I BE BLACK GIRL

AIN'T I A WOMAN

A Person Centered Approach to Reproductive Care for Black Women

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What Black Women Want: A Person Centered Approach to Reproductive Care

EXECUTIVE SUMMARY

This report is designed to understand the reproductive and birthing experiences of Black women in Nebraska. Through intentional dialogue and listening sessions led by UBUNTU Research and Evaluation, we explore Black women's reproductive care journeys, stories, and experiences with special attention to their birthing and labor histories. The findings were compiled and analyzed with the purpose of engaging the larger Nebraska community, healthcare systems, policy partners, and community based birth workers to unveil the reproductive healthcare needs of Black women.

Research describing clinical care for Black women often highlights disparities in access and quality of care for Black women. The listening sessions provided a unique opportunity to delve more deeply into how Black women in Nebraska experience, navigate, and cope with their healthcare providers and the larger healthcare systems they operate within. It is the goal of this project, to use its findings to advocate for systemic changes that can shift the experience of reproductive care for Black women in Nebraska.

Thirteen virtual sessions were held and facilitated by UBUNTU Research and Evaluation with an applied reproductive justice framework to center our beliefs when designing session protocol. Reproductive justice is defined as the human right to personal bodily autonomy;1 free from the constraints of economic, social and political powers and resource access, that bar women from being able to make healthy decisions about their bodies, sexuality and reproductive health for themselves, their families and their communities.2

Below, we provide a figure that describes the domains utilized to create the questions that guided the listening sessions.

Figure 1. Discussion Guide Matrix Domain Descriptions

Institutions	Organizations that interact with women throughout the reproductive healthcare process (e.g., hospitals, primary care providers, insurers, pharmacists, social services).
Environment **Economics** **Culture**	The surroundings or condition in which a person lives, works, plays, prays, etc. The condition of a person as it relates to material prosperity. All the ways of practice or treatment that are socially or institutionally cemented and passed down.
People	Behavior and practice of people in one's life (family, friends, providers).
Practice	The customary, habitual, or expected procedure or way of doing something.
Power	The capacity or ability to direct or influence the behavior of others or the course of events.
Place	Similar to the environment domain, but more access related. Such as, neighborhood resources, policy privileges or gaps and particular features of the environment.

After analyzing the data from the listening sessions, we identified barriers and challenges to having optimal health care experiences and provide recommendations to address the gap between poor quality health experiences and the types of experiences desired by the Black women in our study. In collaboration with the participants, we cultivated a list of actions health care providers and institutions should take to create more dignified, patient-centered reproductive healthcare approaches for Black women in Nebraska. When Black women are centered in curating the solutions to create dignified reproductive healthcare frameworks it will raise the quality of care for all Nebraksans.

Recommendations are broken down by the following themes: shared decision making, trust building, communication and birthing practices.

This includes:

- Developing training protocols to improve provider-patient interactions and communication;
- Enhancing healthcare system capacities to increase their reach, by having shorter wait times and locating services in less populated areas of the state;
- Building in the opportunity for patient experiences to be tailored to the needs of individuals;
- Increasing provider empathy in patient experiences;
- Providing more incentives for providers of color to help increase their prevalence in the state;
- Increasing patient autonomy in reproductive health care situations, such as with: birthing plans, access to doulas and midwives, tailored delivery options such as water births or birthing centers;

- Offering resources such as classes for single mothers and for extended family members, transportation to and from pregnancy and newborn monitoring visits, providing targeted resources to prep for and during the postpartum period and increasing efforts to publicize and link mothers to community programs, such as Essential Pregnancy Services, that highlight housing, education and child care opportunities.

We want to thank the women who generously and vulnerably shared their invaluable feedback and recommendations, without you, this project would not have been possible.

ABOUT THIS PROJECT

This project originated out of a desire to understand the unmet needs of Black mothers and people with the capacity for pregnancy in Nebraska. Catalyzed by growing social movements to highlight the underexposed reality of giving birth as a Black person in America; I Be Black Girl partnered with Ubuntu Research and Evaluation to examine the birthing accounts and reproductive care encounters of Black women in Nebraska.
The statistics are heartbreakingly alarming.[3] Black women are at three times higher risk of death related to pregnancy and childbirth than white women. For Black women over 30, this risk can become as high as five times higher.[4]

Through the design process, the project evolved to reflect the larger reproductive experiences of Black women in Nebraska; in order to capture more varied dimensions of the reproductive health care experience. Recruitment efforts did not yield a diversely gendered sample to speak to, but we got many reflections of Black womanhood that we were able to present here. We hope these findings can be used to engage and inform community members, healthcare systems and policy partners in action, not just in Nebraska, but for the larger community of Black women in the United States.

DESIGN OVERVIEW AND LISTENING SESSION ANALYSIS

Using a qualitative research design, UBUNTU Research and Evaluation developed two discussion guides to center the reproductive healthcare and birthing experiences of Black women in Nebraska. Listening sessions were conducted separately, although women often shared experiences that overlapped between reproductive care sessions and birthing experience sessions.

The sessions were conducted on a virtual platform and due to technical connection issues, in a single instance, a telephone interview was recorded. Participants were recruited using a snowball sampling design, driven by community connections previously established by I

Be Black Girl as well as marketing on social media sites. Enrolled participants were offered a compensation of $75 dollars for their participation.

Each session was up to 60-minutes and followed one of two questionnaires developed to guide the discussion. One questionnaire aimed to understand their reproductive care experiences and another version for birthing experiences. The specific conceptual domains within each of these broad categories are shown in Figure 2 below.

The verbatim transcripts from the listening sessions were analyzed using the qualitative data analysis software program ATLAS.ti. The codebook was developed through two rounds of exploration. First, research team members developed potential codes by drawing on their interviewing experiences with the women in their sessions and from the session questionnaires. After an initial read of the transcripts, the research team met to refine and further develop the codebook. All of the transcripts were reviewed and coded by at least two members of the research team. Codes and themes were iteratively reviewed to ensure continued consensus and that new codes were added as needed.

Data from the listening sessions was then analyzed for general themes and patterns. Particular attention was paid to data coded for trust, decision making, communication and desired changes. These were codes most salient to our understanding of Black women's experiences in reproductive healthcare settings, because we felt they illuminated best how power, dignity and empathy intersect with patient autonomy and decision partnering. We feel that this intersection gives depth and breadth to the extent by which Black women can experience healthcare with particular attention to their own self-efficacy, self-determination and intersectionality, or the interconnected nature of their identities, such as their race, class and gender.

AREAS OF INQUIRY

This project investigated the reproductive care and birthing experiences of Black women. Broadly, we wanted to understand how Black women make sense of their decisions and experiences as folks with reproductive systems and how they see power, access, and perception shaping those engagements. Discussion guides were developed by reflecting on the various facets of life by which Black women interact as they consider how to attend to their healthcare. A matrix was created that required the research team to generate questions reflective of the intersection between domains of people, practice, power and place and institutions, environments, economics and culture. To do this, research literature, evaluative reportings, and news and other media publishing outlets were consulted to understand (1) what had already been explored, (2) what lacked depth, and (3) what social narratives exist and persist in the public discourse.

Figure 1. Discussion Guide Matrix Domain Descriptions

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Following is Figure 2, which details the conceptual domain presented within the discussion guides that were drafted for the listening sessions. We held 8 reproductive healthcare listening sessions and 5 birthing experiences listening sessions, based on interest.

Figure 2. Discussion Guide Listening Sessions Domain Descriptions

Healthcare Provider and Patient Relationship Dynamics	Healthcare Provider and Feelings of empowerment Patient Relationship Dynamics	Finances
Experience with pregnancy healthcare providers/staff	Preventative care Feelings of discomfort	Employment
Experience with birthing staff	Social support systems Judgment	Desired Changes
Social support systems Perceived control (birth/ pregnancy)	Perceived control Perceptions of power (healthcare decisions)Trust building Types of support/resources (tangible, emotional, informational, reflective)	Nebraska

At its core, this project is an examination of reproductive autonomy and reproductive self-determination, and the ways in which social, political and economic factors hinder or nurture the actualization of those freedoms.[5] Race, class, and gender shape the birthing and reproductive healthcare experiences of Black women in American systems.[6] Aligned with this framing, we hoped to foster conversations that were intersectional and holistic.

PARTICIPANT CHARACTERISTICS

A total of 12 Black women participated in the listening sessions.

Ages from **18-54** years old.

Most resided in Omaha, Nebraska.

Capture reproductive healthcare reflections that spanned over the last forty years.

Participants had given birth at least once, with the most being five births and all had experienced seeking birth control, coordinating gynecological and annual healthcare visits and some spoke about abortion related experiences.

Status of insurance for participants included none, Medicaid, private, and employer-based.

There was a mix of relationship statuses including single, married and divorced.

LISTENING SESSION RESULTS AND THEMES

The listening sessions provided critical information about the unmet needs of Black women in these spaces and allowed for us to understand the positive encounters that bred trusted exchanges. The listening session results are organized by categories that highlight broad divisions.

- **Partnership in Practice:** depicts what's been working well when healthcare providers nurture trusting and dignified partnerships with their patients.
- **Power, Decision Making and Communication:** examines the practice of healthcare providers, details the distressing realities that exist for Black women, handling healthcare provider power, divides in communication, dealing with the impact of provider judgment and navigating feelings of vulnerability.
- **Psychosocial Implications of Current Healthcare Dynamics:** explores the cultural, social and personal overtones and ramifications of interactions of healthcare systems and healthcare providers.

PARTNERSHIP IN PRACTICE

Women described ideal interactions with their healthcare providers to be grounded in the notion of decision partnering.3 The decision partner concept emerged to illustrate the healthcare decision making process for a patient when considering all of those in their network who help them decide on their health related actions. While many of the women expressed that their family members, close friends, and partners were within their network of support, almost all highlighted the importance of having the opinion of their healthcare providers. When relationships built on trust and transparency were cultivated between a patient and their healthcare provider, women relayed how seen and how welcomed they felt, and the ease it brought to obtaining and maintaining their health care. The findings below highlight how intentional trust building, dignity and shared decision making experiences have improved their healthcare encounters. Women reflected on the impact of genuine health care provider empathy, clear expectations of procedures, practices and treatment options, viewing patients as experts of their own bodies and as partners in health care decision making and providing patients with sensible workarounds, so for example, recommending generic medications to save money.

Trust Building Between Healthcare Providers and Patients

Trust between healthcare providers and their patients is vital to cultivating a healthy, supportive health care environment. Without intentioned trust building, it may be easy to dehumanize patients during clinical experiences. In sessions, women reflected on the ways in which their healthcare providers fostered trust between them. Encounters where healthcare providers offered dignity and empathy to their patients, women reported feeling that they were more likely to trust their providers. In particular, women described trusted encounters as instances when their healthcare providers related to them on a personal level. Whether that be offering personal anecdotes about their own reproductive care to provide comfort, describing the experiences of others they have interacted with for the women to reflect on, or offering all various possibilities, before making decisions about their health.

This type of connection created a dynamic by which patients felt they could rely on and confide in their healthcare providers:

> *"…my mom made sure me and my brother had a Black female doctor and [I] will always thank her for that, because the doctor would listen to me, sometimes she would have to tell my mom, you need to sit down and be quiet, because I have to listen to her and understand what's going on with her."*
>
> *"He genuinely cares. He gives you the cut and dry, even if it's something that's scary. It's like, hey, this is a possibility, it might not happen, but it can happen. Just throwing that out there. He's very open with everything, and it's not just a 'this is what I just read right here', or 'this is what is common for everyone else', so here you go, deal with that."*

Women frequently reflected on the desire for active listening from their healthcare providers. They mentioned the need for validation from healthcare providers, when recounting their real experiences; desiring for providers to seek to understand and assess, rather than fix and dismiss; and emphasized the importance of their healthcare providers attaining a fuller context of the determinants that led to their current health.

- When more time was spent in the room, with patients during appointments, women felt they were more important to and cared for by healthcare providers.
- When providers did not rush or stunt the time around healthcare visits, women felt more trusting of healthcare providers in the encounter; regardless of visit type (e.g., annual check-ups, laboring, etc.).
- When health care guidance was personalized and informed by patient circumstances, women felt that they were in a more trusting, transparent and knowledgeable partnership.

Some examples of these statements follow:

> *"The two that met my expectations were [those that] listened to me, and then were able to incorporate my personal things [that] I would tell them about my personal life. Like if I was talking about my husband or another child or something like that, they would be able to incorporate that into the next time I would see them. They would ask about them, things like that...there was a concern about me as a person. I trusted them, probably more because of that."*
>
> *"I think it started with the doctor. He just was more patient, more hands on, he spent more time in the room for regular check up visits and such so there was a better relationship formed there."*

Women who shared their experiences, referenced building trust when they were fully informed on the processes, risks, and outcomes of their care. Once they could knowledgeably consent, it instilled a sense of agency and control over their care. When clear expectations were established and acted upon in clinical settings, women reported feeling safer and more prepared. Patients were also most comfortable disclosing health concerns after feeling informed. Below, women speak to this intersection of consent, comfortability, and trust.

> *"He went through all of my charts, he went through everything. He explained everything. He let me know everything I needed to know to make my own decision, on if I was making the right move or not. I thank him for that because I wasn't confused at all, I knew what I was getting into. I knew it may not work. He was adamant about making sure people understood and talked to them about what they were doing."*
>
> *"Just lots of questions about my comfortability, walking me through what was going to happen through each stage of this birthing process..."*
>
> *"I feel like it changes the dynamic wholeheartedly when you're comfortable and when you can be able to fully express yourself, because if you can't tell your doctor everything that is going on with you, especially with your health, because it could be a lot of things that's going on with us, that has to do with your diabetes or endometriosis and POS, that a lot of us don't know [about]."*

Dignity in Healthcare Encounters

The women we spoke with also shared instances in which they felt most dignified. This occurred when healthcare providers gave clear instructions, provided data-driven care that was reflective of medical standards and allowed for patients to make informed decisions.

- When healthcare providers walk patients through their care plans, sometimes more than once when needed.
- When there were explicit descriptors of what the patient would experience, beyond details like, "you might feel pressure".

- When healthcare providers outlined all possible risks that were present, and provided alternative options.

It was also expressed by a number of women, that easily accessing resources that helped to empower them during decision making was significant to feeling dignified in clinical settings.

For example:

> *"I like how you can sign up for your own insurance, you know what's going on, you have to know what you're signing up for, what does it mean, what does it include, and then there are so many platforms with Marketplace. Like specifically ,they give you resources and platforms to look on, within your network, and then when you pull up the providers, you can kind of see the profiles. There are reviews and pictures sometimes and background, and that's pretty empowering, because it allows me to pick and choose. There is no filter for Black women but I can see the pictures and the reviews."*

Recognition and appreciation of the differences (e.g. biological, genetic or behavioral) that occur within humankind, without inserting shame or othering, notably when those differences were pronounced or meant they needed treatment, helped foster a dignified relationship between provider and patient. A woman illustrates this below:

> *"[It's] not the same for every woman, that's not how that works. Everyone's body is different, and he was someone who really helped me understand that. You're not broken, just because you don't work like everyone else, or because you might have something that is a little different, it just means it's just an individual trait of yours."*

Partners in Care: Shared Decision Making

Women desired to understand how to meet their care needs, alongside their healthcare providers. Partnership in decision-making is a practical expectation in the patient/healthcare provider dynamic.7 Women appreciated having a healthcare provider that was open to helping them weigh all of their options for obtaining health and wellness, on their terms. It is especially important for healthcare providers to be viewed as a trusting guide throughout their reproductive journeys. As women mature through their reproductive experiences, starting with puberty and sexual education and moving through birthing experiences and the menopausal stage, they encounter medical myths, preconceived notions and advancing medical advice that may change over their life course.

Having a solid foundation between patients and their healthcare providers can help ensure that women feel comfortable getting the necessary guidance to approach their health; in a way that leaves them feeling in control, and aware of the elements that impact them and their care. Beyond outside influences, women often dealt with the experience of information paralysis, notably, when they had to find information on their conditions or procedures themselves. A shared partnership could help to alleviate these concerns, as patients would have the opportunity to have a knowledgeable advisor to walk them through what they know.

> *"I think it's more of understanding all of my options…I just know of popular ones and then I hear all of the negatives about it, and I get scared. And then, I have the doctor persuading me a certain way and then she'll be like don't Google it because then you're going to scare yourself out of it and then I just end up not doing anything."*

A willingness to talk and answer questions were one of the most salient indicators, to women in the sessions, that they were in a shared, respectful partnership with their healthcare provider. Talking openly and questioning in conversation nurtured women's comfortability and lent them to more likely saying they felt supported during decision making. Women also mentioned the importance of having a connection to tangible resources or referrals, available directly following their healthcare visits. This indicated to them that their provider had listened about what they wanted, had urgency in linking them to the care of their choice and considered the context in which they live, to provide an immediate directive for next steps.

POWER, DECISION MAKING AND COMMUNICATION: EXAMINING THE PRACTICE OF HEALTHCARE PROVIDERS

Women's stories about their experiences with healthcare providers were not always positive. Most of their narratives highlighted experiences of being overlooked, unheard or discounted. Evidence suggests that this experience is commonplace in healthcare settings for Black women.8,9 For example, research shows that Black women use family planning services and counseling more than any other reproductive-aged women. However, they end up rating those experiences much more poorly than their white counterparts. In this section, we highlight responses that speak to the effects of negative healthcare experiences.

Feeling Alone in Decision Making

Some of the most compelling conversations during the listening sessions focused on patients who felt alone in their healthcare decision making. Women described how lonely their healthcare experiences can feel when their provider is not an active participant. One woman reflected on loneliness, in the context of making a decision about her birth control:

> *"…I feel like everyone feels like they go through it by themselves, simply because it's not something that's really talked about. You can talk to your friends or your family about it and their experiences, but my mom, she's not on birth control. My sister, I think she talked about it a little bit and she stopped taking birth control too after a while, because she was like I can take other preventative measures to not conceive, so there are other ways."*

Women also reflected on the loneliness experienced when healthcare decisions were made. Whether that was because there was little consideration from healthcare providers on their individual desires for their care, due to a lack of provider engagement, or because they felt like other providers would be even less concerned, so they took whatever engagement was offered, even if it was not enough. Examples of these experiences follow.

> *"I understand that as it's going on right now, we have to work fast, but you still might want to tell me what's going on. I had to take medicine that helped their lungs after they came out, if they came earlier. I had to take magnesium, they never told me the side effects of magnesium to the point where I was burning up, what is going on? I am on fire. They were like oh yeah, we gave you magnesium, that does that."*
>
> *"I didn't have options to choose from, I just pretty much listened to what she had to say and then made that judgment myself. I didn't really look into different options, because one, I know that there is going to be a very slim chance of me finding a person of color that's a doctor, especially here in Nebraska, so it was better to get her, than somebody else. She sort of understands."*

Without a strong partnership of practice, patients commonly take the initiative in their care. In contrast to the women who felt that they shared in the partnership with their healthcare providers, others felt responsible for turning into their own researcher, physician and pharmacist. One woman talked about the extra steps she has to take to ensure that she has the optimal care she deserves, when in partnership with a healthcare provider who offers little engagement with her care.

> *"…I was researching it, I looked at the information they give you when you get the prescription about all of the possibilities of what could happen if you experience this and all that, and it kind of hits you all at once, and then you go back after a second time or a third time, and you're like well I was thinking about this, I have been experiencing this and what do I do about this? Should I just stop taking it? Should I just cut it off cold turkey? Or, do I taper it down or what do I do? Most of the time they just give you the well, whatever your preference is, because if it is too severe, you should stop because you never know what you're risking. And then they don't have all of the answers either. So sometimes, it's kind of like you feel a little defeated because it's like I'm asking you because you said to ask, but now you're not even giving me the full information that I feel that I need or I should be getting. So I still feel uneasy about it, it's still something that's undecided, because for some people the pros outweigh the cons and for others the cons outweigh the pros…so you never really feel like you're receiving the best way to do something, so most of the time you have to really figure it out for yourself. So most of the time, no, it's like you're not helping, but at the same time, you do have someone to ask or they give you a bit of an idea of how to go about your next step, whether you want to continue or not."*

Healthcare Provider Power

Women recalled horrifying healthcare encounters when their providers exerted their power over their bodies and violated their dignity. This experience for Black women is commonplace and a growing body of research documents it4-6,8-13. During listening sessions, we heard from two women who described harmful birth experiences and coercive practices by their healthcare providers.

> *"I went in because I was having contraction pains, I had never had contractions, so I didn't know they were contractions. My aunt had to tell me they were contractions. They were instantly trying to stop my labor, but they didn't really tell me they were stopping my labor. They were just making these actions on me, just taking over without letting me know what was going on, it was frightening. Then I wound up having to have all of these different medicines, and staying there, and just learned as I go, what happened to me."*
>
> *"I told the doctor, I had a C-section the first time, and I kind of wanted it, but I didn't have to have it. And the second time, I had read about VBAC…You can die from that, and I was telling the doctor I didn't want to do it, but she was like you can do it, you got this… and I was like I don't know. I don't feel safe. I heard you could die with pushing and all that. She was just like, "you got it", but the Lord stepped in my seventh month, and was like she can't do it. She told me, you're not going to be able to do it. I had said the whole time I didn't want to do it, I didn't think it was safe, I wasn't comfortable, so, I'm so glad that I think the kids were breech. That was the deciding factor, they were breech and she couldn't do it."*

Misled and under informed, this woman, among others, described feeling traumatized by her birth experiences.

> *"I was definitely mistreated because I was an African-American woman. I was pregnant, early on in my pregnancy, they told me my child was nonviable and that I needed to have a D&C (dilation and curettage) immediately to save my life, and so I did. During that D&C, the physician punctured my uterus, and [I] lost a bunch of fluids and decided to stop the procedure. After the procedure was done, they told me that the nonviable pregnancy would pass on its own. Three days later, I was in the emergency room, when they did an ultrasound. They figured out I was still in fact pregnant and that the baby was viable. At that point, the doctor told me that if I lost the baby, it would be his fault. I spent the entire 9 months in and out of the hospital unable to hold down a job. I was also receiving Medicaid, which is also a reason I think I was kind of mistreated, which now that child is 13 years, so that did end in a live birth, but there was a lot of trauma that came along with that pregnancy."*

Healthcare Provider Communication

Clear communication was heavily regarded as missing from the healthcare experiences of the women who shared their stories. There were missed opportunities to build trust between healthcare providers and patients, because there was not enough information shared between parties, and the women felt more like a number than a person. Concern for their understanding of what was and would be happening to them, on a person to person level, was often absent. Communication from healthcare providers for when shifts changed, to opting for a particular medication over another, for example, were seldom discussed in detail, if at all. Women described widely feeling a dismissive regard for their wellbeing from their healthcare providers.

> *"A week and a half after I gave birth, I went back to the ER. They didn't listen to me when I said I didn't feel like what I was experiencing was normal. They did three separate vaginal checks on me, and when the fourth person came in, I said no. You guys aren't communicating to each other. I just gave birth and nobody is listening to me. He left, saying he would come back. The only person who came back was the nurse and she had someone write me a prescription for Percocet for the pain. But since I was breastfeeding, I felt that was inappropriate. None of it was okay, but I was young, and didn't know how to communicate it..."*

In some instances, healthcare providers dismissed patient experiences. A young woman described her experiences seeking care:

> *"... just the fact that he was brushing over my issue and thinking that he had helped me, that really sort of threw me off. Because I'm here telling you my issue, and you're telling me almost in a way, saying that I don't have an issue and it's not as serious as I'm making it out to be because you have this high degree, but whatever you recommended me is not giving any positive results. So obviously, something went wrong. The fact that he didn't really sit down and listen, listen to me, that made me realize that this doctor is not it."*

Some women experienced barriers in getting to speak with the healthcare provider in charge of their care or getting the critical knowledge they needed to understand what was happening to them. For example:

> *"I labored all night and into the next morning but I wasn't dilating. That afternoon I was sent home, which I questioned it because I was like, you put an IV in me, you started an induction process now, I'm not sure why I'm being sent home. They told me to go walk around the block, and I was like wait a minute, what does this mean? I don't understand why I'm being sent home, this is ridiculous. In my mind I'm thinking these things, but at that time, I had not been given permission to speak to a doctor. I did not understand my rights to say, you're not being okay to me. I was laboring, I was having contractions every 5 minutes and they sent me home."*
>
> *"I was in a lot of pain, I was having a lot of complications afterwards that weren't fully expressed to me before the procedure was done. I was talking to my primary physician, it feels like this is going on, it just doesn't seem normal, is there anything that I need to be looking for, any signs of anything, and it was just it's fine, it's normal."*

The Impact of Provider Judgment

Throughout the listening sessions, there was a large emphasis on judgment experienced within healthcare settings. Women expressed experiences where they felt that their healthcare provider's personal judgment became their prescribed professional guidance.

> *"We had our disagreements and I did let her know I kind of feel like this isn't going the right way and I don't feel like you're [using your] professional judgment, you're using your personal judgment on things that's going on and that's not how it's supposed to work, and we had words, and it was on her end, personal, because she felt a way about a decision that I made, but that's not your job to do that."*

The intersection of women's identities and how their healthcare providers viewed and treated them was a talking point all of the women considered, as they shared their experiences. In particular, women reflected on their Blackness, their class statuses and their youthful appearances or age, as they interacted with their healthcare providers.

> *"I don't know if it was because I was young, Black or inexperienced, but I feel like it was all of that that impacted my experience."*
>
> *"... I think being young is a huge thing. I think they are perceiving me as irresponsible or silly or unknowledgeable. Those things may be right, but I can notice that."*

Most of the women's introspections occurred in the context of occurring healthcare procedures and how their treatment could have been impacted by provider bias, whether implicit or explicit. Some of their reflections are below:

> *"I had 3rd degree tears. It was much worse than had I had a C-section, but they just kind allowed me to just be, and just assumed, I think because I was young...I do look at it now and I think racially and obviously they were like, my class, my status wasn't of that of someone with money. and when I look back on it now, I do think that race played a huge part of that."*
>
> *"...[my sister] didn't have her first baby until she was 29 years old, but had the appearance of a very young person, she looks young. [The healthcare provider] never stopped trying to insert what she thought my sister should do, instead of allowing my sister to make her own decisions and honestly once you get in that room and you're the patient, you sometimes don't think straight."*

There was also consideration of their insurance status and how that may have impacted their quality of care and the attention they received from healthcare providers.

> *"I had insurance [for the] second and third births, so I was able to access better quality care. I had a better doctor and maybe that was the difference. Maybe that's why there was a little bit more care and concern, because I wasn't a Medicaid patient at that point."*

Research supports this as an often frequent dynamic within healthcare provider and patient interactions, that has become to a certain extent expected by Black women.[10]

> *"...when I went to the doctor the first time to get birth control, it was an older male white doctor that I had gone to and he was quite judgmental about me getting birth control, but we also have an entire system that is catholic-based in our city, and so birth control is an issue. That was when I was going off to college in 1989, and now here we are again. It's just insane to me that we don't seem to be getting anywhere, but I did feel quite judged. I was like, I want to be as safe as possible. There was definite pushback from him about doing it."*
>
> *"...definitely at the whim of whatever the doctor wanted, because he made it sound like I shouldn't even have been pregnant at 35 years old."*
>
> *"...but when I had expressed to her what I knew about the VBAC, we fought about it. It wasn't a one-time conversation, it was a continual let's just see, let's just see, when I'm telling you, I don't want to do that. If something is going to cause you, your life, or something like that, you should have a say."*

The women we spoke to shared experiences of pressure from healthcare providers, based on presumptive notions about who they are and what healthcare decisions they should be making. These types of coercive encounters are well documented[11], and show how healthcare providers can diminish the reproductive autonomy of their patients, and reinforce sentiments of distrust between them.[12] Social positioning of healthcare providers as sole authoritative owners of one's health care, has created a dynamic vulnerable to this.[14] As expected, women emphasized how often they had to fight through the anxiety, that fueled their hindrance to relay their health concerns to their healthcare providers.[13,14]

Navigating Feelings of Vulnerability

When seeking reproductive healthcare, the women in listening sessions spoke frequently about feelings of vulnerability in the context of their healthcare. Interactions with healthcare providers commonly left them feeling exposed, forgotten and unprotected.

> *"I would have anticipated being able to have open communication and a line of trust. That my healthcare would mean something to my doctor and that I would be considered as a person, and not just a chart."*
>
> *"I find that when you're laboring, you see a nurse every 2 hours if you're me, because I wasn't a fast laborer. I'd have to call them, I'm like where is my person?..because I'm confused as to how you left me in the room, with this man, who has never been in the room with a woman who is laboring, and he's supposed to be my 'coach'. I love him, he's amazing and he's a great partner. He is not a birthing coach just because we went to Lamaze class, he has more questions about this than I do."*

> *"The honesty, the treatment, the way that they make it seem like we feel no pain or that we are able to overcome so much, to where it seems like we have to be strong. No we don't. We're vulnerable just like anybody else, if not even more, because we get so much, I don't want to say mistreatment, but we face so many different things that other people face in the world…We wake up every day and handle things. I don't want to handle it at the doctor's. I don't want to handle it at the hospital. I don't want you to tell me that my emotions are too much when I handle my emotions everyday. I keep my composure every day, whether it's my kids, whether it's my coworkers, my spouse, my parent, my sibling, anybody…Like the expectation seems [to be] that we are basically robots…It's a real distance and I don't think people really realize that, especially when it comes to your health. Well, should I not be passionate about my health? Shouldn't I care more than you because it's actually me?"*

Often women were unable to verbalize what exactly about their experiences needed to change, but spoke about lingering emotionality after their encounters with healthcare providers. For example:

> *"Coming out of that first birth experience, I didn't necessarily know what it should look like or what that experience should feel like, but I knew how I didn't want to feel. I couldn't exactly pinpoint this is what I want, but know this is what I don't want, this is what I'm not going to accept."*

As author, poet and civil rights activist Maya Angelou has said, "I've learned that people will forget what you said, people will forget what you did, but people will never forget how you made them feel." The echoes of negative encounters commonly reviverated throughout the stories the women shared about their reproductive healthcare experiences. One woman described her fears related to her own mortality, vulnerability and the experience of childbirth. She expressed the reality of traumatic Black celebrity childbirth experiences, indicating that even if they struggled to be seen properly by medical staff, and they had power and fame, how could she?

> *"It scares me, the infant mortality rate for Black women scares me. The way you still hear Black women being treated while giving birth is scary. When it's celebrities and you're like oh shoot, if that's how they treat this person, what hope do I have of having? You just keep fingers crossed that I come out of this okay that I'll survive and that my child survives. No woman should have to feel like that, of any color."*

Another woman spoke about the trauma of her first birth, as she felt at the whim of her student birthing staff. She described what happened when her gynecologist had to manage two concurrent births and decided to let student physicians lead her labor and delivery. After major tearing and poorly done stitching that had to be resewn by her gynecologist later, she felt alone, and expressed that she feared for her safety at numerous times during her birth.

> *"It was very negative. It was a joyous occasion, but I was a new mom, so I was already scared. So it just added to my anxiety. I didn't think I would ever have kids again."*

Provider insensitivity that causes vulnerability for Black women in healthcare settings is a documented occurrence.[15,16] Black women experience suboptimal healthcare, at a time when they are incredibly vulnerable and are in the process of seeking or receiving help or direction, they are made to feel more at risk and endangered.

PSYCHOSOCIAL IMPLICATIONS OF CURRENT HEALTHCARE DYNAMICS

The findings described above provide further evidence and align with existing research about how Black women engage with systems that have historically oppressed them, in the context of heightened vulnerability, how racial dynamics manifest in healthcare, and give insight into the lasting implications of interacting with healthcare systems for Black women. Below we delve more deeply into these topics. Here, we contextualize Black women's voices in the cultural and racial paradigms at work, in the larger social landscape, to better understand the factors at play, and those that develop over time, when understanding how women seek care for their reproductive health.

SUPERWOMAN SCHEMA: COPING WITH UNMET NEEDS

Most of the women interviewed described what it is like to carry the burden of unmet healthcare needs. Given this enduring dynamic, many women have noted the need to turn inward, to cultivate an internal strength and fortitude, when engaging with their healthcare providers. Frequently regarded as the Superwoman Schema, this notion positions the idea of the 'strong Black woman' as a cultural phenomena that Black women often rely on in stressful circumstances, due to their recurrent experiences with disenfranchisement, oppression and adversity.[17,18]

While sharing their stories, many of the core elements of the Superwoman Schema were described and elevated, as permanent practices that the women engaged in, in order to protect and advocate for themselves. Those core tenets are:[18]

- Obligation to manifest strength
- Obligation to suppress emotions
- Resistance to being vulnerable or dependent
- Determination to succeed, despite limited resources
- Obligation to help others

Most central to experiences with reproductive healthcare were the obligation to manifest strength, the obligation to suppress emotions and the determination to succeed, despite limited resources. The practice of exuding strength without emotionality (e.g. resilience) is one that Black women are acclaimed for; however, if we contextualize these actions, Black women don't often get to choose strength, but adopt this demeanor out of necessity to survive. Two testimonies highlighted this best:

> *"…It's hard to continue to try to fight that because so many people have that idea, well you're so strong, well I don't have options…"*
>
> *"…and you just kind of pushed through it because that's what you do. That's what strong Black women do."*

When discussing how experiences with reproductive healthcare providers have shaped how she viewed herself and her health, a young woman responded:

> *"It made me sort of realize that [if there is not going to be significant change]…we are going to keep jumping through hoops or we're going to have to keep fighting and having to keep explaining. So, it's sort of something that I'm like, I'm going to have to start preparing myself for that. Even when we were talking about birth, if it keeps happening like this and the statistics increase with maternal deaths, then I'm going to have to prepare myself for that sort of treatment. That I'm going to receive the same treatment that this woman received when she was giving birth. It's going to make me more aware and open my eyes and try to look for this type of specific treatment in the future, but right now, I'm just educating myself on it and trying to prepare myself unfortunately."*

Women in the listening sessions mentioned that in order to understand their own health and treatment options, they would have to self-educate; using their own research skills, seeking out perspectives from other women in their lives, who had gone through similar situations, and identifying resources in their communities, using word of mouth.

> *"I had to learn a lot about myself on my own. I made a lot of decisions once I started understanding that I was not feeling like I was getting treated necessarily the same way or with equity or wasn't getting the right information or the information I needed. So, I just started researching how women's bodies work. I needed to know. If I know what my body is supposed to do and my body's not doing it, then I know I need to move forward and do something different…I've been lucky in that I've had a lot of education around my own body but I've felt like when I've encountered doctors who were not as interested in me as a patient and a human being as they were in me as just a body to see what's going to happen…"*

In their testimonies, women said often that their healthcare providers did not listen to their concerns; that they had had bad previous experiences, that caused them to no longer trust their healthcare providers; that they frequently felt second opinions were necessary; and, that they experienced a lack of clear communication, without medical jargon, as reasons for having to do research on their own.

> *"I feel like I have all of the tools necessary to do what I need to do for my health. Even without insurance, it's still possible, just more difficult, but I have the tools."*

Some women, who were also mothers, described how they would talk to their daughters about advocating for themselves. A process akin to preparation and training, for what would inevitably be their own experiences. A mother describes her experiences below:

> *"...my daughters have always said that I'm really hard on them. I'm like I don't want to be hard on you, I want you to be able to stand up for yourself. I will always be your advocate. I will never ever let you be in a situation where you don't have somebody standing with you to do what you need done for you...you need to be able to understand that you have that person, but you also need to be able to speak up for yourself..."*

HEALTHCARE ENCOUNTERS: CONSIDERING THE IMPACTS OF RACE AND IDENTITY

Discussions of race, and the expressed desire to have a Black healthcare provider, were laced throughout the listening sessions. Women felt that having a Black healthcare provider might save them from having uncomfortable or harmful interactions. Memory of historic instances of broken trust and misconduct are much more present in Black communities, which can exacerbate the impact of contemporary cases of harm, and continue to foster distrust.[19] Heir loomed relational dynamics can hinder the sharing of patient knowledge, practices and behaviors.[20] Sharing is vital to patient care, as it gives healthcare providers the context and background necessary for diagnosis and treatment.13In conversation, women mentioned often that their reproductive healthcare visits were discomforting. This most frequently dissuaded women from asking questions or bringing up other thoughts for advice. They had experiences where their healthcare providers could not engage with what they asked or grasp why they had had a certain inquiry, which made them feel hesitant to share their thoughts transparently.

> *"With our family doctor, he was great, nice and everything, but I feel like with him, he was a white guy and I'm Black obviously, and so I felt like there were some things that I would want to ask him but I don't think that he would be able to understand or give me the proper answers or next steps to take just because as a Black woman, he's not going to be able to understand from my perspective, my viewpoint. There were times when I would bring up some issues, and he really didn't know exactly what to say..."*

Below, one woman spoke to the real implications of racial dynamics between healthcare providers and their patients. She notes that they can and have contributed to patient death. Another provided an example of when it impacted her ability to get comfortable with a healthcare provider, who was trying to teach her to breastfeed.

> *“I think this is really important to bring to light, a lot of people need to start realizing this, especially minorities. I don’t think we really pay that much attention or see how problematic it is for us and how much of an impact it is in the future, if we don’t do anything now about it. People die. It’s awful.”*
>
> *“I do remember I wanted to breastfeed and they had a breastfeeding person, lactation specialist, but I didn’t feel particularly comfortable with her, and I feel like I was still kind of awkward in my own skin and it was weird for me. For this older white lady to be trying to touch my breast and move it and I was like no thank you, and so I never quite got the hang of it, couldn’t quite get the baby to latch, the baby was crying and I was crying. It was a whole bad thing and I was like well we’re not doing this.”*

Research indicates that racial sameness between healthcare providers and patients is associated with patient ratings of better care.[21] Patient trust,[22,23] satisfaction,[24] utilization of services,[24] intention to adhere[25] and joint decision making[26] are all increased when both the healthcare provider and the patient have the same race. This was echoed in our data:

> *“I feel seen by doctors of color.”*
>
> *“Even just in the last year and a half, I was at just a regular annual visit and it’s been covid, it’s been all of these things. It’s been a racial uprising. There is turmoil everywhere. And, so we’re talking about me having a little anxiety, and I’m like yeah, I do, definitely, and the immediate response was, ‘Well, I feel that you should talk to our behavioral specialist to try to help you with your anxiety’, and I said, ‘I might think about that’, but they sent her in immediately. I did not ask to see her. I did not give them a positive on it. I wasn’t like, ‘Yes, I should do that and I’m interested in that’. On some level, I felt like, and I’ll tell you the other thing that bothered me was, I’m a Black woman in my 50s, and this was clearly a white woman, in her late 20s, early 30s. So I’m like, she can’t help me. Period. As a professional in this field, you should know that she can’t help me, and the fact that I wasn’t given the opportunity, you did not listen to me when I said it was something I would think about…I didn’t ask for it.”*

However, not all interactions have been safe and without unwanted pressure or influence from healthcare providers, in same race encounters. We asked one woman about a situation where she had mentioned that a Black healthcare provider was used to push her on a decision she was making.
We asked:

> *“Do you feel like she could have potentially used her identity as a black woman to kind of drive or push you in a direction?”*

She replied,

> *“She shouldn’t have but she did…She pushed her own agenda on me.”*

The comfort of racial sameness has often been used to manipulate Black patients into making decisions, because of provider bias. One of the most notorious examples of this phenomena is in the case of the unethical “Tuskegee Study of Untreated Syphilis in the

Negro Male".[27] From 1932 to 1972, the United States Public Health Service studied syphilis at the Tuskegee Institute in Alabama. Researchers did not collect informed consent from those that they enrolled, and did not provide the men in the study with treatment, even after it became widely available in 1947. Left untreated, syphilis can cause permanent organ damage, paralysis, blindness, severe mental illness, and death. Their sexual partners had also contracted the disease; leaving not only the men and their partners impacted but their larger family units.[27]

Nurse Rivers and the physician who served as a study consultant and referred her to the study, Dr. Eugene Dibble, were both integral in the preservation of the Tuskegee Study.[28] They were Black. Considering race and power dynamics of the mid-twentieth century, we can view them as not quite villains. But regardless of the complexity of their complicity; Nurse Rivers, in particular, was used quite crucially, for her ability to serve as a trusted bridge between medical staff and the men in the study. The only full-time staff member on the study, Nurse Rivers' standing in the community, ability to calm fears and tactfully communicate and reassure study participants was vital to the conservation of the project.

At no point were considerations of race insignificant to the dialogues in our listening sessions. They emerged for women when deciding where to seek medical attention, throughout their visits and while weighing treatment recommendations. When asked if they felt race played a role in the decision making of their healthcare providers, most women responded with a yes. This sentiment is supported by existing research literature[29] and represents a significant concern on the minds of Black women when entering into healthcare spaces.

LASTING IMPLICATIONS OF HEALTHCARE ENCOUNTERS

Many of the women in the listening sessions reflected on how their engagement with the healthcare system impacted them and how they felt about themselves over the course of their reproductive healthcare journeys. Most described the process of realizing the power of their own internal voices in these spaces. For some, they felt like the dynamics they encountered forced them to build up their internal efficacy, to press against power dynamics that left their reproductive healthcare needs unmet.

> *"I would say that when I was younger I gave too much power to someone else, I put too much power in their hands. And I'm no doctor, but I do feel that there are times, if we have questions, we should not be silent…I don't mean people should talk back to their teachers or anything, but they're not always right. You can have questions. You can not feel comfortable with an answer. But I have felt, that sometimes when you put yourself in a position to ask questions and try to get answers for yourself, especially when you are a little younger, you kind of get shoved to the side like you're problematic, instead of just trying to make sure that you understand what's happening, because you're the one*

> *that's trying to survive it. I feel that as I've gotten older and as times have shifted a little bit, I feel a lot more comfortable being like, 'That doesn't make sense, explain that better to me'."*

For others, they began to build networks of support to get their needs met elsewhere.

> *"[Information, advice and recommendations] always came through the physicians, but I also built a network of moms that I could speak with during my last pregnancy, just because I felt like, I don't feel that old, I know other people have gone through this. So, I found women with lived experiences having children at 35 and older, and was able to get information and do information sharing with them that way."*

Many women were empowered by the realization that they have the right to leave a healthcare provider that treated them poorly, or made them feel uncomfortable. Commonly, the leave was a manifestation of their own self-determination, catalyzed by the fear of what might happen to them or their children if they did not:

> *"For me, it was more so understanding that we do have rights to everything. Just like doctors, they have different schools, there are different every things, we have options for everything…I got to the point where, this is my body, I'm technically the one in control of my body, so I need to be able to have the power to speak up on anything that I feel is uncomfortable, anything that I feel is not right, so it was more so me being able to be like, I have to do this."*
>
> *"…At first it was kind of intimidating because I'm like, they're doctors they should know, but then it was like, doctors aren't always right, because we're human. We all naturally make mistakes. Especially with me having kids, it was like no, because if they say something is wrong with my child and that's not what it is, I would definitely be upset, so I'm like okay, if I can speak up for my kids, I can speak up for myself."*

Some expressed that they decided to limit their interactions with healthcare providers entirely. Women who spoke to this only went in to see a healthcare provider when they were ill or injured, no longer maintaining preventive appointments, or they no longer went at all.

> *"…I've gotten to the point where I don't even use the health clinic, I don't go…"*

Lasting reflections of engaging with healthcare providers and their systems were negative. Whether that was because of unpleasant healthcare provider interactions, where women had to excessively question and advocate for themselves for desired care, or because they had to rely on information from non-medical personnel; they ended up with suboptimal care or no care, which can leave them at greater risk for disease. And while building resiliency through self-efficacy and empowerment, can be viewed positively, they fuel elements of the Superwoman Schema, which research shows is associated with negative health implications (e.g., hypertension, depressive symptoms, psychological distress, poor sleep quality, and delayed health promoting behaviors).[30,31]

RECOMMENDED CHANGES FOR NEBRASKA HEALTHCARE INSTITUTIONS AND HEALTHCARE PROVIDERS

Women in the listening sessions began their reproductive healthcare journey stories by answering how living in Omaha or Nebraska more broadly have shaped their healthcare experiences.

> *"I believe that it has made me less comfortable going to doctors. I think that I have had a few experiences that have lead me to mistrust doctors, and I would image that some of that was just based on who I had access to at the time"*
>
> *"Living in Nebraska has been very different [from the]...diversity of [my hometown] when it comes to healthcare. I sadly just don't feel comfortable enough to go searching for a healthcare doctor here, one, because again I'm not from here, and two, because I've had horrible experiences with UNL Health on campus, and I've heard horrible experiences even going through the UNMC medical program."*
>
> *"I just know that the Omaha community does have a huge Catholic base, and CHI, which is one of our major health systems, is Catholic Health Initiatives, and I have recently spoken with some people who are like yeah, we've talked to them about having a vasectomy or a tubal ligation and they've tried to talk us out of it."*

Most of the women we spoke to felt that their healthcare experiences, in Omaha and Nebraska more generally, were not optimal and often harmful. Women described instances of unmet needs, healthcare provider bias and coercion. Less than a third of the women felt neutral or positive about their experiences. In seeking to understand how to increase patient comfort and the likelihood of rating healthcare experiences more favorably, we asked women about their desired changes or recommendations for current practices.

According to responses, an ideal visit would have shorter wait times for visits and testing, increased time with healthcare providers, more transparency around healthcare provider race, a greater number of healthcare providers of color, more healthcare providers in rural parts of the state, and an increased likelihood of continuity of care, with the same healthcare provider for each visit. Many of the women emphasized their desires to see healthcare provider training made available and mandatory, to increase capacity for active listening and empathy, ability to create comfortable healthcare environments, shared decision making and to increase their capability to identify framing that may make patient experiences pressured or judgmental.

DISCUSSION AND RECOMMENDATIONS: THEMES

Shared Decision Making

A desire for a decision partner surfaced as a major theme for many of the women while discussing their healthcare. Women expressed a strong reliance on their family and friends for advice. However, healthcare providers were still considered valuable assets in navigating one's health and health care options. A patient's capacity to make informed decisions about their healthcare is greatly increased when their healthcare providers can become their trusted contributors and partner on their health related decisions. This can help to increase patient self-efficacy and capacity to follow through on health-related behavior changes and medication adherence.[32] More commonly, women expressed that their healthcare providers gaslit them, pressured them into making decisions, did not adequately describe and talk through their treatment options, medications or surgical interventions, and often left them feeling under prepared to engage in their healthcare related decision making.

For example:

> *"...I wish I had someone to say hey, that's not right, they shouldn't be treating you this way. You're being gaslit. I wish I had a support like that, that would have been so valuable to me."*

Women conveyed a desire to have more respect embedded into the dynamics of their decision partnering process. It was expressed by multiple women that they felt their healthcare providers dismissed or did not validate their own expertise of their body.

> *"Something I would like to see changed is, one, I need doctors, in particular, to be more open to hey, your patient might know something you do not know. Nine times out of 10 they know something that you do not know because it's their body."*

Healthcare providers and patients both hold invaluable knowledge important to patient health. Diminishing the contributions of patients can hinder healthcare providers from effectively treating their patients. Oftentimes lifestyle factors, habits, behaviors and attitudes impact the health outcomes of patients. Rendering their reflections and the knowledge of their lives invalid, makes a healthcare provider's job all that much more difficult. Centering patients in the healthcare provider/patient dynamic is important to building a partnership and shared sense of decision making, which both greatly improve patient satisfaction, confidence, self-efficacy and self-determination.[32]

Trust Building

For health care to be care, it is necessary to build a trusted relationship[9]. Trust is a critical component of the relationship dynamic that facilitates the sharing of information for healthcare providers, and patient buy-in, important when committing to a treatment, new medication or behavior change. Trust was a theme seen extensively throughout the listening sessions. Some women had healthcare provider experiences that made them feel quite cared for:

> *"I saw her for my whole life, I was really appreciative of her because she listened. She also listened to what my mom wanted. She would explain things."*
>
> *"...she would be like, 'Don't bring [them] in because they are just going to charge you for the same stuff, that I would prescribe you, that you can get over the counter, that you can just go buy yourself, just buy this, it's going to do the same stuff, it's going to work, you're fine'. It was really nice to have her."*
>
> *"...so I ended up meeting with him, and instantly it was just like, he was very concerned and whatever. He heard what I said and he helped find solutions for whatever I was dealing with, even when it was my postpartum. It was like okay, even if you don't want to go the medical route, here is a list of therapists to contact. Things like that. So it's not just that with the reproductive health, if I have any issues with anything else, it's like okay, 'Well here's this, maybe this will help you or here are some resources for that'. He just always had that open comfortability, to where I knew no matter what, I can go to him for anything."*

These are the sort of caring experiences, nurtured by healthcare providers, that can build trusting relationships. Healthcare providers need patients to educate them on the factors and features that shape their health. Extending from particularities about their body, to the nuances of their medical history, and the lived experiences they have had that contributed to their concerns and current conditions.[33] Without that, it may be difficult to build a trusting exchange between healthcare providers and patients. One where patients can divulge financial struggles, emotional stress burdens and issues of safety, which are all associated with poorer outcomes.[34]

For women who did not have trusting relationships with their healthcare providers, those experiences ranged from healthcare provider judgment, bias and discomfort to coercive or traumatic exchanges that led them to seeking new healthcare providers or no new healthcare providers at all. Below, we highlight practices that women expressed were central to the trust building process:

Communication

Issues surrounding communication were brought up frequently by women in the listening sessions. Whether women felt like their concerns were pushed aside, unheard, that they were being gas lit or that their healthcare providers were not being transparent, communication and the lack thereof, was central to furthering discord within the healthcare provider and patient dynamic.

> *"I feel like sometimes there is just a real - what I would consider - disconnect with folks who work in the healthcare field when they kind of go by route, where they're just doing the same thing over and over but without the thought process that everyone of these people is different and everyone of them is going to have a different birth situation and experience, so we can't all just utilize one tool..."*

> *“I know there are talks about this and having this, we need more people in healthcare who are interested in you…I think that we need to be looked at as individual people, and we are not. We are looked at as patients and that puts everyone in a position already of being either misunderstood, not heard, there is so much that happens.”*

Without communication, we cannot build towards equitable, optimal and holistic healthcare encounters? Recommendations below highly how we can move towards more trusting exchanges for Black women.

Recommendations:

- Training healthcare providers in translational approaches to health that can facilitate patient comprehension and comfort.
- Training healthcare providers in active listening and motivational interviewing techniques, to humanize patient interactions.
- Encouraging healthcare providers to provide their patients with more empathy, to help break rigid notions on how the patient/provider dynamic should function.

Birthing Practices

A considerable number of recommendations were related to what women wished they had had access to or how they had desired to have been treated throughout their birthing experiences and the postpartum period. One woman said simply:

> *“More patience and more care for everybody who’s giving birth, no matter what they look like or insurance they have… professionalism and compassion.”*

Below, we list all of the recommendations we compiled:
Recommendations:

- Offering more classes in the following domains: birthing classes exclusively for single mothers and for families, postpartum depression, developing a birthing plan.
- Providing access to doulas and midwives.
- Honoring predetermined birthing plans, when possible for patients, before skipping to provider intervention. When not possible, being explicit about what is happening to patients.
- More patient autonomy in labor and delivery rooms. Women desired having more access to water birthing options, birthing balls in delivery rooms, music throughout labor and delivery,
- Changes to appointment structures that more closely monitor mothers during the postpartum period; with more check-ins, that are more frequent and the inclusion of monitoring a mother’s mental health.
- More programmatic engagement for pregnant mothers that offer free transportation to monitoring visits, incentives such as diapers or formula and coupons or resources to offset the cost of necessary items like cribs or car seats.
- Intentional efforts to publicize and link mothers to community programs, such as Essential Pregnancy Services, that highlight housing, education and child care opportunities that are necessary to support themselves and their children.

In reflecting on what is owed to patients, the physician's Hippocratic Oath provides ethical grounding. An excerpt follows.[35]

- I will remember that there is art to medicine as well as science, and that warmth, sympathy, and understanding may outweigh the surgeon's knife or the chemist's drug.
- I will remember that I do not treat a fever chart, a cancerous growth, but a sick human being, whose illness may affect the person's family and economic stability. My responsibility includes these related problems, if I am to care adequately for the sick.
- I will remember that I remain a member of society, with special obligations to all my fellow human beings, those sound of mind and body as well as the infirm.

The findings from these listening sessions indicate that honoring the extent of the Hippocratic Oath may come at varied levels, depending on how identity, bias and judgment intersect in healthcare settings with power and practice. The day to day and standard practices of healthcare institutions and healthcare providers can remove the personhood from the patient and humanness of healthcare providers.34 It is important that healthcare providers do not forget to bring values of warmth, sympathy and a commitment to understanding, to the shared, collaborative nature of medicine.

To this end, we endorse and recommend cultivating a commitment to a reproductive justice framework for intentional practice in healthcare settings, to recenter the needs of patients more broadly, and Black women more specifically.

REPRODUCTIVE JUSTICE: A FRAMEWORK TO CONSIDER FOR A SHIFT IN INSTITUTIONAL PRACTICE

Reproductive Justice

Reproductive justice is the human right to control our bodies, our lives, our sexualities, our gender, our work, and our reproduction.1 Reproductive justice is the human right to personal bodily autonomy;[2] free from the constraints of economic, social and political powers and resources access, that bar women from being able to make healthy decisions about their bodies, sexuality and reproductive health for themselves, their families and their communities.[2] Reproductive justice asks us to examine power systems that institutionalize gendered, sexualized, and racialized acts of dominance, that instill and reverberate patterns of fear, discrimination, or retaliation in our lives.1 Therefore, reproductive justice moves beyond individualist determinations of justice at the level of personal choice and access to attend to the social realities of inequity.

Audre Lorde said, *"There is no such thing as a single-issue struggle because we do not live single-issue lives."*. Reproductive justice allows us to consider the multifaceted identities we hold, burdens we carry and capacities we have, by addressing the intersecting oppressions associated with the identities that we bring with us, and by centering the most marginalized in our work.[36] Demands for individual protections evolve to attend to community capacity to include the social supports necessary for the realization of reproductive self-determination and autonomy, which is the grounding that allows for this.[36]

Reproductive Justice Framework

The reproductive justice framework positions analysis away from downstream debates, like abortion and birth control, to consider the upstream lived conditions of women and people with reproductive systems, that contextualize their positions within these debates. In its framing, it recenters objectives to focus on the achievement of better lives for women, healthier families and sustainable communities.[36] The application of this framework catalyzes changes to structural power, in order to comprehensively transform inequities rooted in our society and fuel personal and community empowerment.[36]

An example of the power of this framing has been modeled by Asian Communities for Reproductive Justice (ACRJ) in their Three Applications of the Reproductive Justice Lens EMERJ Training Curriculum.37 The frameworks used to understand how to conceptualize, address and obtain reproductive autonomy are: reproductive health, reproductive rights, and reproductive justice.

- Reproductive health, as a frame, identifies which reproductive services are needed.
- Reproductive rights, as a frame, identifies which legal protections are central to enforcing the right to access those reproductive health services.
- Reproductive justice, as a frame, asserts that structural reproductive oppression is the consequence of the intersection of multiple oppressions, that as a social injustice, hinder access and availability of reproductive services, and as an attack on human rights, beget a need for legal protection.[37]

The fight for reproductive health, historically, has focused on reproductive healthcare service delivery and access and legal and policy protections. Expanding the frame to consider a reproductive justice lens, centers organizers, social movements and communities, to push for changes to systems, to challenge power inequalities and shift the dialogue to be more intentional. This increases our considerations from access to services and the elevation of the notions of choice and privacy, to how control and exploitation play a role in expression of gender, body autonomy and sexuality. For example, we can assess experiences more thoughtfully, by examining varied dimensions of race, class and gender. All of which impact patient assessments of acceptability, feasibility and appropriateness.[36]

CONCLUSION

This project intentionally cultivated rich dialogue among Black women about their experiences as reproductive beings. This report weaves their stories together with existing research literature that details Black experiences in healthcare settings, to contextualize and compliment their testimonies. It is our hope that these findings can guide next steps to improve Nebraska's healthcare systems and catalyze partners to more fervently advocate for the reform of healthcare systems and healthcare provider practices, policies and the power dynamics that uphold these harmful actions.

We thank the women who generously shared their invaluable insights and recommendations; who collectively provided a map to guide this work and give direction for future improvements, on behalf of the larger community of Black women living in Nebraska.

LISTENING SESSION SUMMARIES

Session Dates	Session Topics
September 26	Reproductive Health
September 28	Birth Story
September 28	Reproductive Health
October 4 *Morning Session*	Birth Story
October 4 *Evening Session*	Birth Story
October 5 *Morning Session*	Birth Story
October 5 *Evening Session*	Birth Story
October 10	Reproductive Health
October 14	Reproductive Health
October 21 *Morning Session*	Reproductive Health
*October 21 *Evening Session*	Reproductive Health
October 24	Reproductive Health
October 28	Reproductive Health

**Phone session capture*

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