Title V Supplementary Maternal Health Assessment

Perspectives from Mothers

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Context and Background

- Arizona Title V MCH assessment was completed in 2020, and the study highlighted racial and residential disparities in maternal outcomes.
- University of Arizona was contracted by Arizona Department of Health Services to carry out a study to further explore findings from the 2020 needs assessment.
- The focus of this study was on understanding maternity care experiences of women residing in rural areas and African American women.

Research Aim and Questions

Aim

To provide in-depth information on maternal health priorities in Arizona and to inform the Title V Maternal and Child Health Program and the Maternal Health Innovation Program with a focus on African American and rural populations.

Learning Questions

1. What are the barriers and facilitators to accessing prenatal, postpartum, mental, oral and telemedicine health care for pregnant women and new mothers in Arizona?
2. What additional services are needed to improve access to maternal, mental, oral, and telemedicine health care services by pregnant women and new mothers in Arizona?
3. What resources or policies would be required to improve access and utility of these critical services?

Methodology and Approach

Design

- Qualitative methodology

Data Collection

- Interviews with 39 mothers/pregnant women
- 1 Focus Group Discussion with rural mothers

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Sampling Strategy

Study Participants

- Pregnant Women
- Women who have been pregnant within the last 3 years

Sampling: Purposive sampling with assistance from community partners

Inclusion Criteria

- Lived in Arizona during pregnancy, delivery and 1-3 years postpartum
- Residence in an under-served rural area defined as any county except Maricopa and Pima
- OR Black/African American

Other Consideration

- Pre- and during COVID-19 pandemic
- English, bi-lingual Spanish/English and mono-lingual Spanish speakers

Ethical Clearance

- Ethical clearance was obtained from the University of Arizona Human Subject Research Institutional Review Board (IRB).
- Participation was voluntary and informed consent was obtained prior to each interview.

Timeline

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Participation

- Interview guides were reviewed by community partners and were piloted.
- Participants received compensation of $20 for participation in interviews and $30 for participation in the focus group discussion.
- All interviews were conducted virtually, except for one in-person interview at the participant's preference.
- Focus group was conducted virtually via zoom.

Summary of Data Collection

Pregnant Women		**9**
Rural	6	
African American	3	
Postpartum Women		**30**
Rural	25	
African American	5	
Total # Interviewed		**39**

Focus Group Discussion	**1**	**4 Mothers**

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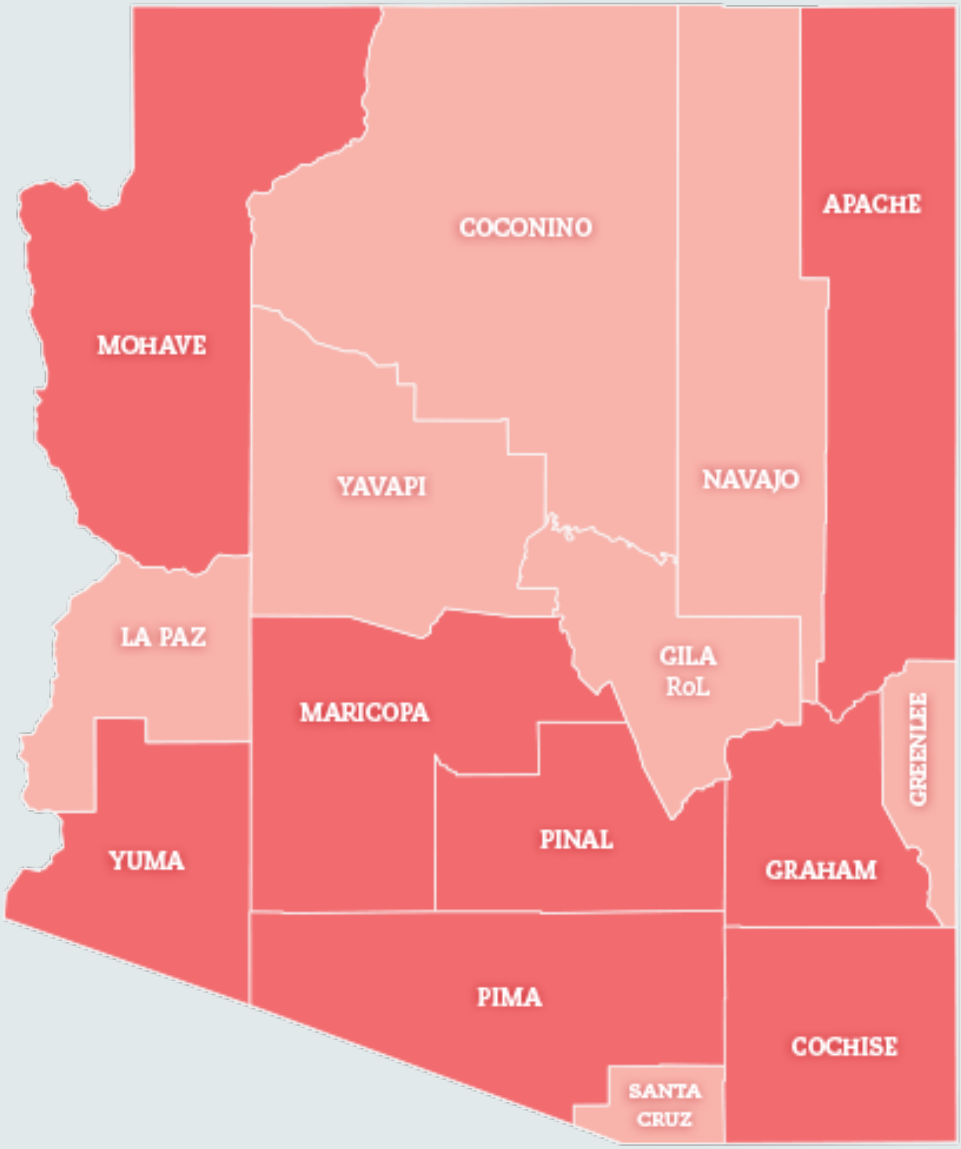
Analysis

- All interviews and the focus group were recorded with participant consent, transcribed, and, where needed, translated into English.
- Transcripts were reviewed to identify themes related to the research questions.
- Summary data were entered into a 2x2 table with themes as columns and each participant as a row.
- This Framework Analysis table was reviewed to identify key findings and pertinent cases.

FINDINGS

Participant Characteristics (1)

- 39 Interview participants.
- Across 8 Counties – Graham, Maricopa, Pima, Cochise, Mohave, Pinal, Yuma, and Apache.
- Participants from Maricopa and Pima were all Black/African Americans.
- Nine pregnant and 30 Postpartum women.



Participant Characteristics (2)

Range of social perspectives including:

- First-time mothers
- Experienced mothers
- Mothers living in a shelter
- Monolingual Spanish-speaking mothers
- Health care providers - clinical and community-based

MATERNITY CARE EXPERIENCES

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Mother's Perceptions of Perinatal Care

- Mothers have preferences that were not always heard or responded to:
  - natural birth, home delivery, doula care
  - more local (specialist) services
- Interactions were experienced as impersonal.
- Mothers would have wanted more help interpreting the information provided.
- These experiences cut across the participant sample of rural and African American mothers.

Mother's Perceptions of Perinatal Care

"I remember my doc, the OB, popping in at the very end when I was ready to push. And that was the end of seeing her. At that moment, I didn't care. But after the fact, ***I didn't feel like it was very personable.*** *But I didn't have a relationship with her anyway."*

– ID74

"I felt alone. Because I felt like my care team just kind of. I had the baby, and that was done. Which I get, but at the same time, I felt dropped. And even at my six-week postpartum appointment, ***I didn't feel supported.*** *I feel like she came in to check on me. And then that was... Everything else was like, are you okay? Goodbye."*

– ID74

Mothers' Perceptions of Information Services

- **Diagnoses** – "just a piece of paper to read" mothers want help interpreting and applying the information they are provided with.
- **Birthing** – natural birth, induction, C-section – need more information to prepare and/or make an informed choice.
- **Childcare** – breastfeeding, sleep, and health.
- **Services** – midwives, doulas, pregnancy classes, breastfeeding support, postpartum support.

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Mothers' Perceptions of Information Services

"They gave me a checklist of are you experiencing this or this or this, and ***I wasn't having any issues. And so, there wasn't any education*** *further."*

– ID37

"I'm a highly educated woman and I wasn't spoken to or addressed in a manner that kind of took those things into consideration. ***It was, everything was very vague and very generalized.***"

– ID57

Mothers' Perceptions of Information Services

"When I was pregnant with my second son here, it was much more just clinical. Each visit was maybe 10 minutes long or less by the time the doctor was in the room, ***they didn't have time for questions.*** *It was just, "Okay, this appointment and there's this test. Let's do it. The end."*

– ID86

"I had wonderful support in every area, educator, hospital, well, the OB-GYN, and their clinic. Even the doctor came by, congratulated me, and gave me a little book with a bookmarker to read to my baby. ***It was a very great experience.*** *"*

– ID81

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Prenatal Care

- All the mothers accessed prenatal care.
- A few had home-based care through a midwife.
- Limited support and care for miscarriage was noted.
- Options are limited:
  - Rural areas: limited availability of providers – few OBGYN, few other specialists, no doula or midwives;
  - African American: avoided some services due to experience of or anticipation of disrespectful care – led to a preference for midwives over OBGYN.

Prenatal Care

"And then, I feel like the whole system needs a do-over because I feel like, every time, if you had a C-section, yet you want to try natural birth, it seems like it's tough to find someone in your corner for you to help you fight because you're tired. When you're pregnant or after pregnant, you're tired. You don't have a lot of energy to fight your own battles sometimes. And, ***you just need someone to help stand up for what you feel is right,*** *instead of other people going and just trying to bend you."*

– ID08

Birthing Care

- Most mothers noted birthing care was adequate or good: *“very easy wouldn’t change anything.”*
- Some mentioned lack of information, consultation, patience, and attention.
- **Case:** one mother experienced birthing care as dangerous and scary as she felt neglected while her vitals were declining (ID#32).

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Postnatal Care

- All mothers attended at least one postpartum visit for themselves at about six weeks.
- Additional visits and access to postnatal resources such as breastfeeding support, contraception, or referrals were variable/less consistent or convenient.
- Some services were not covered by health insurance, especially after 2 months.
- Mothers wanted more postpartum support.
- More support for first time parents was mentioned (how to take care of new-born babies, for husbands/partners how to support their wives/partners during postpartum depression).
- **Case:** one participant on AHCCCS and WIC accessed a breastfeeding specialist, nutrition specialist and nurse (ID#10).

Postnatal Care

"I did not have to see a specialist when I was pregnant. I may need to see a specialist now. And it's not super convenient because even if you know that ***what you need is not something that your regular OB-GYN can provide, you have to go to a check-in appointment with your OB-GYN and pay the copay and wait.***

Take time off of work, wait for them to be late, and have your 10-minute appointment to say your spiel about why you need other services from someone else for them to write you the referral. Because there's no ability to, even though you know which referral you need, ***you can't just book the appointment with the specialist.****"*

– ID71

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Postnatal Care

*"Right. So, **unless doulas were expressly covered in the insurance** that I have or that folks around here have. **I don't know that many people could afford** to do something like that."*

– ID71

*"So, I don't feel I needed any extra support because I really gave myself everything I needed. It would've been helpful to have insurance pay for it because **much of what we did was not covered by insurance.** And so, for instance, **the postpartum doula was a gift from my in-laws and my mom.** And they helped cover it."*

– ID91

Specialist Care: Cases

- Referred to specialist but not covered by insurance (ID#5).
- Unable to adhere with full bed rest recommended for placenta previa as she couldn't afford to take time off work (ID#24).
- Unable to get to mental health appointment due to childcare (ID#13).
- Logistical barriers to getting to Tucson for her referral *"it would require a lot of planning"* (ID#24).
- Specialist from Tucson weekly visit to Safford – challenges getting to the appointment due to her work (ID#29).

FACILITATORS AND BARRIERS

Postpartum Wellbeing

*"**Self-care is really hard when you have two little kids.** Both of my kids have been hospitalized multiple times in the last year. So, my youngest was hospital at four months old for failure to thrive. And then my oldest was hospitalized in May and intubated for organ failure. So, on top of just trying to recover, I also have had medical emergencies with my kids, but just, on top of that, like I said, **it's really hard to find time for yourself when you are working and being a mom and cleaning a house.** So, I try to do little things, like try to go get my nails done or I'm taking a trip this month to go see my friends without the kids."*

– ID32

Mental Health Care

- More than half of participants had a mental health screening, typically after the birth.
- Screening usually involved completing a form.
- A few mothers had a conversation with their providers about mental health.
- None of the participants received a referral for mental health care.

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Mental Health Care

- Several participants experienced postpartum depression but did not access any services for it.
- Some mothers expressed reluctance to take medications during lactation, emphasizing the need for non-medical alternatives such as bibliotheraphy or gratitude journals.
- **Case:** One participant was taking pharmaceutical medications for her postpartum depression and also pursued therapy which she paid out of pocket (ID#13).

Mental Health Care

"I was honest through all of them on my third month when I was probably at the hardest (point) I was at the worst when it came to the postpartum depression, when it came to all of that stuff, it was probably around my third month after having my son, I was pretty honest with what I said. I've never been suicidal or anything like that, so they didn't take me as a high risk, but they didn't offer anything after that. ***They didn't offer any type of services to help me with what I had, maybe they didn't think it was severe enough*** *because I've noticed that you have to either be very suicidal or want to really harm your child in order for them to think well, this is bad.*

"So, because I was at a point where I was feeling I was really depressed, and I didn't want to take care of myself. I barely wanted to even take care of my boys although I did, I felt like I didn't want to, it was just all of that. ***And they were like okay, but you don't feel like you're going to kill yourself, right?*** *And I said, well, "no" and they were like okay, well then you're fine. And I'm like, well what if in a week it leads to that? And then at six months when I felt I was getting a lot better well, there was no need to think of it as a bad thing by then."*

– ID38

Oral Health Care

- About half of the participants received oral health information as part of their perinatal care.
- Some were already aware of the importance of oral care during pregnancy.
- Several had had dental care visits during pregnancy or postpartum.
- Covid-19 and insurance coverage were cited as barriers by some participants.

Oral Health Care

"I did keep up with my dentist's appointments during my pregnancy and then after. Again, I didn't go because I just wasn't going to any providers, but something that I found out after, and ***it was actually from somebody in a breastfeeding group.*** *I think it was just a random mom in one of my breastfeeding groups. She was just basically talking about that if breastfeeding mothers don't have enough vitamins like calcium or vitamin D or whatever, and the baby is breastfeeding, that it'll come from your body.* ***If you don't have enough vitamin D or whatever, it'll pull from your teeth, in your bones, and so it's really important to make sure you're going to the dentist while you're breastfeeding*** *and make sure you're taking all of your vitamins still while you're breastfeeding. I didn't know that, and so that actually prompted me to go to the dentist because I was like okay I've been breastfeeding for a year and a half now. I need to make sure my teeth aren't going to fall out. I feel like that's probably the extent of the information that I got around oral health."*

– ID08

COVID-19

- Impacted accompaniment to clinical visits.
- Several mothers stated their clinic allowed only the patient or only one other person to attend pre-natal visits or to attend the birth due to Covid-19 protocols.
- For some mothers this was a major concern, while other mothers were not greatly affected.
- **Case:** a partner was allowed to accompany the mother, but was unable to attend a visit due to lack of childcare (ID#29).

Telemedicine for Perinatal Care

- Several mothers noted logistical advantages, especially in an emergency:
  - prevents undue exposure of the baby to the clinic setting
  - useful when the mother does not have childcare for other children
  - useful when there is no significant health issue
- Most mothers noted disadvantages:
  - not able to take measurements
  - inhibits the development of a relationship with the provider
  - hard to know what is going on
- **Case:** one participant had the experience of telemedicine and “loved the idea of being able to stay at home and ask for help” (ID#13).

Telemedicine for Perinatal Care

"If you can't get to them, versus if you have a transportation issue, or if you just really quickly want to get in to see them before they have to go see a natural patient-patient, if you can just do a quick video chat to get whatever answers you need, or just to feel secure that you're doing something right, or safe, or whatever somebody may need. ***I think that it's nice to have that option.*** *"*

– ID10

"I think that it is great. I should probably take advantage of it, but I just didn't need to, I suppose. ***I think it's a wonderful opportunity for women*** *because getting yourself and a baby out of the door, no matter how many kids you have, is just a mess sometimes. So, I think it's great. A mom can just sit down while their baby takes a nap and talk real quick about how things are going. I think that* ***would've been helpful during my C-section recovery, because there were lots of questions that I had postpartum*** *with, getting all things clean, making sure that I was doing right. It would've been nice, I just didn't think about using it, I guess."*

– ID50

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Telemedicine for Perinatal Care

"I think it's a great option to have. I mean, obviously I would prefer to see somebody in person, or ***for things where I don't want to have to take all of my kids to the doctor.****"*

– ID53

"I mean, I think telemedicine has its time and place. For me, the reason why I never did it was because it was, well, ***if I'm sick or whatnot, how are they going to be able to, I don't know, look? I don't know, check my heart?*** *How they always listen to your heart, or how they tap your knee.* ***How do they do that virtually?*** *If I'm like, "Oh, I have this thing that's going on," and I want to show them, then I feel that'd be harder too, but if it's just, "Oh, I have a cold and these are my symptoms," something basic, then I feel like it's… "Oh, I need my prescription renewed," or something like that. I don't know. I feel like* ***to get a good, full experience for the doctor, for me, I'd rather go in person.****"*

– ID60

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Health Insurance

- All participants had some health insurance during pregnancy and up to 6 weeks postpartum.
- Lack of coverage was a reason for some participants not getting the following services.
  - specialist perinatal care
  - mental health care
  - oral health
  - doula services
  - postpartum care

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Health Insurance

*"We had our small amount of money and everything, but **after having my baby, we had to borrow money from my sister, my mother-in-law, from everywhere to pay for the hospital [bill].** Even now, we are getting bills for the medications that they gave me on the side. **I felt frustrated and stressed. I was sad and angry.** I told my husband: "We can't get out of this. I want to work, but I want to be with my son."*

– Spanish-ID8

Employment

- Some participants benefited from health insurance from their or their partners' work.
- Some participants felt they cannot afford to take time off work to:
  - adhere to medical recommendations during pregnancy;
  - take maternity leave for healing and bonding with their newborn.
- Some participants left their job to care for their infants.
- **Case:** one participant earned too much to qualify for DES childcare but too little to pay for it. As a result, she missed her mental health specialist care although she had postpartum depression (childcare coverage gap) (ID#13).

Employment

"It's a want, but it's also for financial reasons. ***I was paid for only eight weeks, but the last four weeks were just unpaid.*** *I'm like, you can't do a month unpaid right now."*

– ID72

*"****My difficulty is with trying to work long hours and still nurse for my baby,*** *but then also still pump throughout the workday and at home;* ***that was more stressful than I had ever thought,*** *like trying to be the sole provider of nutrition and trying to do all of the other things that a working parent does. That was highly stressful for me."*

– ID88

Employment

"Yeah, so after I had my son, I went back to work for maybe a month, then decided it was just too stressful. ***I couldn't take care of a newborn and go to work, so I quit my job.****"*

– ID60

*"****I quit my job after I had him because I couldn't afford daycare.*** *I had two kids - I loved my job, and it was making us a little bit of money, but with daycare, it's like you're not making anything. I'd be paying the center my paycheck."*

– ID13

Transportation and Childcare

- Rural residents often have to travel 2-3 hours to Tucson or Phoenix for specialist services.
- For some participants, the lack of transportation and/or childcare was a barrier to:
  - partner attending clinical visits
  - following up on a referral for specialist care
  - postnatal visits, especially if more than one child.
- **Case:** one participant accessed transportation through a special program for pregnant women (ID#35).

Transportation and Childcare

"Yeah. I mean, I think even Sierra Vista don't have anything like that. It's probably because they had referred me for other things, but ***they keep referring me out to Tucson. I don't even have a reliable vehicle to take me all the way to Tucson.*** *And, I don't want to have to keep traveling out to Tucson constantly when* ***it's a burden.*** *It definitely drains the energy, having to travel in a hot car for two hours one way and two hours another. It's a pain."*

– ID69

"That's been challenging. I could drop them off with a babysitter or call a babysitter, but then that's more money. ***I'm spending money on my mental healthcare, spending money on the gas to get there, and then I have to spend money to have my kids watched.*** *That just adds to the stress."*

– ID13

NEEDED SERVICES, RESOURCES, POLICIES

Services and Resources

- Demand for more personal, empathetic and culturally appropriate **clinical care.**
- Demand for more **support services** including pregnancy classes, breastfeeding support, postpartum check-ups and home visits, mental health support and parenting support.
- **Mental health screening** needs to be more personal, based on a conversation – forms do not capture nuances of mental health.

Services and Resources

- Rural areas tend to have a limited number of doctors. More alternative options such as midwives, doulas, and nurse practitioners could address this gap in services, avoiding the need to travel long distances to access care.
- More child-care service options that are affordable are needed, especially in rural areas.
- More accessible **information** on diagnoses, what to expect during pregnancy, birth, and postpartum, and available support services.

Policy Priorities

- Expansion and extension of paid parental leave.
- Public health insurance coverage for pregnant women beyond 60 days postpartum.
- AHCCCS coverage for dental care for pregnant mothers.
- Dental insurance for all pregnant women.

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STUDY STRENGTHS AND LIMITATIONS

Strengths: Data Collection

- Individual interviews provided a space where participants felt comfortable sharing personal experiences.
- Participants found closure by discussing their pregnancy and postpartum experiences.
- Virtual format was convenient for most participants (one interview was in-person).

Strengths: Study Findings

- **Data Saturation** was reached for rural mothers and African American mothers in Arizona – no new themes were emerging from later interviews.
- **Strong Validity:** common themes emerged across a wide diversity of participants, counties and geographies.
- **Generalization:** Participants' stories indicate possibilities and reveal gaps within the Arizona health care system.

Limitations of the Assessment

- Purposive sample: not feasible to generalize specific findings
- Quota sample design with voluntary sign-up: participants may not be typical of the targeted populations.
- Participants' perceptions are framed by their past experiences and cultural expectations - analysis of which is beyond the scope of this study.
- Perspectives of participants' providers was not included in this study – we get one side of the story.

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- Technical assistance in study design
- Suggesting questions for the interview guide
- Assistance with recruitment

Special thanks to all the mothers who participated in our assessment

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Thank you!

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