Nothing Protects Black Women From Dying in Pregnancy and Childbirth

Not education. Not income. Not even being an expert on racial disparities in health care.

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On a melancholy Saturday this past February, Shalon Irving’s “village” — the friends and family she had assembled to support her as a single mother — gathered at a funeral home in a prosperous black neighborhood in southwest Atlanta to say goodbye and send her home. The afternoon light was gray but bright, flooding through tall arched windows and pouring past white columns, illuminating the flag that covered her casket. Sprays of callas and roses dotted the room like giant corsages, flanking photos from happier times: Shalon in a slinky maternity dress, sprawled across her couch with her puppy; Shalon, sleepy-eyed and cradling the tiny head of her newborn daughter, Soleil. In one portrait Shalon wore a vibrant smile and the crisp uniform of the Commissioned Corps of the U.S. Public Health Service, where she had been a lieutenant commander. Many of the mourners were similarly attired. Shalon's father, Samuel, surveyed the rows of somber faces from the lectern. “I’ve never been in a room with so many doctors,” he marveled. “... I’ve never seen so many Ph.D.s.”

At 36, Shalon had been part of their elite ranks — an epidemiologist at the Centers for Disease Control and Prevention, the preeminent public health institution in the U.S. There she had focused on trying to understand how structural inequality, trauma and violence made people sick. “She wanted to expose how peoples' limited health options were leading to poor health outcomes. To kind of uncover and undo the victim blaming that sometimes happens where it’s like, ‘Poor people don’t care about their health,’” said Rashid Njai, her mentor at the agency. Her Twitter bio declared: “I
see inequity wherever it exists, call it by name, and work to eliminate it.”

Much of Shalon's research had focused on how childhood experiences affect health over a lifetime. Her discovery in mid-2016 that she was pregnant with her first child had been unexpected and thrilling.

Then the unthinkable had happened. Three weeks after giving birth, Shalon had collapsed and died.

The sadness in the chapel was crushing. Shalon’s long-divorced parents had already buried both their sons; she had been their last remaining child. Wanda Irving had been especially close to her daughter — role model, traveling companion, emotional touchstone. She sat in the front row in a black suit and veiled hat, her face a portrait of unfathomable grief. Sometimes she held Soleil, fussing with her pink blanket. Sometimes Samuel held her, or one of Shalon's friends.

A few of Shalon’s villagers rose to pay tribute; others sat quietly, poring through their funeral programs. Daniel Sellers, Shalon's cousin from Ohio and the baby’s godfather, spoke for all of them when he promised Wanda that she would not have to raise her only grandchild alone. “People say to me, ‘She won't know her mother.’ That’s not true,” Sellers said. “Her mother is in each and every one of you, each and every one of us. ... This child is a gift to us. When you remember this child, you remember the love that God has pushed down through her for all of us. Soleil is our gift.”

Underneath the numb despair was a profound sense of failure — and an acute understanding of what Shalon’s death represented. The researcher working to eradicate disparities in health access and outcomes had become a symbol of one of the most troublesome health disparities facing black women in the U.S. today, disproportionately high rates of maternal mortality. The main federal agency seeking to understand why so many American women — especially black women — die and nearly die from complications of pregnancy and childbirth had lost one of its own. Even Shalon's many advantages — her B.A. in sociology, her two master's degrees and dual-subject Ph.D., her gold-plated insurance and rock-solid support system — had not been enough to ensure her survival. If a village this powerful hadn't been able to protect her, was any black woman safe?

The memorial service drew to a close, the bugle strains of “Taps” as plaintive as a howl. Two members of the U.S. Honor Guard removed the flag from Shalon’s coffin and held it aloft. Then they folded it into a precise triangle small enough for Wanda and Samuel to hold next to their hearts.

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In recent years, as high rates of maternal mortality in the U.S. have alarmed researchers, one statistic has been especially concerning. According to the CDC, black mothers in the U.S. die at three to four times the rate of white mothers, one of the widest of all racial disparities in women’s health. Put another way, a black woman is 22 percent more likely to die from heart disease than a white woman, 71 percent more likely to perish from cervical cancer, but 243 percent more likely to die from pregnancy- or childbirth-related causes. In a national study of five medical complications that are common causes of maternal death and injury, black women were two to three times more likely to die than white women who had the same condition.

That imbalance has persisted for decades, and in some places, it continues to grow. In New York City, for example, black mothers are 12 times more likely to die than white mothers, according to the most recent data; from 2001 to 2005, their risk of death was seven times higher. Researchers say that widening gap reflects a dramatic improvement for white women but not for blacks.

The disproportionate toll on African Americans is the main reason the U.S. maternal mortality rate is so much higher than that of other affluent countries. Black expectant and new mothers in the U.S. die at about the same rate as women in
countries such as Mexico and Uzbekistan, the World Health Organization estimates.

What’s more, even relatively well-off black women like Shalon Irving die or nearly die at higher rates than whites. Again, New York City offers a startling example: A 2016 analysis of five years of data found that black college-educated mothers who gave birth in local hospitals were more likely to suffer severe complications of pregnancy or childbirth than white women who never graduated from high school.

The fact that someone with Shalon’s social and economic advantages is at higher risk highlights how profound the inequities really are, said Raegan McDonald-Mosley, the chief medical officer for Planned Parenthood Federation of America, who met her in graduate school at Johns Hopkins University and was one of her closest friends. “It tells you that you can’t educate your way out of this problem. You can’t health-care-access your way out of this problem. There’s something inherently wrong with the system that’s not valuing the lives of black women equally to white women.”

For much of American history, these types of disparities were largely blamed on blacks’ supposed innate susceptibility to illness — their “mass of imperfections,” as one doctor wrote in 1903 — and their own behavior. But now many social scientists and medical researchers agree, the problem isn’t race but racism.

The systemic problems start with the type of social inequities that Shalon studied — differential access to healthy food and clean drinking water, safe neighborhoods and good schools, decent jobs and reliable transportation. Black women are more likely to be uninsured outside of pregnancy, when Medicaid kicks in, and thus more likely to start prenatal care later and to lose coverage in the postpartum period. They are more likely to have chronic conditions such as obesity, diabetes, and hypertension that make having a baby more dangerous. The hospitals where they give birth are often the products of historical segregation, lower in quality than those where white mothers deliver, with significantly higher rates of life-threatening complications.

Looking over Shalon’s medical records, her friend Raegan McDonald-Mosley saw many missed opportunities “at multiple parts of the health care system.” (Ariel Zambelich for ProPublica)

Those problems are amplified by unconscious biases that are embedded throughout the medical system, affecting quality of care in stark and subtle ways. In the more than 200 stories of African-American mothers that ProPublica and NPR have collected over the past year, the feeling of being devalued and disrespected by medical providers was a constant theme. The young Florida mother-to-be whose breathing problems were blamed on obesity when in fact her

lungs were filling with fluid and her heart was failing. The Arizona mother whose anesthesiologist assumed she smoked marijuana because of the way she did her hair. The Chicago-area businesswoman with a high-risk pregnancy who was so upset at her doctor’s attitude that she changed OB-GYNs in her seventh month, only to suffer a fatal postpartum stroke.

Over and over, black women told of medical providers who equated being African American with being poor, uneducated, noncompliant and unworthy. “Sometimes you just know in your bones when someone feels contempt for you based on your race,” said one Brooklyn woman who took to bringing her white husband or in-laws to every prenatal visit.

Hakima Tafunzi Payne, a mother of nine in Kansas City, Missouri, who used to be a labor-and-delivery nurse and still attends births as a student midwife, has seen this cultural divide as both patient and caregiver. “The nursing culture is white, middle-class, and female, so is largely built around that identity. Anything that doesn’t fit that identity is suspect,” she said. Payne, who is also a nurse educator lecturing on unconscious bias for professional organizations, recalled “the conversations that took place behind the nurse’s station that just made assumptions — a lot of victim blaming, ‘If those people would only do blah, blah, blah, things would be different.’”

Black expectant and new mothers frequently told us that doctors and nurses didn’t take their pain seriously — a phenomenon borne out by numerous studies that show pain is often undertreated in black patients for conditions from appendicitis to cancer. When Patrisse Cullors, a cofounder of the Black Lives Matters movement who has become an activist to improve black maternal care, had an emergency C-section in Los Angeles in March 2016, the surgeon “never explained what he was doing to me,” she said. The pain medication didn’t work: “My mother basically had to scream at the doctors to give me the proper pain meds.” When white people advocate for themselves or their family members, she said, providers “think they’re acting reasonably. When black people are advocating for our family members, we’re complaining, we’re being uppity, we don’t know what we’re talking about, we’re exaggerating.”

Limited diversity in the medical profession contributes to the black mothers’ sense of alienation. Blacks make up 6 percent of doctors (though 11 percent of OB-GYNs), 3 percent of medical school faculty and less than 2 percent of National Institutes of Health-funded principal investigators. “That’s a real problem that across the spectrum that [black women] are not feeling listened to and respected—that’s a structural problem,” said Monica McLemore, a nursing professor at the University of California, San Francisco, who has conducted focus groups with dozens of mothers as part of a $50 million initiative to reduce preterm births. “The health sector doesn’t want to admit how much of this is about us.”

But it’s the discrimination that black women experience in the rest of their lives — the double-whammy of race and gender — that may ultimately be the most significant factor in poor maternal outcomes. An expanding field of research shows that the stress of being a black woman in American society can take a significant physical toll during pregnancy and childbirth.

“It’s chronic stress that just happens all the time — there is never a period where there’s rest from it, it’s everywhere, it’s in the air, it’s just affecting everything,” said Fleda Mask Jackson, an Atlanta researcher and member of the Black Mamas Matter Alliance who studies disparities in birth outcomes.

“It’s a type of stress from which education and class provide no protection. “When you interview these doctors and lawyers and business executives, when you interview African-American college graduates, it’s not like their lives have been a walk in the park,” said Michael Lu, a longtime disparities researcher and former head of the Maternal and Child Health Bureau of the Health Resources and Services Administration, the main federal agency funding programs for mothers and infants. “It’s the experience of having to work harder than anybody else just to get equal pay and equal respect. It’s being followed around when you’re shopping at a nice store, or being stopped by the police when you’re driving in a nice neighborhood.”

Arlene Geronimus, a professor at the University of Michigan School of Public Health, coined the term “weathering” for how this continuous stress wears away at the body. Weathering “causes a lot of different health vulnerabilities and increases susceptibility to infection,” she said, “but also early onset of chronic diseases, in particular, hypertension and
Weathering can have particularly serious repercussions in pregnancy and childbirth, the most physiologically complex time in a woman’s life. Stress has been linked to one of the most common and consequential pregnancy complications, preterm birth. Black women are 49 percent more likely than whites to deliver prematurely (and, closely related, black infants are twice as likely as white babies to die before their first birthday). Here again, income and education aren’t protective.

The effects on the mother’s health may also be far-reaching. Maternal age is an important risk factor for many severe pregnancy-related complications, as well as for chronic diseases that can affect pregnancy, like hypertension. “As women get older, birth outcomes get worse,” Lu said. “If that happens in the 40s for white women, it actually starts to happen for African-American women in their 30s.”

This means that for black women, the risks for pregnancy likely start at an earlier age than many clinicians — and women— realize, and the effects on their bodies may be much greater than for white women. This doesn’t mean that pregnancy should be thought of as inherently scary or dangerous for black women (or anyone). It does mean, in Geronimus’ view, that “a black woman of any social class, as early as her mid-20s, should be attended to differently” — with greater awareness of the potential challenges ahead.

That’s a paradigm shift that professional organizations and providers have barely begun to wrap their heads around. “There may be individual doctors or hospitals that are doing it [accounting for the higher risk of black women], but ... there’s not much of that going on,” Lu said. Should doctors and clinicians be taking into consideration this added layer of vulnerability?

“Yeah,” Lu said. “I truly think they should.”

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Shalon Irving’s history is almost a textbook example of the kinds of strains and stresses that make high-achieving black women vulnerable. The child of two Dartmouth graduates, she grew up in Portland, Oregon, where her father’s father
was pastor of a black church. Even in its current liberal incarnation, Portland is one of the whitest large cities in the U.S.

Thirty years ago, Portland was a much more uncomfortable place to be black. African-American life there was often characterized by social isolation, which Geronimus’ research suggests can be especially stressful. Samuel Irving spent years working as a railroad engineer; he got a law degree and later ran a city agency, but felt his prospects were still constrained by his race. Wanda held various jobs in marketing and communications, including at the U.S. Forest Service. In elementary school, Shalon was sometimes the only African-American kid in her class. “There were many mornings where she would stand outside banging on the door wanting to come back into the house because she didn’t want to go to school,” her mother recently recalled.

Shalon’s strategy for fitting in was to be smarter than everyone else. She read voraciously, wrote a column for a black-owned weekly newspaper and skipped a grade. Books and writing helped her cope with trauma and sorrow — first the death of her 20-month-old brother Simone in a car accident when she was six, then the fracturing of her parents’ marriage, then the diagnosis of her beloved older brother, Sam III, with a virulent form of early-onset multiple sclerosis when he was 17. Amid all the family troubles, Shalon was funny and driven, with a fierce sense of loyalty and “a moral compass that was amazing,” her mother said. She was also overweight and often anxious, given to daydreaming (as she later put it) about “alternative realities where people hadn’t died and things had not been lost.” When it came time to go away to college, she chose the historically black Hampton University in Virginia. “She wanted to feel that nurturing environment,” Wanda said. “She had had enough.”

By then, Shalon had noticed that many of her relatives — her mother’s mother, her aunts, her far-flung cousins — died in their 30s and 40s. Her brother, Sam III, sardonically joked that the family had a “death gene,” but Shalon didn’t think that was funny. “She didn't understand why there was such a disparity with other families that had all these long lives,” Wanda said. Shalon nagged her father to stop smoking and her mother to lose weight. She set an example, shedding nearly 100 pounds while managing to graduate summa cum laude. At the start of graduate school at Purdue University, she was a svelte 138 pounds, “very classy and elegant, a lot like her mom,” said Bianca Pryor, a master’s student in consumer behavior who became one of what Shalon called her cherished circle of “sister friends.”

They were all bearing the same burden. “There’s this feeling that we’re carrying the expectations of generations, the first ones trying to climb the corporate ladder, trying to climb in academe,” said Pryor, now a marketing executive in New York City. “There is this idea that we have to work twice as hard as everyone else. But there’s also, ‘I’m first-generation, I don’t know the ropes, I don’t how to use my social capital.’ There’s a bit of shame in that … this constant checking in with yourself — am I doing this right?”

Shalon set the bar especially high: She was pursuing a double Ph.D. in sociology and gerontology, focusing on themes she would return to often — the long-term effects of early childhood trauma and maltreatment, the impact of the parent-child relationship on lifelong health. She finished in under five years, once again with top honors — “one of the best writers I’ve had in my academic career,” her adviser, sociologist Kenneth Ferraro, said.

She tried teaching, then decided to pursue a second master’s degree, this time from Johns Hopkins. She was also juggling family responsibilities. Wanda had followed Shalon around the country, earning her own master’s degree and working in nonprofit management. “They were like the ‘Gilmore Girls,’” Pryor said. In 2008, Sam III joined them in Baltimore to take part in a study on an experimental MS therapy. With his family’s support, he’d managed to finish college and run a poetry-slam nonprofit for kids. His next goal was to walk across the stage to receive his diploma instead of using his wheelchair. In February 2009, while he was doing physical rehab to regain strength in his legs,
a blood clot traveled to his lung, killing him at the age of 32. Afterward, Wanda and Shalon clung to each other more tightly than ever.

In 2011 came what Ferraro called Shalon’s “change-the-world opportunity” — a consulting gig at the CDC with Michelle Obama’s “Let’s Move!” initiative. Soon she joined the agency’s prestigious Epidemic Intelligence Service, a training program in applied epidemiology — in her case, with a focus on community health — whose members served as first responders in health emergencies. As part of the uniformed ranks of the U.S. Public Health Service, she could eventually discharge her student debt — more than $165,000 for Hopkins alone — travel, buy a house. “The permanence was very appealing,” Pryor said.

What Shalon wasn’t prepared for was how unfulfilled she was. After Johns Hopkins, she had worked on the frontlines helping at-risk infants, teenage girls and mothers with HIV/AIDS. She was passionate about improving food and housing security to reduce people’s risk for high blood pressure and other cardiovascular problems, but felt like much of her CDC research ended up sitting on a shelf. It bothered her that she rarely met the people behind the data she was analyzing. “She might see the numbers, but I don’t think she actually saw that little girl or little boy have a healthier lunch,” Pryor said.

The stress and frustration triggered the old corrosive self-doubts. But gradually, Shalon saw a way out of the box. She joined the CDC’s Division of Violence Prevention, refocusing on issues around trauma and domestic abuse — a mission she saw as “liberating” for African-American women, Wanda said. She started a coaching business called Inclusivity Standard to advise young people from disadvantaged backgrounds who wanted to get into college or grad school, as well as organizations seeking to become more diverse. She enlisted her mother, now working as a consultant, and Pryor to join her team. And she decided to write a self-help book, on the theory that many people in the communities she cared about couldn’t afford psychotherapy or didn’t trust it. “She was one of those people — one thing is just not enough,” said her coauthor Habiba Tran, a therapist and life coach with a multicultural clientele. “One modality is just not enough. One way of [reaching people] is just not enough.”

Shalon couldn’t remember a time when she didn’t want to be a mother. But her romantic life had been a “20-year dating debacle,” she admitted in the manuscript of her self-help book, in part because “I am deathly scared of heartbreak and disappointment, and letting people in comes with the very real risk of both.”

In 2014, when Shalon was 34, medical problems forced the issue. For years she’d been suffering from uterine fibroids — non-malignant tumors that affect up to 80 percent of black women, leading to heavy menstrual bleeding, anemia and pelvic pain. No one knows what causes fibroids or why blacks are so susceptible. What is known is that the tumors can interfere with fertility — indeed, black women are nearly twice as likely to have infertility problems as whites, and when they undergo treatment, there’s much less likelihood that the treatments will succeed. Surgery bought her a little time, but her OB-GYN urged her not to delay getting pregnant much longer.

Shalon had spent her adult years defying stereotypes about black women; now she wrestled with the reality that by embracing single motherhood, she could become one. The financial risk was substantial — she’d just purchased a town house in the quiet Sandy Springs area north of Atlanta, and her CDC insurance only covered artificial insemination for wives using their husbands’ sperm. In Portland, no one would have blinked an eye at an unmarried professional woman having a child on her own, but in Atlanta, “there is very much a vibe there that things should happen in a certain
order," Pryor said. “And Shalon was not having that at all. She was like, ‘Nope, this is what it is.’”

The gamble — funded with her parents’ help — ended in a series of devastating failures. In September 2015, in the midst of one unsuccessful insemination treatment, Shalon was alarmed to discover that her right arm had become swollen and hard. Doctors found a blood clot and diagnosed her with Factor V Leiden, a genetic mutation that makes blood prone to abnormal clumping. Suddenly a part of the family’s medical mystery was solved. Wanda’s mother had died of a pulmonary embolism, so had Sam III, so had other members of their extended family. But no one had been tested for the mutation, which is primarily associated with European ancestry. Had they known they carried it, maybe Sam’s deadly blood clot could have been prevented. It was a what-if too painful to dwell on.

By April 2016, Shalon had given up. She had a new boyfriend and she was on her way to Puerto Rico to help with the CDC’S Zika response, working to prevent the spread of the virus to expectant mothers and their unborn babies. There she discovered she’d gotten pregnant by accident. Her excitement was tempered by fear that the baby might have contracted Zika, which can cause microcephaly and other birth defects. But a barrage of medical tests confirmed all was well.

More good news: A few weeks later Pryor learned she was pregnant, too. “All right,” she told Shalon, “let’s finally go after our rainbows and unicorns! Because for so long it was just dark clouds and rain.”

In reality, Shalon’s many risk factors — including her clotting disorder, her fibroid surgery, the 36 years of wear and tear on her telomeres, her weight — boded a challenging nine months. She also had a history of high blood pressure, though it was now under control without medication. “If I was the doctor taking care of her, I’d be like, ‘Oh, this is going to be a tough one,’” her OB-GYN friend Raegan McDonald-Mosley said.

Shalon got through the physical challenges surprisingly well. Her team at Emory University, one of the premier health systems in the South, had no trouble managing her clotting disorder with the blood thinner Lovenox. They worried that scarring from the fibroid surgery could result in a rupture if her uterus stretched too much, so they scheduled a C-section at 37 weeks. At several points, Shalon’s blood pressure did spike, Wanda said, but doctors ruled out preeclampsia (pregnancy-induced hypertension) and the numbers always fell back to normal.

Wanda blamed stress. There was the painful end to Shalon’s romance with her baby’s father and her dashed hopes of raising their child together. There were worries about money and panic attacks about the difficulties of being a black single mother in the South in the era of Trayvon Martin and Tamir Rice. Shalon told everyone she was hoping for a girl.

Steeped in research about how social support could buffer against stress and adversity, Shalon joined online groups for single moms and assembled a stalwart community she could quickly deploy for help. “She was all about the village,” Rashid Njai said. “She’d say, ‘I’m making sure that when I have my baby, the village is activated and ready to go.’”

She poured more of her anxious energy into finishing the first draft of the book. She sent Tran the manuscript on Jan. 2, the day before the planned C-section, then typed one last note to her child. Boy or girl, its nickname would be Sunny, in honor of her brother Sam, her “sunshine.”

“You will always be my most important accomplishment,” she wrote. “No words have been created to adequately capture the fear and love and excitement that I feel right now.”

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Until recently, much of the discussion about maternal mortality has focused on pregnancy and childbirth. But according to the most recent CDC data, more than half of maternal deaths occur in the postpartum period, and one-third happen seven or more days after delivery. For American women in general, postpartum care can be dangerously inadequate — often no more than a single appointment four to six weeks after going home. “If you’ve had a cesarean delivery, if you’ve had preeclampsia, if you’ve had gestational diabetes or diabetes, if you go home on an anticoagulant — all those women need to be seen significantly sooner than six weeks,” said Haywood Brown, a professor at Duke University medical school. Brown has made reforming postpartum care one of his main initiatives as president of the American Congress of Obstetricians and Gynecologists.

The dangers of sporadic postpartum care may be particularly great for black mothers. African Americans have higher rates of C-section and are more than twice as likely to be readmitted to the hospital in the month following the surgery. They have disproportionate rates of preeclampsia and peripartum cardiomyopathy (a type of heart failure), two leading
killers in the days and weeks after delivery. They’re twice as likely as white women to have postpartum depression, which contributes to poor outcomes, but they are much less likely to receive mental health treatment. If they experience discrimination or disrespect during pregnancy or childbirth, they may be more likely to skip postpartum visits to check on their own health (they do keep pediatrician appointments for their babies). Lack of paid maternity leave and childcare can create additional hurdles. In one study published earlier this year, two-thirds of low-income black women never made it to their doctor visit.

Meanwhile, many providers wrongly assume that the risks end when the baby is born — and that women who came through pregnancy and delivery without problems will stay healthy. In the case of black women, providers may not understand their true biological risks or evaluate those risks in a big-picture way. “The maternal experience isn’t over right at delivery. All of the due diligence that gets applied during the prenatal period needs to continue into the postpartum period,” said Eleni Tsigas, executive director of the Preeclampsia Foundation.

It’s not just doctors and nurses who need to think differently. Like a lot of expectant mothers, Shalon had an elaborate plan for how she wanted to give birth, even including what she wanted her surgical team to talk about (nothing political) and who would announce the baby’s gender (her mother, not a doctor or nurse). But like most pregnant women, she didn’t have a postpartum care plan for herself. “It was just trusting in the system that things were gonna go okay,” Wanda said. “And that if something came up, she’d be able to handle it.”

The birth was “a beautiful time,” Wanda said. Shalon did so well that she convinced her doctor to let her and Soleil — French for “sun” — leave the hospital after two nights (three or four nights are more typical). Then at home, “things got real,” Pryor said. “It was Shalon and her mom trying to figure things out, and the late nights, and trying to get baby on schedule. Shalon was very honest. She told me, ‘Friend, this is hard.’”

C-sections have much higher complication rates than vaginal births. In Shalon’s case, the trouble — a painful lump on her incision — emerged a few days after she went home. The first doctor she saw, on Jan. 12, said it was nothing, but as she and her mother were leaving his office, they ran into her longtime OB-GYN, Elizabeth Collins. Collins took a look and diagnosed a hematoma — blood trapped in layers of healing skin, something that happens in about 1 percent of C-sections. The OB-GYN drained the “fluctuant mass” (as her notes described it), and “copious bloody non-purulent
“Material” poured out from the one-inch incision. Collins also arranged for a visiting nurse to come by the house every other day to change the dressing. Collins didn’t respond to a request for comment.

Over the next two weeks, Shalon’s records show three more visits to Emory and two nursing visits at home. She feared that the incision wasn’t healing fast enough, perhaps because the blood thinners she was taking to prevent an embolism — another C-section risk — were hampering coagulation. But a wound specialist said everything looked OK. Shalon was worried about Soleil, too: Breastfeeding was harder than expected, and she’d stopped taking narcotic painkillers because she thought they were making the baby groggy. But less powerful painkillers weren’t working; between the pain and the anxiety, she was hardly sleeping. “Patient has poor endurance,” the visiting nurse noted on Jan. 16. “Leaving the home is a TAXING and CONSIDERABLE effort.”

What troubled the nurse most, though, was Shalon’s blood pressure. On Jan. 16 it was 158/100, high enough to raise concerns about postpartum preeclampsia, which can lead to seizures and stroke. But Shalon didn’t have other symptoms, such as headache or blurred vision. She made an appointment to see the OB-GYN for the next day, then ended up being too overwhelmed to go, the visiting nurse noted on Jan. 18. In that same record, the nurse wrote that Shalon had to change the dressing on her wound “sometimes several times a day due to large amounts of red drainage. This is adding to her stress as a new mom.” Her pain was 5 on a scale of 10, preventing her from “sleeping/relaxing.” Overall, Shalon told the nurse, “it just doesn’t feel right.” When the nurse measured her blood pressure on the cuff Shalon kept at home, the reading was 158/112. On the nurse’s equipment, the reading was 174/118.

“We provide caring and compassionate care to all of our patients,” the Visiting Nurse Health System said in an email. “She was in our care for less than four days but we gave the very best care we could.”

Under current ACOG guidelines, blood pressure readings that high should trigger more aggressive action, such as an immediate trip to the doctor for further evaluation, possibly medication and more careful monitoring. A history of hypertension and multiple other risks should raise more red flags, Tsigas said. “We need to look holistically at the risk factors irrespective of whether or not she had a diagnosis of preeclampsia,” she said. “If somebody has a whole plateful of risk factors, how are you treating them differently?” High blood pressure in the postpartum period should always be considered an emergency, she said.

“It would have made sense to admit her to the hospital for a complete work-up, including chest xray, an echocardiogram to evaluate for heart failure, and titration of her medication (both pain meds and hypertension meds) to sort out what she needed to feel OK and get [her] blood pressure out of the severe range,” wrote one doctor, a leading expert on postpartum care, who agreed to look at Shalon’s records at ProPublica’s request, but asked not to be identified. “Education on signs / symptoms of stroke seems insufficient — we don’t want to wait until someone is having a stroke to get their BP treated. A next-day follow-up for a BP of 174/118 seems questionable for a postpartum woman. Same-day assessment in her provider’s office, or in the ER, would have been very much within the bounds of common practice.”

Instead, Shalon was given an appointment for the following day, Jan. 19, with an OB-GYN at Women’s Center at Emory St. Joseph’s, which handled her primary care. By then, Shalon’s blood pressure had fallen, and there were “no symptoms concerning for postpartum [preeclampsia],” the doctor wrote in his notes. He wrote that Shalon was healing “appropriately” and thought her jumps in blood pressure were likely related to “poor pain control.” Wanda and Shalon left feeling more frustrated than ever.

At home over the next couple of days, Wanda noticed that one of Shalon’s legs was larger than the other. “She said, ‘Yeah, I know, Mom, and my knee hurts, I can’t bend it.’”

When McDonald-Mosley looked over the voluminous medical records a few months later, what jumped out at her was the sense that Shalon’s caregivers didn’t seem to think of her as a patient who needed a heightened level of attention, despite the complexity of her pregnancy.

“She had all these risk factors. If you’re gonna pick someone who’s going to have a problem, it’s gonna be her. ... She needs to be treated with caution.” The fact that her symptoms defied easy categorization was all the more reason to be vigilant, McDonald-Mosley said. “There were all these opportunities to identify that something was going wrong.
To act on them sooner and they were missed. At multiple levels. At multiple parts of the health care system. They were missed.”

Shalon’s other friends were growing uneasy, too. Back in New York, Bianca Pryor had her own pregnancy emergency — her son was born very prematurely, at 24 weeks — so she couldn’t be in Atlanta. But she and Shalon talked often by phone. “She knew so much about her body one would think she was an M.D. and not a Ph.D. To hear her be concerned about her legs — that worried me.” Pryor encouraged her, “Friend, are you getting out of the house? Are you going for your walks? She told me, ‘No, I’m on my chaise lounge, and that’s about as much as I can do.’”

Habiba Tran was so upset at Shalon’s condition that she took her frustrations out on her friend. “I was cussing her out. ‘Go to the f— ing doctor.’ She’s like, ‘I called them. I talked to them. I went to see them. Get off my back.’”

On the morning of Tuesday, Jan. 24, Shalon took a selfie with her father, who’d been visiting for a week, then sent him to the airport to catch a flight back to Portland. Towards noon, she and Wanda and the baby drove to the Emory Women’s Center one more time. This time, Shalon saw a nurse practitioner. “We said, ‘Look, there’s something wrong here, she’s not feeling well,’” Wanda recalled. “‘One leg is larger than the other, she’s still gaining weight’— nine pounds in 10 days — ‘the blood pressure is still up, there’s gotta be something wrong.”

The nurse’s records confirmed Shalon had swelling in both legs, with more swelling in the right one. She noted that Shalon had complained of “some mild headaches” and her blood pressure was back up to 163/99, but she didn’t have other preeclampsia signs, like blurred vision. She checked the incision — “warm dry no [sign/symptom] of infection” — and noted Shalon’s mental state (“cooperative, appropriate mood & affect, normal judgment”). She ordered an ultrasound to check the legs for blood clots, as well as preeclampsia screening.

Both tests came back negative. As Wanda remembers it, Shalon was insistent: “There is something wrong, I know my body. I don’t feel well, my legs are swollen, I’m gaining weight. I’m not voiding. I’m drinking a lot of water, but I’m retaining the water.” Before sending Shalon home, the nurse gave her a prescription for the blood pressure medication nifedipine, which is often used to treat pregnancy-related hypertension.

Emory Healthcare “is dedicated to the highest quality patient care,” it said in an email. It declined to answer questions about Shalon’s care, citing patient confidentiality.

Shalon and Wanda stopped at the pharmacy, then decided to go out to dinner with the baby. While they ate, they talked about a trip Shalon had planned for the three of them to take in just a few weeks. Ever since Sam III had died, Wanda and Shalon made a point of traveling someplace special on painful anniversaries. To mark his 40th birthday and the eighth anniversary of his death, Shalon had gotten the idea of going to Dubai. (“It’s cheap,” Shalon had told Wanda. “The money is worth so much more there. It’s supposed to be beautiful.”) She had long ago purchased their tickets and ordered the baby’s passport. Now Wanda was worried — would she be feeling well enough to make such a big trip with an infant? Shalon wasn’t willing to give up hope just yet. Wanda recalls her saying, “I’ll be fine, I’ll be fine.”

They got home and sat in Shalon’s bedroom for a while, laughing and playing with the baby. Around 8:30 p.m., Shalon
suddenly declared, “I just don’t know, Mom, I just don’t feel well.” She took one of the blood pressure pills. An hour later, while she and Wanda were chatting, Shalon clutched her heart, gasped and passed out.

Paramedics arrived to find Shalon on the floor near the foot of her bed “pulseless and not breathing...” They tried to stabilize her, then rushed her to Atlanta’s Northside Hospital, just a couple of miles from her home. In the emergency room, doctors discovered that the breathing tube had been “incorrectly placed,” according to the ambulance service report — into her esophagus instead of her lungs. She never regained consciousness. Four days later, on Jan. 28, Wanda and Samuel withdrew life support and she died.

The news spread quickly among her colleagues at the CDC. William Callaghan, chief of the maternal and infant health branch, recalled in March that his boss, who had visited Shalon at the hospital, called to let him know. “It was a chilling phone call,” said Callaghan, one of the nation’s leading researchers on maternal mortality. “It certainly takes, in that moment, what I do, it made it very, very, very concrete. ... This was not about data, this was not about whether it was going up or it was going down. It was about this tragic event that happened to this woman, her family.”

Northside declined to do an autopsy, telling Wanda and Samuel that none was required, they recalled. (The hospital declined to comment.) So Wanda paid $4,500 for an autopsy by the medical examiners in neighboring DeKalb County. The report came back three months later. Noting that Shalon’s heart showed signs of damage consistent with hypertension, it attributed her death to complications of high blood pressure.

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Wanda always knew she would be spending a lot of time caring for her granddaughter. She and Shalon loved the idea of the three of them making their way in the world together, trying to change it for the better.

Instead, Wanda has had to find a way to go on without her daughter and best friend. She took a break from her consultant work and moved into Shalon’s cozy townhouse, now crowded with baby books and gear, to assume her new role. Soleil was colicky, prone to gastric problems that kept both of them up all night. Shalon’s villagers stopped by often to help, but much of the time Wanda was on her own. Her grief was most acute at nights, but she couldn’t let it
interfere with her duties to Soleil.

Eventually the colic went away and Soleil thrived. In June, Wanda and her five-month-old granddaughter went to Chattanooga for the annual meeting of U.S. Public Health Service scientists. A new honor — the Shalon Irving Memorial (Junior) Scientist Officer of the Year Award — had been created to celebrate Shalon’s legacy, and Wanda had been asked to say a few words. She handed the baby to one of Shalon’s CDC colleagues and took the small stage.

“Striving for excellence is a choice,” she told the audience through barely suppressed tears. “It is a commitment. ... It’s a struggle to become the person you want to be. It’s harder than you want. It takes longer than you want. And it takes more out of you than you expected it should.”

Shalon personified excellence, Wanda said. “I don’t know if Shalon became the woman that she ultimately wanted to be. But I do know that she wanted to be the woman she was.”

She also knew how Shalon wanted to raise her daughter, and she was determined to do the same: reading to her, traveling with her, taking her to gymnastic and music classes. “She wanted Soleil to go to Montessori school, so I’m looking for a Montessori school for her,” Wanda said. “She wanted her to be christened, we got her christened.” Wanda and Soleil have developed a routine: Every morning they say hello to the photos of Shalon on the living room walls. Every evening they say goodnight. Sometimes Wanda shows Soleil the flag from her mother’s casket, now encased in a wooden frame. She set aside other mementos for later — the academic writings, the certificates and awards, the manuscript of her book with Tran. If all goes according to plan, it will be published early next year.

One Saturday afternoon in October, Wanda received another book, this one compiled by Shalon’s friends from the Epidemic Intelligence Service and entitled “Letters to Soleil.” She put the baby on her lap and said, “I’m gonna read you some letters about your mom.” One thing Wanda has tried never to do is cry in front of Soleil. But as she began reading aloud, she was sobbing. “And Soleil just kept looking at me — she couldn’t understand what was going on. And about a minute later she took my glasses off with her hands and put them down and then laid her head right on my chest and started patting me. Which made me cry all the more.”

Wanda in the living room of the town house she shares with Soleil. A photo of Shalon is in the background. (Sheila Pree Bright for ProPublica)
Shalon was a letter-writer too. One day not long after the funeral, Wanda found a note that her daughter had written to her two years earlier, around the sixth anniversary of Sam III’s death. Shalon had left it among the other important items in her computer, trusting that if something ever happened to her, Wanda would find it. The letter reads like a premonition of her own death: Shalon wasn’t afraid for herself, but agonized over how it would affect her mother.

*I am sorry that I have left you. On the particular day that I am writing this I have no idea how that may have occurred but know that I would never choose to leave.*

*I know it seems impossible right now, but please do not let this break you. I want you to be happy and smile. I want you to know that I am being watched after by my brothers and grandma and that we are all watching you. Please try not to cry. Use your energy instead to feel my love through time and space. Nothing can break the bond we have and you will forever be my mommy and I your baby girl!*

Now 11 months old, Soleil has her mother’s precociousness, energy and headstrong yet sweet disposition. Like the sun she was named for, “she just lights up a room when she smiles,” Wanda said. She comes into Wanda’s bed every night and wakes her early to play. “She’ll bite my nose and kick me — ‘Nana, time to get up! Time to get up!’” And so Wanda does.

*Do you know someone who died in pregnancy, childbirth or the postpartum period? Please tell us your story. If you want to reach out to us directly, email us at Maternal@propublica.org.*

*Correction, Dec. 8, 2017: An earlier version of this story said that black women are 300 percent more likely to die of pregnancy- or childbirth-related causes than black women. In fact, according to CDC data from 2011-2013, black women nationally are 243 percent more likely to die than white women.*