A PIECE OF MY MIND

Paul E. Sax, MD
Division of Infectious Diseases, Brigham and Women’s Hospital and Harvard Medical School, Boston, Massachusetts.

Rosa

Let me start by saying we have 2 grown children. Well into their 20s, they are navigating adulthood in interesting ways that broaden and enrich our lives. We look forward to seeing them whenever we can, plan vacations around our mutual availability, and feel very grateful.

We feel especially grateful because it wasn’t easy. Like many dual-physician couples, we put off having children until we were done with our training. Medical students and physicians tend to be planners, the kind of people who have excellent executive function and organizational capacity; my wife must be in the 99.9th percentile for this skill, but you can’t plan biology. We didn’t know this at the time, but there are some things simply beyond our control.

But 3 miscarriages, 1 of them quite late, had other plans for us—all devastating in their own way. We knew we were far from alone in feeling this heartbreak of disappointed expectations from multiple pregnancy losses, but that didn’t make it easier at the time.

Which brings me to something else that happened we didn’t plan for and the primary reason for writing this essay. It’s a different story, one much on my mind given recent events in our country. Let me take you back to what happened, as it remains as clear as if it occurred yesterday, though it was more than 2 decades ago.

Although overwhelmed with sadness and loss, my wife and I immediately knew that the reduction was the right choice for us....Others might have made a different decision.

We’ve just told our verbally precocious 2-year-old son that he will soon have siblings. That’s right, 2 babies are coming! We’re expecting twins. The news had just settled in; we’d told our immediate family and started planning for a crazy time. Let the chaos descend on us! Two cribs for the babies, a small bed for the 2-year-old, all their gear and mess and diapers. After 3 miscarriages, we eagerly awaited the bounty.

But biology, again, had other plans for us. At our next ultrasound, a time that many couples recall with joy, the tech was strangely silent and serious as she did the scan. We had already experienced deep disappointments at these ultrasounds during all but 1 prior pregnancy, and her saying nothing filled us with trepidation.

“I need to go get the radiologist, I’ll be right back,” she said. But my wife already had tears in her eyes.

We waited only 10 minutes or so, but it felt like a very long time. “Maybe they always are like this with twins,” I said. But my wife had tears in her eyes.

The radiologist was blunt. “One looks fine. The other has no left ventricle,” she said. “And there’s no visible aorta either; there’s severe atresia. I’ve called over to the hospital, so you can meet with a cardiologist to discuss your options.”

My wife is a pediatrician. She knew what a baby born with a hypoplastic left ventricle and no aorta meant. But we dutifully went to talk to the cardiologist, who repeated the fetal scan to confirm the findings, then kindly as possibly laid out what would happen to this baby at the time of delivery.

Clinically, we were looking at immediate transfer to the neonatal intensive care unit for medical management, and then extracorporeal membrane oxygenation (ECMO). A series of palliative surgeries, usually done for hypoplastic left ventricle, might not even be possible due to the severity of the aortic atresia. This meant an early heart transplant, with waiting for an appropriately sized donor heart, then chronic immunosuppression. If the baby lived long enough, a second transplant later in life.

There was another option, something euphemistically called “a reduction.” The fetus with no left ventricle and aortic atresia would, in utero, have its severely abnormal heart injected with potassium to stop the heart from beating. It’s a specialized procedure, but some obstetricians in Boston could do this. When my wife directly asked the cardiologist what she would do if she were in our situation, given what she saw on the ultrasound, she told us that every cardiologist she knew, herself included, would choose this option. We really appreciated her candor.

“Let me give you some time to think about it,” she said, and left the room.

We didn’t need any time. Although overwhelmed with sadness and loss, my wife and I immediately knew that the reduction was the right choice for us, for my wife as a mother, for me as a father, for our son as a future brother, and for all of us as a family. Others might have made a different decision. I respect that, this right to choose.

The fetus that died was a girl. We were going to name her Rosa, after a physician that my wife admired during medical school.

Rosa is now our adult daughter’s middle name. And I’m grateful every single day that we had this choice and do not take it for granted.

Corresponding Author: Paul E. Sax, MD, Division of Infectious Diseases, Brigham and Women’s Hospital and Harvard Medical School, 75 Francis St, Boston, MA 02115 (psax@bwh.harvard.edu).

Section Editor: Preeti Malani, MD, MSJ, Associate Editor.

Conflict of Interest Disclosures: None reported. Additional Contributions: I thank my wife and children for allowing me to share this story.

jama.com

© 2022 American Medical Association. All rights reserved.