The Million Dollar Cesarean

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My husband and I devoted six full Wednesday evenings to fully prepare for the birth of our first child. We joked about competitive swaddling, learned the different stages of labor, and how to measure time between contractions. What we didn't learn in that six week class on childbirth was that I might die during delivery.

In all fairness to the instructor, it wasn't that birth specifically that would try to kill me. But my first birth did set off a series of events that would later culminate into a two month postpartum hospital stay, a medical journal article, and eventually, national attention. When I received my signed certificate of completion for the birthing course (yes—there really was one), I was completely unaware of the impact a woman's first birth can have on her reproductive future and health.

My first pregnancy was picture perfect. I enjoyed watching my belly grow and smiled whenever my iPhone alerted me to which fruit my baby most resembled that week. After an entire pregnancy's worth of uneventful appointments, at 36 weeks I was shocked to learn that what I thought had been my son's butt jutting against my ribs all this time was actually his head. I had a full term breech baby.

I lived in San Francisco and had a vague awareness that cesareans were becoming alarmingly common in the United States. I had heard people talk about the overuse of interventions like inductions and Pitocin, which could cause a cascade of complications often resulting in a cesarean. That's why I had chosen the long haul series birthing class over a Saturday crash course. That's why I had hired a doula. That's why I watched *The Business of Being Born*. I thought if I was prepared and had a game plan everything would work out.

I never wanted a cesarean, but I was also rational and risk averse. I wanted a healthy baby. I knew that a cesarean was major surgery, had a longer recovery time, and that things like blood clots and infections were more likely to occur (although still very rare). But I also knew many people who had cesareans, multiple cesareans even, and they were

all fine. It felt selfish to put my baby at serious risk by pursuing a vaginal birth instead of just taking the hit myself. And isn't keeping your baby safe the universal top priority of motherhood?

At exactly 39.5 weeks pregnant I gave birth via planned cesarean. I was relieved that the surgery went fine, casual even, not the big scary event that it had been in my imagination in the days prior. It was faster than I expected, and my son was perfect. We named him Everett. Consistent with my pregnancy experience, I had no postpartum complications.

At my six week follow up I asked my obstetrician what it meant for my future, if there was anything I should know, now having a prior cesarean. She smiled and replied that I was young and healthy and had recovered well, no impact at all.

I now find it remarkable that I even asked that question.

I had no idea that a cesarean carries risks that extend long beyond time of delivery.

The following year went by quickly as we adjusted to parenthood. It was thrilling to watch Everett become interested in toys and learn how to sit up, roll over and crawl. Everett was a model baby. He slept well, he ate well. He was deliciously chubby and when I parted his fine bright blond baby hair to the side, he literally looked like a cherub.

On the day of Everett's first birthday party I found out that I was pregnant. I had learned about VBACs, Vaginal Birth after Cesarean and was excited for a birthing do-over. And everything looked good for awhile.

At my 18 week anatomy scan I learned that we were having another boy and that I had placenta previa, placenta covering the cervix. I was alone, hormonal, and unsuspecting. I had never had a scary doctor's appointment before. I knew that placenta previa meant another cesarean and immediately burst into tears. The nurses were nice and acknowledged my disappointment. Doctors consoled me by repeating that my baby looked great. They told me I could stay in the room for as long as I needed. I went through a box of tissues and tried over a ten minute span to catch my breath enough to call my husband. He never missed another appointment.

I went home and googled Placenta Previa to no avail. Via Wikipedia I learned that placenta previa plus a prior cesarean is the perfect storm for a complication that I had never heard of called placenta accreta. No one had ever mentioned that if a future placenta implants over a scar in the uterus, it can attach too deeply putting the mother at high risk of massive hemorrhage at delivery.

"But you've only had one cesarean," was my obstetrician's reply. "I mean that never happens."

She had seen an accreta case in her residency ten years prior. It had resulted in emergency hysterectomy to save the mother's life.

I asked the maternal-fetal medicine specialist at my next imaging appointment.

"We'll keep looking for evidence of accreta on your ultrasounds, and your obstetrician will go into your delivery prepared. But you're going to be fine. I mean, you've only had one cesarean."

Ten stressful, yet in actuality, uneventful weeks went by. Although it felt like a pregnancy on eggshells, I never had a previa bleed and my appointments all were pretty normal. My practice treated me like a routine pregnancy, sometimes even insisting I see another obstetrician at the office when mine was booked.

I don't know exactly when my ultrasounds began to show evidence of an accreta, because no one told me. I would've thought the maternal-fetal medicine specialist at every ultrasound, who claimed to be the lead in detecting accreta, would've remembered my case. I mean, I've only had one cesarean. I don't know if she forgot, or if someone else was supposed to tell me, or if charts got messed up, or what happened. All I know is that at 28 weeks I learned I had placenta accreta by her referring to "your accreta" when she hadn't yet told me that I had one.

It was an egregious communication flop at best and added a huge layer of shock and confusion to news that was already terrifying. It was the last among many red flags to alert me that this practice was not where I wanted to receive care.

My husband and I went home from the appointment in silence. We didn't speak much that night. There were more hugs than usual. Long, deep silent

hugs, that made my eyes tear as we held each other close. It took all my energy to hold myself together. I tried to focus on caring for our 18 month old son while my husband googled like mad. He learned that accreta was scary business, that the diagnosis is fatal for one in fourteen women who receive it. He found there was a tertiary trauma center that specialized in accreta cases 40 miles away. The next morning when their phone lines opened at 7AM, I called and told them my story. I said that I was concerned about the quality of care I had received.

They fit me in for an ultrasound almost immediately and told me to come with a full bladder. After the ultrasound they sent me for an MRI. Both were indicative of placenta percreta, where the placenta grows completely through the uterus wall and can invade nearby organs. The maternal-fetal medicine specialist, the ultrasound technician, the radiologist, and her most distinguished peer, were all "concerned" about my bladder.

The tertiary trauma center required a referral to accept me so late in my pregnancy. My previous practice in San Francisco refused to write me one, insisting that they treat accreta. I pleaded on the phone with them in tears, to obstetricians, administrators and managers. They wouldn't budge. It was a clash of protocols that left me, the patient, stuck. I ended up tracking down the since retired obstetrician who delivered my first son and she wrote me a referral. Shortly after transferring care, I was admitted at 32 weeks.

I have great insurance, live in an urban area with abundant medical resources, am educated, and skilled at advocating for myself. Even with these factors in my favor, it was challenging and stressful to get the care I needed.

I made it to my planned delivery at 33 weeks and 6 days. My son Leo did great, an impressive 5 pounds and 12 ounces for his gestational age. I did not fare as well and would spend the next two postpartum months in the hospital. Weeks after delivery, retained placenta caused me to develop a deadly blood clotting disorder, Disseminated Intravascular Coagulation. I required transfusion of twenty-six units of blood products during an emergency hysterectomy with cervix, bladder resection, ureter

re-implantation and appendectomy. The placental invasion was so extensive that even my appendix was covered in placenta.

For as unlucky as I was to develop placenta percreta in my second pregnancy, I was incredibly fortunate to have the family support system that I did as well as many skilled doctors and nurses at my second practice who were personally invested in my case. I cannot overstate how empathetic and capable care both played critical roles in my ability to make it through that time emotionally intact.

When it was all said and done, my case required a staggering amount of resources. I spent over eight weeks at a top academic hospital, including two stays in ICU. My care team included obstetricians, maternal fetal medicine specialists, gynecological oncologists, urologists, hematologists, anesthesiologists, interventional radiologists, infectious disease experts and more. The medical costs associated with my case were billed at over a million dollars. While I am happy to say I've made a full recovery, it was a tough road. And I cringe when I think about what could have happened if my husband hadn't found that experienced accreta center.

Placenta accreta used to be astonishingly rare. Now that a cesarean is the most common surgery in the United States and responsible for 1 in 3 births, accreta rates have skyrocketed. Yet, the first time most women hear the word "accreta" is when they're diagnosed.

My case illustrates that placenta accreta is the potential future cost of every cesarean. I wonder

how many cesareans would be performed if more people heard stories like mine.

I don't regret my primary cesarean and I'm grateful that the option exists. If a cesarean hadn't been available to me, I don't know how Everett would've fared. And I do know how both Leo and I would've done at my second delivery if a cesarean hadn't been possible. It's ironic that a cesarean is what almost killed me, when a cesarean is also responsible for saving both my sons' lives and mine.

I now know many accreta moms; we seek each other out. Regardless of how many cesareans we've had, or if they were necessary, we all spend our too long hospital stays wondering how this dire dilemma in our maternal care system is not more widely discussed. We wonder how we consented to any cesarean without ever knowing that we were stacking the cards against ourselves. We wonder how no one ever told us that getting pregnant post cesarean could mean putting our lives at stake to take a gamble on our reproductive futures.

I am passionate about bringing attention to placenta accreta and safely reducing cesarean birth rates. I co-founded the National Accreta Foundation, www.preventaccreta.org, which seeks to eliminate preventable maternal mortality and severe maternal morbidity attributable to placenta accreta. My story has been featured in Vox News, the Wall Street Journal, and the official journal publication of the American College of Obstetricians and Gynecologists (ACOG).