo. Some strategies that the group has discussed include:
   a) Reducing unintended teen pregnancy by making long-acting birth control free and easily available;
   b) Reducing sexually transmitted diseases among teens;
   c) Reducing smoking during pregnancy;
   d) Promoting good prenatal care and safe sleep practices.
   e) Better coordination of services for women and families;
   f) Providing health care and other service providers with training in cultural competency/ cultural sensitivity.

4. What are your thoughts or reactions to these strategies? Would you add anything, change anything, or take anything out?
Results

- Primary themes involved
  - Safe sleep
  - Maternal health behavior
  - Healthcare
  - Stressors

- Recommendations from focus group participants
Themes regarding: Safe sleep
Inaccurate/confusing information

- 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 hospital providers, home visitors, family, and product packaging
  - “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

- Cosleeping is easier because women are tired at night and just want their infants to go to 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.”
  - “It’s... stressful and then at night you’re like over tired”
Themes regarding: Maternal Health Behavior

Smoking cigarettes and marijuana
Perception of invulnerability to risk

- Despite education about risks regarding infant safe sleep and smoking during pregnancy, mothers believe that they are not vulnerable
  - “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.”
  - “I smoke when I’m pregnant and it doesn’t do anything.”
  - “I feel like I will put a baby on their stomach if there is like nothing in the crib or whatever cause like my niece and nephew slept on their stomach and there’s like nothing wrong with them.”
Resistance to the idea of giving up smoking cigarettes and marijuana

- Smoking of cigarettes and marijuana while pregnant to reduces stress and nausea
  - “I mean they tell you oh, please stop, okay I’ll cut back or else I’m gonna try to strangle somebody.”
  - “Marijuana helped me like from throwing up and it gives me an appetite, like sometimes I can be like if I don’t smoke or something like that I can be like sick like I’m on heroin or something like that, I’m just balled up, can’t move, can’t do nothing.”
Misinformation about the effects of maternal behavior (such as smoking) on child development

- Inaccurate information about the risks of using cigarettes and marijuana while pregnant
  - “The doctor told me it was okay to smoke here and there.”
  - “There haven’t been no studies showing that marijuana has like a bad effect.”
  - “It’s not about what you put in your body.”

- Belief that fate is more responsible for birth outcomes than are mothers’ health behaviors
  - “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.”
  - “It’s just God, if it’s meant to be, it’s meant to be.”
Themes regarding: Healthcare

Medication, hospital experiences and perceptions of health care providers
Concerns about medications

- Concerns about anti-nausea medications
  - including recalls and unpleasant side effects
  - “....Zofran, it started making me like constipated and stuff like that and I didn’t like that.”
  - “They had a recall on that, it was giving kids birth defects, there’s a lawsuit going around.” (regarding Zofran)
  - “Zofran don’t help... and I get sick on Zofran.”
Negative feelings about prenatal care appointments

- Appointments were a “waste of money”
  - “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.”
  - “And then they charge you so much for it.”

- 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”
  
  - “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.””
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?”

- Perception that providers try to shift the blame for infant deaths onto mothers, when it was perceived to be the fault of the providers
  - One mother whose infant had died found that the doctor put the wrong diagnosis on the death certificate
Distrust of medical system and providers and perceived racism (cont’d)

- Concern that doctors are overworked and exhausted and may not provide them with adequate care.
  - “I think one of my kids passed due to the fact the doctor was just tired, and he was ready to go. He was really just ready to go and like, ‘okay just come to my office in 2 weeks’.”
  - “I think the doctors be tired so they just say whatever to get ‘em out. I really do. It might not even be racism half the time, just tired.”
Concerns about the religious nature of the hospital

- Concerns about how hospital religious affiliation would affect the way they and their infant would be treated if there was a medical emergency
  - “I like Bronson better than Borgess. Borgess won’t save the baby, they’ll save you before they save the baby.”
  - “They’ll save you before they save the baby if something were to happen.”
Difficulty navigating the various service systems

- Aid programs often have too many requirements to fulfill in order to get assistance
  - “Okay, yes, I do need a job but right now like I’m going through all of this like can I get a break and just like can I go through this program. I mean, like, help me a little bit, like they want you to do too much for like a lot of stuff that’s not really helping you too.”
  - “Since I’m so far along I don’t have to do any volunteer work, but everybody else would have to do volunteer work... They expect too much for too little.”

- Uncertainty about what is required to get assistance and various services
  - “I don’t get applications. I do everything online, I’m not going to keep going out the house, 9 months pregnant looking for a job.”
Low income women get poorer medical care and the hospital staff are dismissive of their concerns

- The hospitals don’t care about low-income mothers
- “They tell me that I am not eligible for a car seat because my car is not working. But you can’t leave the hospital without your baby without a car seat. They said that I could get on the city bus.”
- “I wasn’t eligible for it because my car was not working ... and they like well how’d you expect to leave the hospital? And I’m like I have family, I have support.”
Gender preferences for providers

- Midwives and female providers are less caring and gentle than male providers
  - “I’d take a male doctor to have a baby all day because they are more caring.”
  - “They less caring, the women doctors are a little bit less. The men, are so gentle and they coach you and they just you know like Dr. X?”
  - “And then the ones even with no babies, oh they the worst.”
Frustration with inadequate follow-up regarding home visiting services

- Home-visiting agencies lack in adequate follow-through with provision of tangible resources and referrals

- “...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.”

- “... And then with a lot of the referrals that they say they goin’ give you, you never really receive them.”

- “And then when I called she’s like oh you’re not a part of the program anymore...Like when I was a part of the program I was waiting for the referral and you never sent it.”
Themes regarding: Stressors

Financial barriers, unplanned pregnancies, teen pregnancy
Financial stress

- Financial struggles and the expense of children/difficulty with insurance
  - “Even with a job though in our society. You cannot provide even living in subsidized housing and having a job and not getting food stamps. You’re not going to be able to provide for your house, especially with a child on the way”
  - “I actually have health insurance and I had to fight to the death. I’m talking hours and hours and hours to get Medicaid. I pay thousands of dollars a year that covers nothing.”
  - “You don’t want to go in and go to the doctor’s appointments because they’re so expensive.”
  - “And after fighting and fighting and fighting... I didn’t want to bring him to his hearing testing. It’s different things like that ‘cause I have to pay for it out of pocket... And when I called it’s like a 300 dollar visit.”
Stress related to having children

- Having children is stressful in a number of ways
  - “I think that it’s just like very stressful having a baby and like the money aspect, obviously, and... just getting things done.”
  - “It’s... stressful and then at night you’re like over tired”
  - “It helps when you got ... [a] big support system and you have people to help you out.”
Unplanned/unwanted pregnancies

• Pregnancies often unplanned and sometimes unwanted
  ▫ Got pregnant while on birth control
  ▫ Difficulty getting access to birth control for teenagers (that it’s not available in a pediatrician’s office)

• “I think that with unwanted pregnancies... they should really like give options to the mothers.”
• “My sister just had a baby, she’s fourteen... she missed her appointment for her birth control... they won’t do a birth control through her pediatrics.”
Recommendations from the women
• Educate other caregivers (other than the mother) about safe sleep.

• Provide people with baby monitors.

• Provide people with information about the SIDS rates in our community.

• Expand home visiting services, specifically Healthy Babies, Healthy Start.

• Provide mothers with information about product recalls.

• Provide child care at parenting classes.

• Provide people with education about options for unplanned pregnancies, such as open adoption.
Recommendations (cont’d)

• Provide a hotline for parents with babies.

• Provide more resources for new moms.

• Have someone who “shadows” infants from birth through 2 months of age.

• Doctors should work shorter hours and get more breaks.

• Provide free birth control to everyone.

• Teach teens about safe sex.

• Weekly checkups and joint focus groups for new moms.
Questions?
Thank you

Western Michigan University, Lee Honors College
Kellogg Foundation
Participants of YWCA and Infant Mortality focus groups
YWCA Kalamazoo
Kalamazoo Infant Mortality Community Action Initiative
Catherine Kothari, Western Michigan University School of Medicine