

*The Family Voice***Dads Are Parents, Too***Paige Schram***ABSTRACT**

The mother of an infant born with a heart defect reflects that the focus of careproviders is often on mothers, to the neglect of fathers, even when fathers are the primary caregivers. She urges careproviders to move beyond expectations that may seem most expedient, but which may negatively affect their relationship with children's parents.

As our family moved through our experience with a medically complex child, it became clear to my husband and me over time that the mothers and fathers we encountered have very different interactions with careproviders. In almost every other arena, men experience preference and privilege over women. In wages, education, and nearly everywhere else, men carry distinct advantages in our society. However, our experience has been that, in a medical setting, fathers are often the second-class citizens when it comes to communication with the members of the care teams.

It started while we were still expecting. We discovered our son's heart defect at 20 weeks, halfway through a "normal" pregnancy, and knew that he would need surgery within the first week of life. We

had a series of prebirth meetings with the Obstetrics, Neonatal Intensive Care Unit, and Cardiac Care teams to review what the care plan would be once our son arrived. Throughout those appointments, the members of the care teams spoke primarily to me, and only asked me if I had questions—even though my husband was sitting right next to me. At our last appointment, when we met with the surgeon, he did engage both of us equally, and it was only after that meeting that my husband finally said something to me because that experience was so dramatically different from the rest of the day. Due to the hectic nature of the day, I had not even noticed, but he felt like he was an afterthought, not really a part of the conversations.

The story repeated itself after our son, Owen, was born. More often than not, physicians, nurses, and the support staff spoke primarily to me as the mother despite the fact that, once again, my husband was sitting in the room right next to me. We became used to it and would sometimes make jokes about it, but it was a pervasive thing that did cause some resentment.

After Owen was discharged, I went back to work and my husband stayed home to care for our son because his health status would not allow us to expose him to a day care setting. When it came time to choose a primary cardiologist for Owen's ongoing care, we ended up choosing the doctor who spoke

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directly to us both. Since my husband was the primary caregiver, it was important to have a doctor that he was comfortable with. Over time, and as the careproviders got to know us, they would observe our dynamics and began engaging us both.

It seems as though careproviders make assumptions out of expedience. They tend to assume fathers are less engaged and too often they focus their discussions and questions on the mothers. This invalidates the experience and the importance of the fathers, and reinforces traditional gender stereotypes with respect to the roles of mothers and fathers as they relate to caregiving. Fathers feel the same stress, pain, and worry that comes with a child who is ill or has a chronic condition. Fathers need to be equal participants in interactions with the members of the care team. The unique voices of fathers are too often missed when the focus is placed solely on the moms.