



Severe Hypertension in Pregnancy and Postpartum Focus Group Report

Oregon Perinatal Collaborative



Acknowledgments:

The Oregon Perinatal Collaborative (OPC) gratefully acknowledges the volunteer multidisciplinary members, representing clinical and non-clinical expertise, of the Hypertension Bundle Workgroup who helped develop and review the content of the toolkit, as well as plan for implementation.

We are also grateful for the members of the Hypertension Focus Group that included Black, Indigenous, and Pacific Islander people who experienced pregnancy related severe hypertension or preeclampsia in Oregon and shared their experiences to help inform the toolkit elements, including specific recommendations.

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Inclusive language notice:

This toolkit is intended to improve care and outcomes for pregnant and postpartum people who have a wide range of gender identities. For this reason, we use both gendered and non-gendered terms including “birthing person/people,” “patient,” “mother,” and “maternal,” to reflect this range of identities. We affirm that respecting individual patient preferences regarding gendered language throughout their care is essential to respectful, patient-centered care.

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2024 OPC Black, Indigenous, and Pacific Islander Severe Hypertension Focus Group Report

Background:

In April 2024 the Oregon Perinatal Collaborative conducted a focus group for Black, Indigenous, and Pacific Islander mothers and birthing people who had experienced pregnancy-related severe hypertension or preeclampsia in Oregon. We chose to focus on these communities because Black, Indigenous, and Pacific Islander people in Oregon are disproportionately affected by perinatal mortality and morbidity and we wanted their lived experience and expertise to directly inform our work to improve care and outcomes for severe hypertension and preeclampsia.

Nine people participated in this 2-hour focus group facilitated by Crystal Coyazo, Senior Healthcare Evaluation Associate with Comagine Health. Participants self-identified as Black (both African immigrant and African American), Pacific Islander, or Indigenous and had given birth in Oregon within the past 3 years. Participants were given a \$100 gift card. This report is a summary of their responses for use in the program and toolkit development of the Oregon Perinatal Collaborative severe hypertension initiative.

Focus group participant experiences of severe hypertension & preeclampsia:

The focus group participants shared information about their experiences with severe hypertension and preeclampsia, the care they received, and their recommendations for improvement. The following are the core themes that emerged from the focus group.

Lack of knowledge about hypertension and Preeclampsia before diagnosis:

Most participants were unfamiliar with hypertension and preeclampsia before their own diagnosis. In retrospect they were concerned about how little information they had. When a participant had information about hypertension it was from previous experience with a family member.

“I had no basic knowledge prior to pregnancy.”

“I only heard of preeclampsia during my pregnancy. I feel like people are not enlightened enough. And this may be a barrier to proper self-care or seeking medical care.”



Anxiety around diagnosis:

Participants reported high anxiety around their diagnosis and what it might mean for their pregnancy.

“I went to the hospital, and I was having different symptoms, and I was examined I was checked, and they came up with a diagnosis of preeclampsia. I was so devastated because I didn't expect that to come up with my pregnancy.”

“When I was first diagnosed with preeclampsia, I really was worried. I was worried to the point that I sometimes went online to search for different remedies... and check for different options during pregnancy... So I discovered that 75 to 80% of pregnant women with preeclampsia, most of them, go through cesarean section. Yeah, that got me worried.”

Need for more clear and complete information about preeclampsia:

Participants frequently returned to their desire for more clear and complete information about their diagnosis and what to expect.

“[We need] clear and detailed explanations from healthcare providers about the condition, its progression, and potential risks to help the patient understand what to expect.”

“I had to change doctors when the preeclampsia began. The first doctors didn't really explain it. I didn't feel like they fully explained what was going to happen or what caused it. So most of the time I'd find myself googling my symptoms and what is preeclampsia because personally I like knowing stuff.”

Provider communication challenges:

Some participants experienced challenges communicating with their providers and one described the need to keep asking questions even in the face of barriers.

“The doctors acted busy and overwhelmed and I felt they were being standoffish.”

“I can relate to [another participant] saying the doctors can be busy and give you that attitude... but when it's important you don't let that stop you from asking questions.”



Fear of death:

Some participants shared about their fear of dying from preeclampsia. It will be important for providers and nurses to understand the profound impact of this fear during and after the experience of preeclampsia.

[Speaking about an interaction with her midwife] *“I told her, I’m scared for my life. Will I make it? She said. Yeah, you will make it sure. I had to pull myself together. I had to sum up courage. with her words of encouragement.”*

“So, it’s just how your body can pretend to be responding to treatment today, and by the time it’s evening it’s worse. Your life is in the balance. It’s that lethal.”

Midwife and doula support:

Participants described feeling supported, understood, and comforted by their doula or midwife.

“My doula was really kind and patient with me. Having her, I was able to really discuss explicitly and conveniently with her as compared with the doctors.”

[About her midwife] *“I got so close to her because... she also had preeclampsia during pregnancy that she really understood how the condition is... She was always there for me, giving me a lot of information, advice, and everything. So, I was just so close to her, to the point that I couldn’t hold back any information. I was free to open everything to her.”*

“One of the midwives in my case was friendly and supportive. You know, giving you that extra help, listening to you, and not being so professional... [It] just made it a lot easier for me.”

Postpartum recovery:

Participants described how important a period of rest and recovery was after their experience of preeclampsia and birth. They also described challenges, especially around mental health, during this time.

“I really needed to rest. I was told I needed to take maternity leave before my time...for preeclampsia... I wish the duration of the leave could be extended. I really needed time to rest and take care of myself and recover fully, so that I will not break down, because my health is very, very important.”



“When you're feeling bad, when you're feeling down, whether mentally or physically ... it can cause a major malfunction and emphasizing of how useful it can be to have people who support you because at that time we might be pushing people away. the feeling of helplessness, and yet not wanting pity, you know, and then you don't, sometimes you don't want to recover. It's you embracing the darkness and the helplessness, and you just wanna manage. Trust me, it can be a very thin line between depression and ...how bad can it get?”

Need for family/community support:

Participants shared how important family and community support is when going through preeclampsia and especially during recovery postpartum.

“It's really nice that you have your family who can look after you post birth because then it gets even worse. You will have to take care of yourself. You have to heal.”

“[Not having family nearby for postpartum support] really got me worried cause you know with cesarean section you still need people around to help you do things until you are fully recovered... and I didn't really have anyone around, and I didn't really have that as an option. I really wanted something different.”

Mental health support during and after preeclampsia

Participants shared that mental health support was essential during and after recovering from preeclampsia. They described the mental health impacts of the experience in their lives and advocated for therapy and support groups to be a regular part of treatment offered for anyone with preeclampsia. This was one of the strongest themes of the focus group.

“And when the society looks at it as, oh, you're a woman, this is what you were created to do, to give life, so it's not big to you. But it really is a big deal [tears up]. Sometimes you ...lose control of your feelings... you are unable to perform your duties as a mother, you might resent having your kids around.”

“Alongside medications that you have to take it should be very recommended, like there should be prescribed therapy for mothers. I know not everyone wants to do therapy and therapy doesn't exactly work for everyone the same way but it's useful and time and again, little traumatic events add up.”

“It's true that therapy should be paramount in after pregnancy care, it did work for me.”



Making sense of the experience:

Even months to 2 years out from the birth, participants were still deeply affected by, and making sense of their experiences of birth and preeclampsia.

“At least I gave birth successfully. I am alive. My kids are alive.”

“I'm grateful for the little moments of joy that my babies give me and I'm happy that I'm like on my way to healing and reconnecting with friends and family. Just getting back to how I used to be. It was really crazy.”

Traditional Medicine:

A participant described the conflict between traditional medicine and modern medicine and expressed the desire to be able to access both with ease.

“Your question brought something to my mind about traditional medicine like being in conflict with modern medicine. So it's like, we can do better together. We don't have to be at war. ...I feel like we could do it if we tried to blend things together. We all have different perspectives and, you know, beliefs, and this is what has been working for this group of people for a long time.”

Recommendations for improving care for severe hypertension and preeclampsia:

Focus group participants were asked for their recommendations on how care for pregnant and postpartum people with severe hypertension and preeclampsia could be improved. The following is a summary of their recommendations divided into specific areas for improvement.

Recommendations to improve experiences and outcomes for Black, Indigenous, and Pacific Islander families:

- Provide access to culturally-matched providers.
- Provide access to continuity of care with midwives and/or doulas.
- Provide clear and complete information about preeclampsia diagnosis and disease process.
- Organize community education on pregnancy health and complications in coordination with community leaders and religious leaders.
- Respect traditional medicine and make room for it to be used alongside clinical medicine.



Recommendations for Providers:

- Ask about questions and fears in appointments and inpatient encounters and make time for unhurried response and discussion.
- Connect patients who have severe hypertension and preeclampsia diagnoses to mental health supports such as therapy and support groups.
- Provide evidence-based, high-quality care and careful monitoring.

Health Education Recommendations:

- Provide comprehensive reproductive health education in school, in communities, and online.
- Provide education about hypertension and preeclampsia during early prenatal visits.
- Improve provider education on patient-centered care for severe hypertension and preeclampsia.
- Create and promote easy to access online education materials about severe hypertension and preeclampsia for pregnant people and for healthcare providers.

System-Level Recommendations:

- Improve mental health supports for people with severe hypertension and preeclampsia (especially postpartum support). Participants emphasized the serious toll their experiences with preeclampsia had on their mental health.
 - Provide access to support groups, particularly long-term, not just short-term groups.
 - Provide mental health support to family members of people with these diagnoses.
- Create systems so pregnant people can access continuity of care with a midwife and/or doula.
- Increase the length of protected maternity leave.
 - Educate employers about the importance of maternity leave especially for people with pregnancy complications like preeclampsia.
- Create systems that support high quality, evidence-based care and careful monitoring.
- Provide free access to high quality physical and mental health care for people with limited resources.

Report compiled by Silke Akerson.