The Perils of a Pregnant Pause

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MY BROTHER, SISTER-IN-LAW, and I walked through the double doors of the pediatric cardiovascular intensive care unit (ICU) to visit Erin*, my 5-day-old niece who had had open-heart surgery 2 days earlier. At birth, Erin had had an oxygen requirement and a murmur. Soon, an echocardiogram had revealed a ventricular septal defect and type B interrupted aortic arch, requiring transfer to a more specialized hospital for the needed surgical repair.

Just looking at Erin broke our hearts. There she was with 1 endotracheal tube, 2 chest tubes, 2 pacing wires, 1 right atrial line, an arterial line, 3 peripheral intravenous lines, ECG wires, and a temperature/perfusion monitoring lead. If we had not fully appreciated the seriousness of her surgery beforehand, the image of her little 7 pound, 7 ounce body with all of those tubes and wires surely drove it home.

My brother, David, asked the cardiovascular ICU nurse, "So, how's Erin doing?" The nurse responded, "Well . . . . . ." and paused for about 5 seconds at the most, looking up at the ceiling.

Five seconds: 1 one thousand, 2 one thousand, 3 one thousand, 4 one thousand, and 5 one thousand.

As I watched the nurse's face, I knew she must be gathering her thoughts, sifting through the blood gas results and transient electrolyte abnormalities to present only the most important issues to the three of us.

But when I glanced at David and Erica, my sister-in-law, I saw a very different interpretation of the nurse's pause. My brother's face had become deadly serious, his body stiff. Erica looked frankly upset, close to tears. What had I missed here?

Erin's nurse began to give the update: the ventilator settings were down; the abnormal heart rate still sometimes was happening, but much less so. They had even started gavage feeds. All was well.

After the visit, both David and Erica had much to say about that pause. "I know it was all good news, said Erica. "But the visit really started on the wrong foot." "Yeah," said David. "That pause really ruined the visit for me. I'm just not feeling very good today about the whole thing."

Some background might be helpful here. Erica has type 1 diabetes. She managed her diet and insulin heroically during her various pregnancies, despite impressive morning sickness. In fact, her HgbA1c had been so normal that her endocrinologist took to calling her "the fake diabetic."

Despite this achievement, she and David survived 2 miscarriages as well as a termination because of multiple malformations. In addition, during this pregnancy, Erica had premature labor and bleeding, necessitating bedrest for months. The 2 of them had had much in the way of medical bad news.

So an innocent pause from a nurse had an enormous impact on my family. At some level I understood why. But at another level I did not truly understand quite yet.

A few days prior to the ICU nurse's pause, David had provided me a clue. The pediatricians had brought Erin to the NICU straight from the delivery room. David had met with the nurses and doctors immediately after the transfer and then again about 12 hours later. My brother, a bright college graduate, reported to me that he had not understood everything that the staff had discussed during those meetings. However, he said, "But everyone looked really relaxed and happy, so I think Erin's going to be okay."

It was the next day that I began to understand at a deeper level the reasons for David and Erica's reaction to the pause. We met again in the ICU and asked to speak with the fellow. As he updated us, I found myself nodding, even when I did not completely understand a reference he had made. I caught myself not wanting to look stupid by asking questions, especially after introducing myself as the "pediatrician in the family." And, of course, I did not want to create more work for him, understanding how busy he was. Importantly, I found myself reacting to every non-verbal message the fellow conveyed. He smiled quite a bit. He did not look stressed. Things were going to be okay. That was the moment I finally understood David and Erica's understandable reaction to the nurse's pause.

If I felt out of my comfort zone moving from a general pediatric clinic to a pediatric cardiovascular ICU, I could only imagine how out of place my brother and sister-in-

law felt. If I needed to be reminded that JET stands for junctional ectopic tachycardia, a rare syndrome that typically occurs after cardiac surgery, I couldn't even begin to envision the number of medical terms and acronyms David and Erica had to learn. Even when the staff went to great lengths to describe terms and provide explanations, the jargon inevitably slipped in. One nurse was quite surprised when Erica admitted she didn't know that OT means occupational therapy.

Living through this with my own family gave me more clarity on what we as healthcare providers need to do. First we need to remember that when appropriate, families need reassurance: quickly and clearly. As Erica said, "First you tell a parent (if it is true, of course) that everything overall is okay. THEN, you can sort through the details."

Second, we need to acknowledge and legitimize the emotions of the moment, even when we have many other things on our "to do" list. Erica noted, "Even if there isn't more time to spend, acknowledging that you understand how the situation could feel overwhelming, with perhaps a brief touch of an arm, would feel so calming."

Finally, and most importantly for this story, we need to increase our awareness of our own non-verbal communication. When patients are very sick, the people who love them often are worried about death or serious morbidity. Just entering an ICU to visit a close friend or family member entails some contemplation that they might not make it. That fear, combined with being in a foreign environment with a complex language that are both hard to understand, leads loved ones to have their non-verbal "antennae" set to pick up on the most minor of messages.

Now, 14 years later, my niece is an active teenager coping with remote learning in a pandemic, teaching her neighbors how to bake chocolate eclairs and wishing she could get back to being a "flyer" for her cheerleading squad. (Yes, that's the one that gets thrown in the air.) Those ICU days seem so long ago.

However, being on the other side of the healthcare provider - family relationship during those early days of Erin's life, I gained a tremendous appreciation for the profound power of our non-verbal communication as providers. Ultimately, families and friends of our patients are desperate for information they can understand, even when it comes from a tone of voice or . . . . . a pause.

* I have obtained permission from Erin and her parents, both to share this story as well as to use their real names.