

Stillbirth is more common than you think — and we're doing little about it

In the United States, there are more than 20,000 stillbirths each year, a rate worse than that of many other countries.



By Sarah Muthler May 16

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Most mornings, I awake to the sound of my 2-year-old son talking to himself in his crib. I enter his room to fetch him, stepping around the books he scattered across the carpet the night before. On the wall hang prints of a fox, a bear, an owl. I decorated this nursery — for a baby girl — three years before I had Henry. The only sign of her is a box of tiny ruffled clothes in the closet.

Everything had gone well during my pregnancy with my second daughter until the final few weeks. My obstetrician found that I had more amniotic fluid than normal.

When I went for an ultrasound during my 36th week of pregnancy, the screen was motionless. I thought the machine was broken. It was not. My daughter had died. Genevieve was delivered that same day, and she looked as healthy as a baby who is not breathing can look. Grief swallowed me.

Among many unthinkable questions, like which funeral home we preferred, nurses asked my husband and I whether we wanted an autopsy. Our doctor discouraged us from spending several thousand dollars on one. She said that DNA testing on Genevieve and me was more likely to determine a cause. We received the death certificate — cause of death unknown — less than two weeks later.

Stillbirth might seem like a tragic relic from a bygone era, but it's relatively common. About 24,000 stillbirths, defined by the Centers for Disease Control and Prevention as the death of a fetus at 20 weeks of pregnancy or later, occur every

year in the United States. Black women in particular are vulnerable: One of every 87 pregnancies for this group ends in stillbirth, a rate double that of white women. Overall, stillbirth is 10 times more common than SIDS (Sudden Infant Death Syndrome).

This is not the case in every country. The World Health Organization ranks the U.S. stillbirth rate 25th in the world, with 3 per 1,000 babies stillborn. Top-ranked Iceland's rate is less than half that. And the United States has made some of the slowest progress of any country in reducing stillbirths. Between 2000 and 2015, the U.S. rate declined by 0.4 percent per year, putting us at 155th out of 159 in the world. We were joined at the bottom by Chad and Niger.

Unlike other countries, the United States has no national system to report and evaluate stillbirths, though the CDC says this is a crucial step in reducing them. About half of stillbirths are unexplained. Stillbirth experts say that the government's failure to fund data collection and stillbirth evaluation is preventing progress. So too is the lack of insurance coverage for autopsies and genetic tests after a stillbirth. If we don't know more about why they happen, we won't be able to prevent them.

Stillbirth research is far behind that for infant death. "It's really been an overlooked health problem that is a huge burden for women, and people don't realize how common it is," said Ruth Fretts, an assistant professor of obstetrics and gynecology at Harvard Medical School and a leading stillbirth researcher. She noted that cases of SIDS have been thoroughly evaluated for 30 years. Researchers found that SIDS was more common in babies put to sleep on their stomachs. The government instituted a campaign for doctors to educate parents about SIDS risks, and the SIDS rate decreased 50 percent.

Stillbirth has not received the same interest because the public underestimates its devastating toll and also tends to view it as inevitable, Fretts said. (Plenty of strangers, and even some family members, told me after Genevieve's death that everything happens for a reason.) Stillbirth is sometimes equated with miscarriage, which usually happens in the first 12 weeks. But while the majority of miscarriages are caused by genetic errors and cannot be prevented, stillbirths

are often preventable; 14 percent of stillborn babies in the United States have congenital abnormalities, according to the March of Dimes.

“We still need to get an understanding of why stillbirths are happening,” said Uma Reddy, an OB/GYN with the National Institutes of Health. With so many stillbirths unexplained, it’s difficult for doctors to predict which women will have one. In one decade-old study that looked for causes of stillbirths, the most frequent cause, cited in 29 percent of cases, was obstetric complications. That category includes things such as preterm labor and placental abruption, in which the placenta detaches from the wall of the uterus. The second most frequent cause, cited in 24 percent of cases, was abnormalities of the placenta. But that study, conducted by the Stillbirth Collaborative Research Network, wasn’t large enough to inform changes in prenatal care.

Researchers expect to someday develop screening tests for stillbirth similar to the blood tests and ultrasounds used to check for other pregnancy complications, said Bob Silver, chief of maternal-fetal medicine at the University of Utah Health Sciences Center. Research on prenatal problems linked to stillbirth, such as preterm labor, can help reduce deaths, but more money is needed specifically for stillbirth research, Silver said. Increased funding would help doctors address the huge knowledge gaps they currently have, he said. Being able to predict stillbirths would also decrease maternal and infant deaths, Silver said, because they often stem from the same problems.

Other countries are doing a far better job of unraveling the causes of stillbirth, according to data reported by the medical journal the Lancet in January. The Netherlands cut its rate of stillbirth by an average of 6.8 percent per year between 2000 and 2015, partly thanks to a national program to evaluate stillbirths that was implemented in 2010. Doctors explain the importance of an autopsy and placental exam to parents, and those exams are provided for free. A medical team also reviews each case of stillbirth. The testing and evaluation performed by doctors in the Netherlands helps them pinpoint problems in medical care and correct those problems, Fretts said.

The United States has made few meaningful attempts to address stillbirth. In 2014, President Obama signed into law

the “Sudden Unexpected Death Data Enhancement and Awareness Act,” calling for the federal government to continue collecting data on stillbirth through the channels that states have in place. It provided no new funding for stillbirth evaluation or research. Most states require only that stillbirths be reported via a death certificate. The certificates are filed weeks before families receive any test results, so a cause of death is rarely included.

“There’s no meaningful data out of death certificates, except that it happened,” Fretts said. And some states define stillbirth by gestational age, others by weight of the baby, further muddying the little information that is available on stillbirth.

To collect better data, the United States also must increase testing after a stillbirth, Fretts said. Only 30 to 40 percent of stillborn babies here undergo an autopsy because of the thousands of dollars grieving parents have to pay out of pocket to have one done.

“It’s phenomenally expensive,” Silver said, to do a complete evaluation of a stillbirth, which involves examining the maternal health history, having a perinatal pathologist conduct an autopsy and placental exam, and running advanced genetic tests on the baby. Silver said that with more research, doctors could learn which tests are most useful after a stillbirth.

“Right now, our recommendations are to do sort of every test on Earth that might be helpful,” Silver said. “We need to figure out the most cost-effective testing for stillbirth.”

At hospitals where the Stillbirth Collaborative Research Network has provided free testing and counseling, more than 85 percent of parents have chosen to have an autopsy of their baby, Fretts said. In three-fourths of cases, a probable or possible cause was found. Doctors can’t say with certainty how many stillbirths could be prevented, but they know, for example, that a quarter of cases involve placenta problems, and if the placenta quits supplying nutrients to an otherwise normal baby, that baby likely could have been saved with an early delivery.

Even when no cause is determined, a complete stillbirth evaluation is helpful, Reddy says: Doctors can at least rule out certain conditions in the mother for her next pregnancy so that they don’t spend money treating a problem that isn’t there.

And finding the cause of stillbirth can bring a small measure of healing to grieving families. The Lancet reported that 60 to 70 percent of mothers had symptoms of depression a year after a stillbirth. Four years out, half of those women continued to experience depressive symptoms.

For me, the only balm for depression was the hope that I would bring home a new baby, but that required nine anxious months of pregnancy.

I received extensive monitoring during my next pregnancy. When I reached my 36th week, the point that Genevieve had died, I scheduled the earliest doctor's appointment on Monday. The baby still looked healthy, and my amniotic fluid was higher but not to a point considered worrisome. When I returned Friday, my fluid level was so high that my perinatologist said that if he sent me home, he could not guarantee that my baby would be alive Monday. He sent me to the hospital.

Henry was born pink and crying that evening. Relief poured through me. For months, I had carried the weight of monitoring this baby's every movement, and now I could finally place him in my husband's protective arms.

My obstetrician was intent on figuring out what was going wrong during my pregnancies. She sent my placenta to a pathology lab to be analyzed. The results showed some sort of rogue cells growing on my placenta that my doctor could not explain. She said the cause was likely a quirk of my genetics and would be understood someday but not soon enough for me. Genevieve had indeed been healthy.

This year, our family will mark Genevieve's fifth birthday. A few weeks later, we will watch a parade of new kindergartners enter the elementary school across the street from our home. I am thinking about giving away the box of baby clothes I bought for Genevieve, but I'm not sure. I want to remember the uncomplicated hope of the woman who carried that baby.

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