



## MEDICAL MATTERS: When They Are Us

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My head bent over as I tried to pray. Sitting on the hard bench in the hospital chapel, I couldn't stop thinking about how we had gotten here, over the last two and half months when we received the diagnosis that brought us to this point, sitting side by side immersed in our own thoughts in a small, poorly lit hospital chapel. The moment was so clear in my mind it was as if it just happened that morning.

I was lying on the ultrasound table for my 'routine' twenty-week anatomical ultrasound, a procedure so routine that my husband was not even going to come with me until I told him I wouldn't find out the gender unless he was there! Lying there for what seemed like an eternity, I felt that something was wrong. All I could think was, *this wasn't what happened with my other child. This is just taking too long.*

I opened my eyes and saw the radiologist going over the same image again and again. Then she said it, "I am having trouble finding the thoracic outlet vessels. In my experience this is generally seen with transposition of the great vessels. I think you should go see a pediatric cardiologist." *What, what is she saying?* Blankly, I tried hard to focus on what she was saying, tried to recall what that was, yelling at myself inside that I had not taken embryology more seriously. I knew that we must have learned about it in medical school but cardiac defects are those rare things that don't happen to anyone—you just learn

about them. *How could this be happening—we were both doctors—my husband was about to start his cardiac surgery training that month! How could our daughter have a cardiac defect?*

I kept repeating the same thing over and over as we walked through the hospital to the pediatric cardiologist's office. *These things don't happen to us. We are doctors—we treat people with things like this but we don't get them ourselves. How can I get through my pregnancy knowing that my daughter was going to be born needing surgery—literally, that she would die if she didn't get it and she could die while undergoing the operation. How would I be the mother of a patient?*

In medical school we had learned a lot about communicating with patients but nothing that we had learned or practiced or done could have prepared either one of us to be, not the patient, but the family. I could have handled it if I was told that I needed to be poked and prodded, have scalp lines placed, have my head shaved, have half a dozen people hover over me every day—but to watch it happen to my infant daughter—that was a whole different story. Medical school taught me about the problem, about the treatment, but it never taught me about what it would be like to watch my newborn fight for her life in a sterile NICU surrounded by even sicker newborns instead of in her beautiful crib at home. I never took a class that told me how to be the person on the other side of the bed, how to balance being the squeaky wheel advocating for my child with avoiding at all cost becoming 'that family' that everyone avoids because they are so tiresome and difficult.

I know, too, that I never learned how to handle a husband and father who can barely sit on his hands while listening to his daughter's cries as the NICU fellow tries again and again to place a line in her very little arm.

And here we are sitting in the chapel, unable to speak to one another, each immersed in our own thoughts about what was happening inside that operating room, our lives suspended for hours as we waited and hoped for the best. As we grappled with the permanent break in the life-defense we had

constructed, we became doctors needing to heal not just others, but also ourselves. We had allowed ourselves to indulge in the delusion that our medical degrees conferred upon us a free pass from illness. Yet, here we were, nauseated at the thought that our daughter's life was in the hands of someone else—that we could do nothing for her beyond just praying that she would come out alive.

In the end, that is the thought that I could not push away, that we are all at risk of not only becoming sick but of becoming 'that family.' Regardless of our training or knowledge, we can only protect our loved ones so much. This experience reminded us that as doctors, we have a duty to learn about the family—not just the disease and not just the patient—but the family that is sitting at the bedside, hoping that their loved one makes it though, the family whom you look past, whose worried eyes you avoid—my family.



*Editor's Note:* For more information about the transposition of the great arteries (TGA) in neonates, see

Damien Bonnet MD, Anna Coltri MD et al. "Detection of Transposition of the Great Arteries in Fetuses Reduces Neonatal Morbidity and Mortality." *Circulation* (American Heart Association) 1999; 99:916–918.

For more information on doctor-patient communication and relationships, see

L.M.L Ong, J.C.J.M. de Haes, A.M. Hoos and F.B. Lammes. "Doctor-Patient Communication: A Review of the Literature." *Social Science & Medicine* . 40:7 (April 1995): 903–918.

Howard Waitzken. *The Politics of Medical Encounters*. New Haven: Yale University Press, 1993.