Emily: I'm Emily Kumler, and this is Empowered Health.

Neel: We should talk about what's going on with black women, but just to paint the whole picture, so there's higher rates of maternal mortality today than 20 years ago[1] for everyone. And it's about 700 women every year are either pregnant, have just given birth, or are new parents who die in the first year of giving birth for every one of them, there's a hundred who have severe injuries. For every one of them, there are thousands to tens of thousands who suffer from physical or mental illnesses that could've been avoided. And for every one of them, there's probably hundreds of thousands who suffer from general societal disempowerment because of the economic toll of being a mom. So that's like the big picture problem. Now, if you are black in the United States of America, that problem is three to four times worse[2] than it is if you're white. And this is true, irrespective of your education, of your income level. That's not what it's about. It's just about being black somehow.

Emily: Full Stop. I think we need to just take a second about those numbers. They're so outrageous and I think part of what isn't well understood is that they're all basically preventable.[3] These are not medical situations that nobody knows how to handle, they're medical situations that are being mismanaged because women aren't being listened to and cared for properly. I feel like birth and death are the two certainties in life and we have completely messed up birth for women where we've now created the situation where rightfully women, especially African American women are terrified and when we start to factor in all of the different things that we should consider when it comes to giving birth, being terrified of your doctor or of the medical establishment should not be one of them. So that was Dr. Neel Shah[4]. He is the director of the delivery decisions initiative at Ariadne Labs. He's also an assistant professor at Harvard Medical School and the vice president of the March for Moms[5]. He's also perhaps my favorite watchdog because he once said to me that you cannot separate women's health from social justice. That so many of the problems in women's health from not being represented in clinical trials to birth and c-sections, which is his area of expertise. Are all intertwined in cultural sort of movements or ways of the ways that women are cared for. So we're going to talk a lot about race and maternal mortality in the United States. Here's Dr Shah.

Neel: I've thought a lot about this and I'm not the expert. I want to stay in my lane too cause I'm not a black woman. Right? So like I think that there's expertise that comes from proximity of the problem that I don't have, but my best understanding as somebody who tries to care for women is I think that our medical training bias in medicine[6] is something that can either work in our favor or not in our favor because medicine is an artisanal craft at the end of the day. And so

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1 https://www.cdc.gov/reproductivehealth/maternalinfanthealth/pregnancy-mortality-surveillance-system.htm

2 https://www.cdcfoundation.org/sites/default/files/files/ReportfromNineMMRCs.pdf

3 https://www.cdcfoundation.org/sites/default/files/files/ReportfromNineMMRCs.pdf

4 https://scholar.harvard.edu/shah/home

5 http://www.marchformoms.org/

6 https://hms.harvard.edu/news/combating-bias-medicine

when a brand new intern in July enters the hospital, all they're expected to do is look at a person and know if they're sick or not. How do you do that without objective information? You basically take all your stereotypes and you jumble them up and you decide like are they pale or not. But of course if you're black, you don't look pale, right? You look different, right? And then every case study you get from the beginning of medical school is, it tells you the race of the person right away and it's so you can start stereotyping and sometimes our biases

Emily: Is that done in a helpful way like this race is more likely to have this kind of condition

Neel: Well yeah, that is how we're taught. But I mean like what we don't do is unpack what it is about the race that does that, right? Is it race or is it racism? Because when you say that it's race, like African American moms are more likely to have hypertension. The assumption in the background is that it's somehow genetic when that's not what's going on necessarily. That there are all these mechanisms. I mean there's this idea of what we call weathering[7], just experiencing discrimination over the course of your life and chronic stress and how that can impact your wellbeing. But then there's just really at the point of service that we profile people and it starts with

Emily: is that like a necessary evil or is that something that isn't necessary? But it's just common practice?

Neel: I think that when it's necessary and it works well, we call it intuition. And when it's not necessary, we might call it bias. But in other progressive workplaces, what we're starting to do is recognize our biases and try to mitigate them. And what we do in medicine actually is we don't even bother with that. We sort of train you to hone your biases and amplify them without realizing that there could be unintended consequences like Serena Williams

Emily: Right and for the perspective of the patient. What do you suppose to do in those situations if you feel like nobody is listening to you?

Neel: It's so hard. You know, cause it's really this vicious cycle when women express their concerns. And by the way, there's not just a racial bias in medicine. There's a gender bias in medicine[8] too. I think that women are heard differently[9] when they express concerns. And I see this not necessarily when women interact with OBs, because of course we primarily take care of women, but when women go into emergency rooms with problems with their pregnancy or if they delivered their baby and then they go back with like a really bad headache, they're young and healthy for the most part except for this, they don't look like the 65-year-old man with chest pain. Right? And so we think about them differently.

Emily: Whereas a headache could be a symptom of what

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[7] https://www.ncbi.nlm.nih.gov/pubmed/1467758
[8] https://www.pnas.org/content/115/34/8569
[9] https://www.theatlantic.com/health/archive/2015/10/emergency-room-wait-times-sexism/410515/

Neel: It could be a symptom of an impending stroke[10]. This is one of the leading causes of death in moms is postpartum preeclampsia[11]. I think about this all the time, like if a middle-aged man walked into an emergency room with chest pain, there is a rule about how quickly they need to be seen[12] and there's a metric for how quickly you go from diagnosing a heart attack to going to a cath lab,[13] which is the treatment. If a woman walks in with a pregnancy complication, there is no rule for how quickly they need to be seen and there's no metric for how quickly you need to respond with the solution, which like there's no other way of looking at it except for through the lens of gender bias.

Emily: I feel like the idea of gender bias in medicine is also interesting because females are now starting to, more women are graduating from med school[14] like does that help that?

Neel: Yes. The vicious cycle is like you go in, you express concerns, you don't feel heard and so you trust the person less

Emily: And you're less likely to go back[15], right?

Neel: You're less likely to go back and that's exactly what we see. I do think it's changing a lot though. I mean with the problem on the race side, a big part of the solution is making sure that we have more, a more diverse workforce and that the people that are taking care of you look like you. This is particularly true in, it's true probably everywhere, but I think about this in places like Memphis, Tennessee, which is like a very impoverished city with a large African American population and somehow very, very few providers of color. That's clearly got to be a big part of the solution. And similarly, I think having more women not only be in the profession but be in leadership positions is going to make a big difference. And it's already starting to.

STORIES EXCERPT: There's just too many layers of this that I have to fight through to get the person on the other end to look at me as a human being. So yes, I say race, but then I also say, and I think another thing that contributed was class, you know, maybe if I'd walked in as an attorney, as a black attorney, the treatment would be a little different. But I walk in as a single mom, right? No partner, I'm sick. And the only thing I can think is either I got really sucky insurance and you determine how you're going to treat me based on my insurance, or what else could it be? Because there are other women that come here and they walk out a lot happier than me.

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[10] https://www.stroke.org/do-i-have-a-migraine-or-is-this-a-stroke/
[11] https://www.preeclampsia.org/stillatrisk/53-health-information/50-about-preeclampsias
[12] https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5589074/
[13] https://www.nejm.org/doi/full/10.1056/NEJMoa1208200
[14] https://aamc-black.global.ssl.fastly.net/production/media/filer_public/5c/26/5c262575-52f9-4608-96d6-a78cdaa4b203/2017_applicant_and_matriculant_data_tables.pdf
[15] https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4351276/

Emily: That was an excerpt from the film Stories of Black Motherhood[16] which was created by Fatima Dainkeh[17] who's an African American woman who studied public health and is right in the middle of trying to figure out how to help black moms both in terms of recreating the narrative around black motherhood and she's super optimistic and sort of incredibly powerful I guess I would say in terms of trying to express points of joy. One of the points that she makes to us is that so much of what we think of as a stereotype of black motherhood is negative. And that we need to sort of put that, flip that around a little bit and make it a story of empowerment. And she's looking specifically at this intersection of timing of birth and how black women experience this. And she does this in an incredible way in that film which will link to on our site empoweredhealthshow.com and all the show notes. And she and I are going to talk a little bit about solutions to the problem as well as like why does this sort of misunderstood and that if there are real problems in systems, how it kind of has to start with the individual doing some self-examination. Here she is.

Fatima: My name is Fatima Dainkeh pronouns she, her, hers. I've been living in the Boston area for about two and a half years. And what brought me to Boston was a program at the school of public health at BU. So I graduated with a masters in public health in May of 2018 and my focus was around maternal child health and this really long name that's short for CAPDIE[18] but the long version is community assessment, program design, implementation and evaluation. Currently, I work at YWCABoston[19] as the interim manager of dialogues. And what dialogue means is that we pretty much work with nonprofit organizations, schools, companies and businesses to have a conversation around race. And sometimes we follow up with those organizations over a span of one year to help them create an action plan that can help their organization become more racially equitable.

Emily: I think one of the things that your film did for me was it really, I think by giving voice to these women who are even just saying like race is on my mind when I go into a healthcare system because I know that people are looking at me differently. And you know, I think there are plenty of people who will listen to this and say like, that's ridiculous. Like I'm a doctor. I don't look at African American women any differently than I look at white men. But you know, I think there is, whether that's, you know, a hundred percent possible or true or whether it's not. I think the idea that this is an experience that a group of people are having is worth listening to. And so, you know, I think one of the things that I was struck by was in the film, one of the moms that you talked to, I think it's Tanya, maybe she talks about how she has a, there's an African American ob who comes in and that there's sort of this soothing experience that happens for her where it's a sense of relief because it's somebody who she feels like she can identify with. And I think this is so important because I think there's so many barriers of entry to the healthcare

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[16] https://www.youtube.com/watch?v=sxgngO_7d_U
[17] https://www.ywboston.org/people-list/fatima-dainkeh/
[18] https://www.bu.edu/sph/education/degrees-and-programs/master-of-public-health-programs/certificates/community-assessment-program-design-implementation-and-evaluation/
[19] https://www.ywboston.org/

system to be a provider, right? So like to be a doctor, to be a nurse, to be a midwife even, and that this idea that women are experiencing, I mean, I think we have to call it discrimination, right? The experience is profoundly different. For one group than it is for another statistically. And that we don't have care providers who are aware enough of how scary that would be. And I've been, you know, I get in trouble for my analogies, but I always feel like it's sometimes a good way of thinking about a problem and I don't have a good one for this. Ao, you know, I, again, I sort of feel like if you can talk a little bit about the area of public health, you know, Dr. Neel Shah is somebody who we're going to feature heavily for his research. And he had said to me in one of the interviews I've done with him that like, there's just a bias that you learn in med school and that it's almost like a time management tool that's taught to you about like how to profile people. And he's like, it's pretty fucked up because it's white men who designed those protocols[20] and they don't actually know what it's like to live in another body. So for them to profile somebody walking through the doors of an emergency room is inherently flawed.

Fatima: Yeah. I mean, I think you hit on so many points and I'm like thinking there's so many, many things. So one of the things that I do at YWBoston, I spoke about it earlier, is that I talk to people in different areas, in different fields of work about racism, right? And as you said earlier, you know, people are uncomfortable to talk about race. So first of all, that's an issue that we have, right? Because if we know that it's a problem, why can't we talk about it? Right? And if we can't talk about the problem, how will we find solutions? But the other piece that you just mentioned about bias is the piece that I really want to highlight because I think what people don't realize is that just like you said about Dr. Shah is regardless of the medical healthcare system, what I want people to understand is that racism is bigger than the hospital, right? So when, when a mother is going to the hospital, that is an important point in time, right? Because they're receiving care at a critical point. You're carrying another human being inside of you. What the film tries to show is that racism exists even before the mother gets in the hospital. Right? And when mothers are talking about, I have issues around education and equity, I'm only given a glimpse of what it might mean for them to be a mother of a child. In public health we talk about the life course model[21]. All you really have to do is think about that mother before she had a child. And think about that mother as a child, right? And imagine what their experience has been. And when we're talking about bias, it's bigger than the healthcare system. I think the attention around the hospital is important and the stressors that black women are going through is beyond a racist doctor or a doctor who has bias and does not know. So at YW, we talk about bias as, and most people defined implicit bias as something that's unconscious. It's underneath, right? You can't necessarily see it or understand that that's exactly what you're doing. When these mothers are going into the hospital, they're experiencing that. And doctors are saying like how you said, well I am not quote unquote racist because I went to medical school and I care about all of my patients. We're not negating that you don't care. Right. And it's not a dig at the being of yourself, but this idea that because you go to medical school because you have years experience that you were not human and therefore you know don't have an unconsciousness

[20] https://www.sciencedaily.com/releases/2008/10/081015132108.htm
[21] https://www.who.int/ageing/publications/lifecourse/alc_lifecourse_training_en.pdf

working does not allow for us to move to a space to recognize that it doesn't matter how many years of school I've had in understanding medicine and understanding the body as a human being, you're going to have biases. The only way you can realize that is if you accept that and then say, okay, how do I work towards not having these biases and it's an everyday work. It's not a one hour workshop. You know, a lot of these hospitals and healthcare systems are having like trainings around biases that one time is not going to do it because you are literally trying to unlearn years of what you've been taught. And this learning happens as, as a child in your environment, in the movies that we watch, in everything that we're sort of looking at and it just seeps in right. And it's not an excuse for us to act that way. And it's a moment to understand how bigger and deeper bias is and how it can manifest because it can be very harmful. Where one of the mothers that I interviewed that did not make it into the film tells me about having a c-section and after having a c-section telling the doctor that she doesn't feel great and you know, they were like, okay, you'll feel better later, like maybe some rest at home. We'll send an at home nurse for you. She didn't heal until over a year. And when she went to the doctor and continue to say, you know, I do not feel good. Something is wrong with my body. The doctor was like, okay, let's have a look. And unfortunately like literally touched her stomach, you know, you know, I mean you go to the doctor, they're like, let's, you know the, how does it feel if I touch on your abdomen and all these questions and touches her stomach and literally I lie to you, not whatever cut was not properly heal. He put some like so much pressure that the cut opened and she's bleeding, she begins to bleed at the checkup. Right. And if she wouldn't have gone to that doctor and continued to name these things, she could have died. And this is just an example and she's probably lucky that she lived that long, but most mothers don't have the opportunity to continuously go to the doctor and name, here's what's happening.

Emily: Well, but also how screwed up is it that we're calling her lucky? That sounds incredibly unlucky, right?

Fatima: Yeah.

Emily: I mean I feel like there's so many parts to that to sort of tease apart. And I think this idea of women being their own advocates, is like really what I hope this podcast allows women to do is to say like, you're not crazy if you think there's something wrong with your body, you're right. And you have to find the right person who's going to listen to you. Exactly. But that's such a privileged idea. I mean, I know that as a white woman who's a reporter, I'm dogged in a way that most people just aren't. Right? And we're taught to respect authority and we think of doctors and healthcare providers as being the authority. And I think we have to have, you know, that's a safety mechanism we have to keep in place. We can't say like, don't trust your doctor. Right. That's not going to be helpful either.

Fatima: Right.

Emily: So, you know, what do you say to somebody who's thinking about either being, you

know, getting pregnant, already pregnant or having had an experience like this? Like how do we kind of help these women charge them up so they feel entitled to good healthcare? I mean, one of the other things that really struck me in your film was you have the woman who is talking about how, you know, maybe if she had been a lawyer, people would have cared for her better. And that is heartbreaking. I mean, it's heartbreaking all of these stories, right? But there was something to me about the idea of actually what was happening in that moment was that she was judging herself unfairly. Right. And saying like, maybe if I had done something differently. When no that's not, that's not right at all. You don't need to do anything differently. You're showing up and you're asking to be cared for just the same way everybody else deserves to be cared for. And so, you know, I mean I feel like if you, you know, you do all this great work with, I mean you do a lot of work with youth, it sounds like too, which I would love to talk to you a little bit about in terms of sex ed and stuff like that. But in terms of these kinds of stories, like having talked to a lot of these moms, is there some takeaway that you feel like it's really important for us to explain to people?

Fatima: Yes. And when you say people, is this just like the general public? Are you thinking healthcare professionals?

Emily: Everybody. I mean, I'd love to like whatever you feel like is the, we could do 20 different messages for different people.

Fatima: Absolutely. So one of the things, and this is a big philosophy of mine, is that people are not going to understand what they're not ready to understand. And I think this is a very, very important for us to realize because this is not even trying to put frameworks or anything around this. This is just the human nature of people of humans, right? The ability for me to go to a workshop and get whatever information I need to understand about bias, the work and the decision for me to, for it to land in a way for me to understand. And then for it to manifest into behavior change, that onus is on the individual. Right? And so for me, when I was doing this project, I was, my main focus was black mothers, right? How do I create something where black mothers can see themselves to know that they're not alone to see love in the film?

Fatima: I can't tell you how many people came up to me to say thank you for showing black mothers in this way, right? Because there's this narrative around blackness in general, when people hear a black, it's like a dark cloud and I do not want to create any work that will continue to perpetuate that narrative because it is absolutely not true, right? Yes, there are inequities that are happening and yes, racism is real and that is not the being of a black body, right? And this idea of putting this information out there unfortunately creates a culture of negativity around blackness. Right? And so the question then becomes, and how do you balance the two? And for me, when I created this film, it was more so how do I create a space for black mothers to connect, transform, and heal, right? The amount of black mothers that emailed me, amount of my friends who texted me to say, I just watched this film with my black mother and she loves it. Right? And they bonded and they heal. That's the most important thing for me. I think it's important for people to realize that as any human you love people, right? And

yeah, unfortunately black people have not been seen in that light because our history in this country and not only in this country, beyond this country, as someone who's from Sierra Leone, West Africa, I can tell you about colonialism and I can tell you about colorism that exists outside of the border. So when we're talking about racism, it's so in context of the United States and the systems that have been created. They're way broader than that and what I want everyone to understand, you know, general public is that the work that needs to happen really is within. No system can change without people changing. Talk about systems as if they are you know robots and there's nothing controlling them. And even robots are made by people, right? Systems consist of people. If people do not change, systems will not change. And as cliche as it might sound, it is very true that it is the individual work. Right? And so for black mothers you mention, for mothers who has given birth for people who may be interested in given birth and for just people who want to live, right. It's not even just about black mothers, right? I'm just- in general black health in general. Black outcome in general are poor.[22] And that's, that's just the general picture. And so we have to question ourselves what's happening in our country, right? And why are we okay with these inequities across the board? Like it's beyond health, it's education, it's housing, it's income, right? And all of that of course, bubbles down to outcome help. What I would want people to question is how am I showing up? If you can't show up for somebody else, then there's a question of something is happening inside of you that then you have to question, why can't I show up for someone else? And usually that's because there's something internally happening with you, right? If you can't see humanity in someone else, then you're probably not seeing humanity in yourself. And that work no training can fix that. That person had to then figure out what is happening inside of myself that I can't see another person as a human, what is happening inside of myself that these biases exist and and for black mothers creating space them to talk about what it is working. We do so much work around what's not working great. Because when you know what's not working, you have an idea of what you don't want. So I'm not saying there's anything wrong with that. It's important now for us to bridge that and say what is working for mothers who are having successful birth for mothers who are being able to recognize that, okay, society deems me as quote unquote oppressed, but I'm able, I am living a life that I appreciate. What are some of those protective factors that exist within those mothers and those communities. And to say that it is possible, because if we say we're going to wait for policies, we're going to wait for government. What we're forgetting is that we can't legislate behavior. Everyone has an idea of how life should be because we can't control people. And I think we're doing so much work in trying to control people and forgetting that, oh, how are we showing up for black mothers? So as a black woman, I want to know how I can do this work for people in my community to say, what exactly do you want and need? And when I entered these communities, and when I'm going doing interviews, they're not always talking about the problems they're talking about the changes that they want to see. They're having faith in things that have yet to manifest, but they believe that it can manifest. Right? And that's the work that I'm interested in. Right.

Emily: So tell me about some of those things.

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[22] https://familiesusa.org/product/african-american-health-disparities-compared-to-non-hispanic-whites

Fatima: Absolutely. And so for example, some of the hopes that the mothers talked about towards the end of the film was, I want my child to be free. I was sitting there during the interviews and even talking to you right now, it makes me very emotional, right?

Emily: Yeah, of course.

Fatima: Because yes, the want to be free. I mean if we think about history, this is very unfortunate, right? For someone to be in 2019 to still say those words.

Emily: Just a basic human right.

Fatima: Basic, basic human rights.

Neel: It's really been within the last year that I think we've started to really render that problem visible.

Emily: Is that because of Serena Williams[23]?

Neel: I think she's a big part of it. I think Serena Williams, you know Beyonce had a story to tell about it. But yeah, Serena Williams has been great and there'd been a number of journalists actually who've just really told the stories of extraordinary, like there was a CDC epidemiologists studied maternal mortality who died in childbirth[24] in an avoidable way and when we were really, really unpack all of those stories, it actually really shows a larger rift in society where every one of these stories, black women seem to be believed less when they express concerns about how they're feeling, including Serena. She's the world's greatest athlete. She knows her body pretty well. She's world famous, so she should be able to advocate for herself. And she told them what was going wrong and they didn't believe her

Emily: She even told them what medicine she needed and stuff, right?

Neel: She did and they didn't believe her. Even Serena Williams. And in every one of these deaths there's some kind of story there where the mom or the family is expressing concerns and it's harder to hear it.

Emily: I think what's really interesting about Dr. Neel Shah's work is that he's really sort of taking apart the systems are the bedrock of his entire profession. And he's trying to figure out how can he improve those systems to care for women in a better, more complete way. And the

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[23] https://www.vogue.com/article/serena-williams-vogue-cover-interview-february-2018

[24] https://www.npr.org/2017/12/07/568948782/black-mothers-keep-dying-after-giving-birth-shalon-irvings-story-explains-why

next person that we're going to talk to has really done that. She sort of revolutionized the birthing model in a way that she's now having profound results with.

Ebony: My name is Ebony Marcelle[25]. I'm the director of midwifery at Community of Hope Family Health and Birth Center. [26]My midwifery is social justice and I am an expert in caring for underserved African American women and facilitating normal birth in the high equity high education setting.

Emily: I feel like I wanted to start off by just asking you to explain a little bit about what the differences is in terms of care. Between like an ob and midwife.

Ebony: Absolutely. So the biggest difference is our philosophy of care[27]. We don't see birth as an illness or as a disease, something that we have to fix. We believe it's a normal life occurrence. We also provide relationship-based care. So it's, our interactions are a lot more intimate and we have longer appointments. Which is what most women want and need, but the bigger, bigger differences as well include the fact that we're not surgeons. And we do not manage high-risk patients. So if she's very complicated, super sick, we're not taking care of her. But we are the experts in caring for moms who choose not to have pain medication. We are the experts in caring for women who decided to have their babies outside of the hospital.

Emily: So just to pick up on the relationship aspect of what you guys do, because I think that's such a big part of the birthing experience, right? And maybe, perhaps where we have gone wrong in the United States. Because I think there's such an intimacy and such a vulnerability about giving birth. And I feel like I've said a hundred times on this episode that it's like, you know, it's the most sort of common occurrence that we all share, right? Everybody's born. Most women have babies. And the sort of current care model where it's like you go in, you get a drug, like they check you really quickly like you see what's wrong, you treat a couple of symptoms and like you're out. That doesn't really work with this experience. And I feel like for somebody like you who's really in the trenches and then looking at this through the lens of race and how black women, in particular, are less listened to, less cared for, less believed, all of these sort of inherent biases that we see in the systems around health care. How does that play out in a different way in a midwifery model?

Ebony: So I think the first thing is really, really gauging our care to meet women where they're at and also empower them. And so a lot, a lot more can happen if I'm spending more time with her. So most typical OB appointments[28], she actually ends up a lot of time spending more time with auxiliary staff then she does directly with the provider. And we try to flip that. So we try to have more time with us then with the auxiliary staff she interacts with. And then we provide a holistic model. So we are not just interested in all the clinical aspects but also the social and having

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[25] https://www.communityofhopedc.org/marcelle
[26] https://www.communityofhopedc.org/healthcare/birth-services
[27] https://mana.org/about-midwives/midwifery-model
[28] https://www.medscape.com/slideshow/2018-compensation-ob-gyn-6009662#24

conversations about support during the pregnancy, not just after. And what I feel like what makes us a lot different here where I'm working is that we've really moved to provide a lot of care coordination working with women who are disenfranchised. They need help, they absolutely need help and they need policies that are not super strict and that are very flexible. And they need systems that are supportive.

Emily: And you feel like that you see better results when there is a more supportive care model. Cause one of the things that I feel like I've heard, you know, sort of whispered around is like, well it's a lot of costs for all these extra services and like somebody needs to show me that like having a doula actually increases the, you know, or decreases rather the risks associated with this. And I don't know that there's ever been a study done on that, but I feel like you have the experience in the trenches to kind of answer that criticism in a way.

Ebony: Absolutely. I mean there's data that shows having a doula or even having someone consistently present during your labor reduces your chances of a c-section.[29] That's cost savings right there cause we know the difference between the cost of a vaginal birth and a c-section[30]. We know that providing the support, reduces the chances of a preterm baby. providing group care we know reduces the chances of low birth weight and preterm birth rates.[31]That's saving a lot of money. NICU was at a minimum $10,000 a day. So, I hate hearing that because we actually save them a ton of money by providing this model of care because our babies are healthier. They're not sick, they're closer term, if not like earlier. I mean late, late, pre-term with great weights and so we are helping them.

Emily: Yeah. And I mean I think the other point to make here that's important is that a lot of the deaths that are happening are happening postpartum, like at home where nobody is checking in on these moms. And very often a doula or a midwife will follow up in a way that an ob just doesn't do or doesn't usually do.

Ebony: Yes. And you know, I always kind of crack jokes all the time about how like now they ACOG[32] said it's sexy and now and sexy. So now ACOG is talking about earlier, early postpartum care. But midwives have always done early postpartum care and especially with a lot of out of hospital birth, they actually provide more visits than we do. So a lot of times moms are seen four or five times in that postpartum period versus usually what standard ob care. It's six weeks and I'll see you at six weeks. So, one thing that we do here is we definitely, if they have the baby in the birth center, we are at their house within 24 hours and usually day three is a combination of a newborn appointment, but we do early postpartum groups, which it's not to be confused with the continuation of education. It's really about care coordination and support.

Emily: And that's for the mom and the baby. Right. I mean, I feel like

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[29] https://www.ncbi.nlm.nih.gov/pubmed/28681500
[30] https://www.businessinsider.com/how-much-does-it-cost-to-have-a-baby-2018-4#50-alabama-1
[31] https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0192523
[32] https://www.acog.org/

Ebony: Exactly

Emily: There's such an interesting thing in terms of all of the baby mom stuff getting bundled together when it seems like they're really very different biological systems like they're very different psychological needs. I mean, it doesn't, I don't understand why those got, you know, sort of package together. I mean, I guess I do kind of understand why, but yeah. I think it's interesting to imagine the midwife being able to go and sort of care for both in a, you know, specific kind of way.

Ebony: I mean, I think what often happens is that the baby comes and the mom is neglected. All the focus is on the baby. You see a lot of women who make sure that they get their baby to their appointments, but they don't go to their own appointments. And so part of my thought process in creating this group was honestly for convenience

Emily: Make it easy and then people will do it.

Ebony: Exactly. And to find a way to bring care to her. You know, when and a lot of settings, there's a lot of, you know, you know, lactation wants to see you. Maybe you want to talk to somebody from behavioral health. Then you need to try to figure out what your fertility awareness planning is gonna be. And like, it's so many things just kinda hit at you right it two weeks when your baby who's really, really cute but kind of mean because you don't get a lot of sleep. And so, you know, you're going through all of these things. And I just felt like I kept seeing women get bombarded. And so I wanted to create a way for them to get all they need, but in a way that they can receive it better. Does that make sense?

Emily: Absolutely. I mean, in some ways that seems so logical that it's sort of strange to imagine that's not the norm. Can you talk a little bit about how you went about designing the program or and now facilitating it?

Ebony: Sure. So it actually was an idea. I was a Duke nurse leadership fellow for a year. And part of the fellowship is to create an innovative, you know, quality improvement plan. And so I identify that our breastfeeding rates definitely I wanted them to be higher after six weeks. And so my initial thought process was, well, if we layer it like this and have some more interaction, breastfeeding rates will go up and we'll just add all the extra care coordination for extra support. But what I've found is moms really appreciated the style of the visit. And they really, learned from each other. Like the women just like help each other out. There's usually a mom who this is maybe her third baby. And so teaching the newer moms about ways to put them to sleep, ways to, you know, prepare their milk to go back to work. I just love watching them teach each other. And then also the mom who maybe wasn't really comfortable breastfeeding in public, you know, she'll see another mom who's super confident and gain some confidence watching her. So the group dynamics were just really, really strong and empowering and supportive. And so now, you know, we have moms who were like, hey, is there another group after this? Right. Do we get to

come back. And they're just really, really happy to be amongst, you know, their peers who are right in the same phase of this recovery that they are, which is that two to four week period. But I think for me and I say this, you know, really honestly, there were a lot of pieces of the system that I didn't like, but I never felt like I could say anything about it. And so my plan was to get into a place where I could create and have a say and then, you know, do what I want, essentially do what I want and do what I felt like I knew, you know, indigenously intuitively was the right way to provide care for this exclusive population of women. And so for me, what that looks like is having folks who look like you take care of you. It's huge, it's extremely important, you know, to have more midwives of color to take care of this population. The reality of it is though, is like, you know, midwives of color for certified nurse midwives, it's like five, maybe 6%[33] of the entire profession. So like, there's no way to just say, hey everybody, I'm going to fix everything right now and just have more midwives. That's not the answer. We definitely need more midwives of color. I think I'm having more conversations about midwifery models of care. Because we also have midwives that are in like high education, high equity settings and have a very medicalized way of practice. And so, being able to have providers that look like them, provide the midwifery model of care, have the care coordination, we need all those pieces. Having in house behavioral health is worth $1 million right there. Dealing with women who have high rates of PTSD, sexual abuse, trauma. Being able to walk out of my office where I'm you know seeing a patient and say, Hey, she needs someone to talk to you today and right now. That right there is, is priceless. Cause in most settings you kind of get a referral, right? I mean you have to kind of figure it out and then does your insurance cover it or not? Do you have the money for it? And it just ends up being most of the time overwhelming and doesn't happen.

Emily: And so you had made that happen.

Ebony: Yup.

Emily: How hard was it to do that?

Ebony: Well, I have to tell you, I just have a really incredible administrative team. Like I feel very lucky that I worked for an organization that trusts me and has been extremely supportive and they listen to me.

Emily: Amazing

Ebony: Yes and what I was saying about how I feel like care needs to be provided, you know. Even like, like policy changes, like the midwives see late patients, they see late prenatal patients, we see late babies. If they come in for an appointment, we do not turn them away. And that's not really popular with most health care providers to see late patients. But they were okay with me, you know, instituting that policy and to, you know, hire predominantly a midwife of color

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33 http://www.midwife.org/acnm/files/ccLibraryFiles/Filename/000000007090/QuickeningSummer18_final_09_09_2018_optimized.pdf

staff and have the conversations about, hey, we're dealing with the community that has generational distrust with a lot of systems. And the only way we're going to change that is to change these things. I don't think I could have had that conversation everywhere that I've ever been employed.

Emily: So I mean, are there, I feel like what would be, it sounds like in an ideal world we would have you go around the country and replicate this.

Ebony: Yes.

Emily: Right?

Ebony: Yes.

Emily: How do we do that? I mean, is there like some sort of plan for that? Because I think this part of the racism card thing that we're talking about and trying to unpack a little bit is that I think there's such a push back, right, on no, you don't need somebody who looks like you. You need somebody who's going to care for you. And I think that there's something very entrenched in that that comes from the idea of only a certain type of person used to be a doctor. Right? And so there wasn't a choice. And I think, you know, there's a, there's a difficulty in the idea of like, well, if only 5% of midwives are black, then this isn't a solution to fix the problem today. So what do you do today? And I think that's worth exploring. But I also think the idea of sort of like calling on people who might be interested in this field is also really important. Right? Because, to go back to the idea of like the push back a little bit, I think there's something really interesting about the, you know, the whole makers phenomenon of like, if you can see it, you can be it. And trying to profile women who have done jobs right, that we don't traditionally think of as female jobs as a way of inspiring girls to think about pursuing those careers. And I feel a little bit like what you're saying in terms of this philosophical approach is something we hear a lot, right? And as women we feel it a lot. I mean, I was recently in a doctor's office and there were three men in the room with me and I was like, this feels weird, right? Like it feels a little weird that there's not a woman in here with me. Were they- was there anything like, you know, no malintent. Nobody, they didn't even notice, I'm sure. But I did. And I think, there's another woman that we've have spoken to who put a film together that's incredibly powerful and the whole point of the film is basically talking about Black Motherhood and how to change that narrative to something really powerful and positive rather than, you know, the sort of stereotypes that are out there that are incredibly degrading. And so, you know, I think it's sort of interesting because I feel like what you're doing is in practice you have changed the model and you are caring for women in a way that they weren't being cared for before. But you're also, and correct me if any of this is wrong or you know, not accurate in some way. But you're also basically saying like, this is a temporary solution and it's better than what we had. But the actual solution is going to be to get more women of color working in this profession so that we can brown things out properly.

Ebony: Because, you know, I always say this, when I'm teaching, in healthcare, it's really easy to feel like you have a pass. You're like, oh no, absolutely. I'm doing the right thing. I'm a healthcare provider. I didn't do this– you know, that this was really hard for me to get through school wise, financially. And like, of course I'm trying to take care of good people. How could you think anything else? But not understanding that our systems are so entrenched in racism and folks just can't really see it. And on top of that, there's just this avoidance of the past, but that past affects the future. So, you know, one point I always like to give is, you know, I hear providers who are not of color complain about, you know, I have patients who don't want to take birth control. I can't believe she doesn't want to use it. This is crazy. And you know, I'm always like, well, probably because she can feel your judgment. So you have to check that. But the other pieces you have to acknowledge what historically has happened with African Americans and health care systems. Tuskegee[34], Henrietta Lacks[35], the Mississippi project[36]. Those are real. And we're not talking about, those are experiences that maybe happened generations ago, like, you know, like hundreds of years ago. My mom can remember it. My parent can talk about living through segregation. My grandmother talked about living through the depression, Jim Crow, you know, like we're not talking about eons ago. And so to think that that trust is quickly fixed. 400 years. Of course, it's not fixed.

Emily: Right or that it's somehow inconvenient, right? And therefore should not be talked about.

Ebony: Exactly. So I think trying to create a space for people who are not of color to feel comfortable having those conversations and not get defensive, that's really going to be really, really important. And also acknowledging the power struggle that also exists in medicine. Like you do what I tell you to do because I told you to do it cause I'm really smart and this is what I think you should be doing. And not trusting women and families and not allowing women to have more autonomy over their own bodies. You know, those are the harder conversations that really also need to happen. So, you know, yes. Like I am, you know, some possible quick fix solutions. And I've been very blessed to have a very supportive administration and being able to, you know, hire midwives of color and this small, you know, community. I'm not going to pretend like, oh, we can just replicate this tomorrow and all the different cities. It's going to take a lot of time. But in the meanwhile, we also have to dismantle this system. The system is broken. It's not working. Why are we the only country in this world, maternal mortality is going up. We spent all this money, we spend all this money.

Emily: One of the things that I was struck by that I feel like, I think I wrote the story for the New York Times[37] and then I also had a story that was in Cosmopolitan[38] magazine on c-sections and maternal mortality. And in the course of looking at that, I couldn't really get into race in the New York Times piece. They're just, I had a thousand words and there was too much

[34] https://www.cdc.gov/tuskegee/timeline.htm
[35] https://www.hopkinsmedicine.org/henriettalacks/index.html
[36] https://mississippiencyclopedia.org/entries/mississippi-health-project/
[37] https://www.nytimes.com/2019/03/05/well/family/reducing-maternal-mortality.html#commentsContainer
[38] https://issuu.com/emily9804/docs/cosmo

international comparison that I was focusing on to do it justice. But I was really struck by the fact that I have asked several people now and at an event the other night I had somebody who sort of said to me that I was right. Although you know, not with any sort of statistical backing to it that if you were to back out the deaths of white women from those stats, would there actually have been an increase over time? Right. Like we talk about how it's more dangerous for a woman to give birth today than it was when our moms gave birth. But is that actually true for white women? I don't think it is. I think it's about the same and I'm not a math person, so I need somebody who's an economist to be able to back that out. But I'm sort of, I was wondering whether it was almost, it's so egregious for black women that they have, the deaths that have happened have pushed the statistics for all. Right. And in doing that we have neglected to recognize that this is specifically a problem for black women. And if that is the case and those deaths are preventable, then we really are talking about a political sort of socio-political problem that we're framing in a medical context. Right?

Ebony: Yeah. I mean, but it's a lot easier to blame.

Emily: Right.

Ebony: You know, like it's a lot easier to blame the woman blamed their behaviors, blame their lifestyles.

Emily: Right. And that's why I feel like the work that Dr. Neel Shah is doing, who we're going to feature heavily in these episodes is so interesting because I think enlisting Harvard Business School to do the sort of comparison that he's done with hospitals[39], but also to be able to factor out that like this isn't about, you know, pre-existing medical conditions. It's not about obesity. It's not about malpractice insurance. It's not about all of these sort of typical go tos that point the finger at one specific symptom or symptom of the, you know, sort of larger systemic problem. I think that's so like vital to figure like sort of being able to look at the collective problem and fix it.

Ebony: It is, but it's going to make a lot of people uncomfortable.

Emily: Talk to me about that

Ebony: I just feel like there's still a lot of folks who are not ready.

Emily: How do you see that? Like where do you see that?

Ebony: I see that. So I teach, I do a guest lecture at Georgetown every quarter with midwifery students and I'm so appreciative of my colleagues, former classmates, former midwives that I've worked with who really realized that it was an important element to add into their education. Of the midwives before we're sending them out to tell them to catch babies. But every quarter when

[39] https://www.hbs.edu/faculty/Pages/item.aspx?num=52998

I'm teaching this class, there are students who are angry, they are angry and they, you know, I had a student recently tell me, you know, I feel like you're just here to tell me that white people are bad. And I was like, wow, if that's what you got from everything I've told you the last two hours, you missed it. It's not what I'm trying to do.

Emily: When I was working on the New York Times piece, one of the sources that I interviewed mentioned to me that Merck for Mothers[40] was going to solve this problem because they have such a global reach and financially they have so much money to put behind it that I really wanted to reach out to the organization and talk a little bit to them about how they're approaching this problem. So we called up Dr. Mary-Ann Etiebet[41].

Dr. Etiebet: My name is Mary-Ann Etiebet and I'm the lead of Merck for Mothers, which is $500 million global health initiative to end preventable maternal deaths worldwide. I joined the team about two years ago and I'm so honored and proud to be part of this work. My background that is multifaceted. I'm actually an HIV physician by training and by practice up until about two years ago when I joined the Merck for Mothers team and I will say that when I, as I was doing that work both in the US and globally, it just became clear that there were so many places where women were falling through the cracks and unnecessary harm and death, you know, were happening to women in the health care system. And so, as I've thought about, you know, what I'm able to bring to the table in terms of solving, you know, for these issues around women not having access to high quality care, hearing and knowing about what the Merck for Mothers team was doing just created a huge opportunity for us to think differently about solving this problem and bringing all sorts of actors to the table who traditionally had not worked together.

Emily: So, I sort of wonder from your perspective, the birthing environment for women in the United States in 2019. How much of that story is actually about the idea of listening to women in 2019 or giving women a voice and a sense of credibility and how some of our bias, I mean, we can say racism, we can say bias, we can take the whole gamut of this, but how African American women basically by and large across the, across the sort of women's health spectrum, are largely marginalized, right? I mean, there's no kind of no doubt about that. Is there?

Dr. Etiebet: No, no there isn't. I want to share a set of statistics with you, which I think really shines light on that issue. We know that disparities, racial disparities exist in a whole slew of health conditions. Black Americans are 22% more likely to die from cardiovascular disease[42] than white Americans, they are almost 90% more likely to die from diabetes[43], but they are

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[40] https://merckformothers.com/

[41] https://merckformothers.com/who-we-are.html#

[42] https://www.heart.org/idc/groups/heart-public/@wcm/@sop/@smd/documents/downloadable/ucm_472910.pdf

[43] https://minorityhealth.hhs.gov/omh/browse.aspx?lvl=4&lvlid=18

243% more likely to die from pregnancy or childbirth-related causes.[44] And so I think you see when it comes to maternal mortality, there is that confluence of gender and race that I think, you know, those two things together really creates the space where we are right now in 2019, where nationally black women are three to four times more likely to die in pregnancy and childbirth. And when you actually break it down at the state level and a state like New York state, there are 12 times more likely to die.[45] You know, that's unacceptable, unconscionable. And you know, we have to do something about it. To your point about listening, I think it's so important, but I want to move us away from just a conversation about we need to listen to black women or we need to hear their voices. What we really need to do is make sure that their experiences, their recommendations are integrated, into systemic and institutional structures so that the solution include their perspective. And you know, what would make the difference for them? You know, I am anxious just a focus on hearing these voices is not going to be enough. We need to talk about how what we are hearing gets integrated into the systems. And I just give you one example. One of the partnerships that we have is with the New York City Department of Health and Mental Hygiene.[46] You know, as, as you wrote in your article, you know, we've seen that we are getting more resources being plowed into the states based maternal mortality review committees, which is so needed. Most of those committees focus on investigating every desk. What we also need to do is investigate the near misses because when we investigate the near misses, we are now able to interview the woman and hear from her perspective what went wrong on how, again, from her perspective, what should be done the next time so that there's not another near miss, you know, for the next woman who comes into those hospital doors. And so we, you know, institutionally integrating voices of black women into structures such as state maternal mortality and morbidity reviews as we're seeing happening in New York City, I think is one step. It's an essential step. But it should not be, you know, all that we do.

Emily: So my understanding is that you wrote a great Op-Ed[47], which we'll link to in Stat News, that for every death, every maternal death, there are five women who have a near miss or a close call where they, you know, we're saved from the brink basically. Are those proportions the same in terms of breaking down maternal mortality and race as well as the near misses? Like are more African American women experiencing these close calls?

Dr. Etiebet: Yes, and you'll see the issue that we all face is that we don't have enough data. The same way that we were not tracking robustly and investigating every death, we're also not tracking robustly and reporting, you know, on both near misses or how they're categorized as severe maternal morbidity. But again, another partnership Merck for Mothers has had with the New York City Department of Health looked specifically at severe maternal morbidity in the city

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[44] https://www.cdc.gov/reproductivehealth/maternalinfanthealth/pregnancy-mortality-surveillance-system.htm?CDC_AA_refVal=https%3A%2F%2Fwww.cdc.gov%2Freproductivehealth%2Fmaternalinfanthealth%2Fpmss.html

[45] https://www.merckformothers.com/docs/new_york_Factsheet.pdf

[46] https://www1.nyc.gov/assets/doh/downloads/pdf/data/maternal-morbidity-report-08-12.pdf

[47] https://www.statnews.com/2018/08/16/pregnancy-related-deaths-state-review-boards/

and found roughly the same rates of racial disparities and severe maternal morbidity and those near misses that you're seeing in mortality. So again, correcting adjusting for education, for income, for geographic, location. You still saw that African American women were three to four times, three times more likely to suffer adverse events or adverse consequences after pregnancy and childbirth. And I think that's, as we look at the field or as we look at this issue, we're seeing– the same way that we're seeing the rise in maternal mortality, we're also seeing arise in those near misses, those adverse events and adverse consequences. We're that same disparity play out in both of the scenarios. We have to be very careful that the work that we do to solve for maternal mortality at one does not increase the disparities that we're seeing in mortality, but also does not increase the disparities that we're seeing in morbidity. And we're only going to be able to do that if we put health equity and solving for disparities front and center of our efforts, and come at this issue through a health equity lens.

Emily: Our goal for this episode was to give you sort of a broad purview on this burning crisis. And the fact that this is something that is happening at such a higher rate for black women than it is for anybody else. That to not talk about race as a part of this issue in a really systemic way is missing a huge part of the problem. And I hope that in this episode we've done a good job of looking at the fact that this isn't actually just about birth. This is really about a condition and a way that we're thinking about how we treat people and who we listened to and how we listen to them and how seriously we take them. And that we can all do a much better job of sort of looking inward and trying to figure out how do we care for each other and how does that care differ from one person to the next. And I think one of the things that is a big takeaway for me in this episode is the idea that, you know, what, when somebody is feeling really vulnerable and scared, which I think everybody I know who's given birth has gone into that situation feeling like they want to have an empowering experience. But if they were to really be honest, they would say it's pretty terrifying. It's not as terrifying because your body is going to do something that you don't know how to do and you don't know what it's going to be like. But you're also changing your identity forever when you become a mother. And that is a transformation that I don't think people can understand if they haven't been through it. And I don't think that men even can completely understand no matter how sympathetic they are. But you add on top of that a mistrust of healthcare systems and it's gotta be kind of terrifying. So I'm happy that we were able to sort of showcase this and add a little bit more of a positive spin to the fact that there are really fantastic birthing stories that are happening. And that, you know, deserve more attention and there are really, really brilliant, amazing people working on this problem. We're going to do a followup episode it's going to launch next week that's going to be looking at how this problem could be solved. Who are the players in the game solving the problem and what their potential solutions are and where we are in that process. I hope you'll join us next week. Thanks so much.