

## Insights

# How Health Care Systems Can Isolate Women

**“I felt lonely in a moment that was a miracle. How do you reconcile those two things?”**



Rouse and her beautiful family.

Latoshia Rouse is the mother of triplets who were born prematurely, at 26 weeks gestation. She is also someone who knows too well that health care systems can both support and fail families. From struggling to find prenatal care to experiencing a dangerous postpartum hemorrhage, Rouse’s story reveals extensive holes in the health care system—holes that resulted in stress, frustration, fear, and isolation at every stage of her pregnancy journey...holes that remained despite the many compassionate and dedicated health professionals Rouse met along the way.

To improve quality by addressing these gaps, health care teams need to partner with families. They are the only ones who can accurately share their lived experiences and describe what needs to change. To shed light on the pressing need for improvement across the continuum,

Rouse shares each phase of her story here.

## **Prenatal care**

After Rouse found out she was pregnant with triplets, her fertility specialist told her to call her regular OB-GYN about maternity care. But when Rouse called to schedule an appointment, the office said that her doctor didn't deliver triplets and that she needed to find care elsewhere. No one told her where that would be though. Rouse spent days calling different practices trying to find someone who could deliver her babies, but practice after practice declined.

"I was an African American woman with a single income household and diabetes, and I was pregnant with triplets. They knew about the numbers and the odds, and that scared providers. I was a walking disparity waiting to happen," says Rouse.

Rouse's fertility specialist had also referred Rouse to a Maternal Fetal Medicine specialist (MFM) to monitor the higher risk pregnancy. Rouse considered asking if her MFM could deliver her babies but decided against it because the practice was too far away.

"I knew my babies were going to come early and I wanted to be able to see them as much as I could in the NICU, especially given my circumstances," says Rouse, who had a 3-year old son at home. "I knew it would be better for my babies to have me close, and I would have had to travel an hour back and forth while taking care of my son while my husband worked."

Eventually, Rouse connected with an obstetric office that agreed to deliver her triplets. Her relief, though, was short-lived. The provider she had been seeing stopped showing up at her appointments, and no one offered Rouse an explanation for his absence.

"One day, I'm called into the office and told that there was nothing more they could do for me there, because of my high-risk pregnancy," says Rouse. "They never gave me any information or referred me to another provider. They just walked me out of the office."

"It made me feel like I was being fired and being walked out after losing my job."

For the second time, Rouse began her search for someone who would deliver her babies. She reached out to friends on social media and finally found a doctor in her county. She had one visit in the office before giving birth to her three babies more than 13 weeks premature. In the 26 weeks and six days of her pregnancy, Rouse never had the opportunity to get to know the OB-GYN who would help her deliver her babies.

## **Delivery**

Rouse had a successful vaginal delivery, but she went through it without emotional support. Her husband was rushing to get there, but he couldn't make it in time, and she had not had the chance to develop a relationship with her provider.

*"When I think back over my delivery, the one word I would use to describe it is lonely," says Rouse.*

“I felt like I was going through everything alone. There were people standing around me—doctors and nurses—but there was nobody there coaching me, nobody holding my hand, nobody telling me I was doing good. What you see in the movies, with a support person there with the mom for the delivery, that didn’t happen for me. At one point, I remember asking, ‘can someone hold my legs?’ and they told me to hold my own legs. So I did, and I just kept pushing.”

“I got what I wanted: I had a vaginal delivery and all my babies are alive even though the odds were against us, and it was miracle. But that’s what is so hard. I felt lonely in a moment that was a miracle. How do you reconcile those two things?”

**After delivery**, Rouse went to recovery and her babies were taken to the neonatal intensive care unit (NICU). Rouse had been given pain medication but was shaking uncontrollably and felt isolated from supports. “A nurse was sitting in this really tall chair observing me, but I couldn’t see her,” says Rouse. “She would ask me questions and talk to me, but I couldn’t see her face.”

Rouse began to feel better once her NICU neonatologist came into the room to talk to her about her babies. And when Rouse’s husband arrived shortly after, she finally felt that everything might be okay. She wasn’t alone anymore.

“I’ll never forget how I felt when the NICU doctor came in and sat with me,” says Rouse enthusiastically. “He was so excited to have these three 26 weekers in his NICU, and he came in and treated me as if I had full term babies almost—he was asking me about their names and telling me how they were acting and what he thought their personalities were going to be, and just how amazed everyone was. He brought so much energy, and I felt like I was entering a new phase where we would be with a group of people who were excited to have our babies.”

“It was the first time I saw someone actually smiling and excited about my babies, and that meant a lot because I wanted to be excited about my babies.”

Her neonatologist kept Rouse and her husband informed throughout the day, sharing updates regularly, as well as photos of their three newborn babies. Rouse describes him as a pillar of support throughout her whole NICU experience, and expresses deep gratitude for all the doctors and nurses in the NICU—they taught her about the benefits of breastfeeding and skin-to-skin care, and made sure everyone in the NICU knew each baby’s name and individual needs. Throughout her babies’ stay, they provided compassionate, personalized care, and always kept her and her husband informed on how each baby was doing.

## **Hemorrhage**

Twenty days after her babies were born, Rouse woke up in the middle of the night because she felt something wet. She didn’t know what it was, but when she put her hand on her bed, blood splattered.

“I went into the bathroom and realize it was just so much blood—my bed, my floor and my bathroom looked like an emergency room,” recalls Rouse. “At that point, I went and got a towel because that was the only thing I could think of that could hold it.”

Rouse called 9-11 and her mother; her husband was out of her town for work. She sat on her couch, swapping her first towel for a second while waiting for the paramedics. She remembers feeling better when she heard the ambulance: “Someone was going to get me out of there.”

Instead, the paramedics started asking her questions while Rouse sat trying to stop the massive bleeding with a towel. “They wanted to know what happened, what I had taken...they asked me, ‘what did I do?’. I started to feel faint and asked for water, but they said I couldn’t have it because I was going to get an IV. My mother was standing in the corner crying, and I was just trying to maintain calm; I couldn’t be upset about what was happening because I needed to get to the hospital and didn’t want anything else getting in the way.”

The paramedics asked Rouse if she could stand up. When she said no, they persisted, holding her by her arms to help lift her. Weakened by blood loss, Rouse fell. It was only then that the paramedics carried her out of her house to the ambulance and started her on intravenous fluids.

U.S. maternal mortality rates for Black women are three to four times higher than rates for white women.

“There was no doubt in my mind that that happened because of racism,” says Rouse.

After arriving at the hospital, Rouse was told her bleeding had almost stopped and there were more emergent cases to prioritize. She spent the day in a small room, regularly pumping milk for her babies in the NICU. Nurses checked in on regularly, and her OB-GYN visited her once as well. While her bleeding had slowed, it did not stop and eventually required surgery.

Rouse had hemorrhaged sometime in the middle of night; she arrived at the hospital before dawn and she did not go into surgery until approximately 9 pm that night.

Rouse later learned that her surgery had been touch and go. Her surgeon told her that at one point they didn’t know if she was going to stop bleeding. Once stable, Rouse was discharged with instructions on managing low iron levels. The many other factors affecting her health—that she had three babies in the NICU, a 3-year old at home and her emotional needs—were never addressed. “My doctor who did the surgery was very comforting, but she didn’t offer me any resources. And when I went back to see my babies in the NICU after discharge, there was no pause. It was almost like I had to ignore what had happened and just keep moving.”

## **An advocate for change**

Over the next few months, Rouse continued to visit her babies in the NICU, until each were finally able to come home. Her triplets are now 6-years old. Since their birth, Rouse has committed herself to changing experiences for other moms, working with organizations and hospitals across the country on quality improvement initiatives seeking to address the gaps Rouse experienced.

“I love doctors and nurses—they helped give me a miracle. But we still need to ask, ‘can we do more?’,” says Rouse. “We need to ask, ‘What other improvement can we make?’ And we need to try to make sure the whole person is seen, rather than looking at just one moment or piece of data.”

“All of us have lessons in our stories—I share mine to make it better for all the families who come behind me.”

Rouse is a family partner on the [National Network of Perinatal Quality Collaboratives \(NNPQC\)](#), a national initiative funded by the Centers for Disease Control and Prevention (CDC). As the coordinating center, NICHQ partners with PQCs seeking to deepen and accelerate improvement efforts for maternal and infant health outcomes.