Perfect "Children's Parents"

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ABSTRACT

The author, the mother of hospitalized twin daughters, probably felt more comfortable in the hospital than most parents, due to her medical background. Members of the medical team told her they felt they could communicate more easily with her because she "got it." While the author is grateful for the care and support that her family received, she thinks about other parents in the hospital who may have lacked her medical background, or whose child was not doing as well, or who couldn't be at the child's bedside every day. The author urges medical staff to consider, to a greater extent, their possible biases against parents who are not "perfect parents" or who don't seem as able to "get it."

My husband and I were the perfect pediatric hospital parents. White, middle-class, first-time parents with good insurance who would do anything necessary for our twin daughters. Dutifully taking notes, asking questions, and at the bedside every day for hours. Add to that, I had a medical background and could speak the language. "Do you have a medical background?" was frequently asked within five minutes of meeting a new specialist, careprovider, or nurse, followed by the noticeable look of relief when I answered yes. I was immediately welcomed into the conversations about my daughters' care and in many cases the tone of the conversation had turned. Not only was I "Mom," but I "got it." The care we received was first-class in every aspect. When things went well, we celebrated. When complications arose, I was able to get answers I could understand. Because of the care my entire family received, we will forever be indebted to our amazing care team and are constantly in search of ways that we can give back and thank those who are responsible for the healthy, giggly girls we enjoy today.

So why am I writing about bias, you may ask. During our extended stay, and possibly because of the comfort the care team felt with me, I was privy to some concerning conversations. I remember one afternoon later in our stay—one daughter had already been discharged and the remaining daughter no longer required a nurse of her own—we were sharing a nurse with a family down the hall. My daughter was stable and doing well, whereas the other family was having a tougher go. Their child was a toddler, this was not a maiden visit for the family, and the care team knew them well. After spending the vast majority of her time in the other patient's room, our nurse stopped by to apologize for not being more attentive. I reassured her that we were fine and I knew how to push the call button if we needed anything. She thanked me and then mentioned that the other family just didn't "get it" the way we did. "You all are such a breath of fresh air compared to some of our other families." I realized that she was frus-

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trated, but in hindsight I can't help but wonder what were the assumptions and communication barriers that were in play. Was this a family who didn't have the strong support system that we did and didn't have the luxury of being at the bedside every day? Were they trying to juggle a job and other kids and just didn't have the bandwidth to fight with a toddler who wanted to pull out the intravenous line? I believe, at a basic level, all parents want the best for their children, but everyone has stressors that pull them in different directions. Add in a hospital stay and a foreign language of medical terms and you have the makings for conflict. Several studies report that families of patients who are in the intensive care unit suffer from posttraumatic stress disorder.[1] So, if you find yourself repeating the same directions to your patients over and over again, it may be that they truly didn't understand the first three times. Sometimes it is necessary, when people don't "get it," to not assume that they don't care, but rather to ask what assumptions am I making that are preventing my message from getting through, or what information do I need from the family to find the appropriate way to communicate?

One of my daughters needed a feeding tube that would bypass her stomach and provide nutrition directly into her small intestine. Unfortunately, she was too small for the commercial tube, and her gastroenterologist concocted a homemade tube within a tube that was literally taped together with a popsicle stick. One wrong move or loose piece of tape could lead to the internal tube coming out and my daughter going back into the operating room to have it replaced. After the team struggled to secure the tube with tape, and two incidents of the internal tube becoming displaced, I asked if I could give it a try. As a farm kid who had multiple opportunities to fix problems with duct tape, I'm proud to say that my tape job held for a month, allowing my daughter to grow enough so she could use the commercial tube. But would every parent have had the opportunity to try? As caregivers, please to ask yourselves why you trust some parents more than others. Are they truly putting their children in danger, or do you not understand their point of view?

Anyone who chooses to work in pediatric medicine has demonstrated a desire to be compassionate and caring. But it is important to recognize the inherent biases that may lead some families to get the rock star treatment while others are left frustrated with their care. Listen to your patients and your parents, and try to understand what barriers stand in their way, rather than assuming you know their story. Through compassion, communication, and genuine understanding, hopefully all of your families will "get it."

NOTES

1. A. Balluffi et al., "Traumatic Stress in Parents of Children Admitted to the Pediatric Intensive Care Unit," *Pediatric Critical Care Medicine* 5, no. 6 (November 2004): 547-53.