Coming Home at Last: The Challenge of Continuity in Critical Care

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Received for publication November 15, 2020; accepted January 28, 2021.

ACADEMIC PEDIATRICS 2021;21:921–922

THE PATIENT AT the end of the hall has been there for almost 15 months. She has never known life outside of an intensive care unit and her mother and siblings live 4 hours away. Over the summer, while her family celebrated her twin sister's first birthday at home, she spent hers with us. We know her smile as well as her medications, her favorite toys and shows as well as her history. After all, this has been her home.

Over this time, her mother has made the 400-mile round-trip journey to visit her every week, and while at her bedside, she has learned everything about her daughter's care and how our medical team provides it. She has watched the shuffle of providers pass in and out of her daughter's room—nurses, respiratory therapists, cardiology fellows, critical care fellows, attendings—all working through their shifts, soon replaced by other faces. More than once she has mentioned her concern that continuity was at times an issue and that sometimes important information didn't seem to get passed on. Still, I was surprised one night when she asked if I would be willing to be a point person for her daughter's care, and, as she put it, to "drive the bus."

Her request was simple enough, and the root of the problem seemed clear. Dual-trained providers in cardiac units typically do not round with patients' primary cardiologists, and as she had never left the hospital, she naturally did not have a pediatrician. In short, the intensive care staff was serving as her moment-to-moment provider, her primary cardiologist and her pediatrician, and at times it didn't seem like we were doing a very good job of it.

Although I knew that the concept of a "primary intensivist" was certainly out there, we did not have a defined role for this in our unit, and in speaking with a few colleagues at a number of pediatric cardiac critical care units around the country, I was not able to find a place with a true model of this in working form. Given that a stay of several months or more is not uncommon in many cardiac units, there seemed to be little logic behind this.

I started to think about the real consequences of this lack of continuity that stemmed from the revolving door of providers. Every Monday morning, the service attending would assemble their team, start rounds, and with good intentions and plenty of experience, change the plan, over and over again. As intensive care physicians our job is to bring a fresh and knowledgeable set of eyes to the situation, but a fresh set of eyes in a dealer's choice environment can lead to change "just because." That, it seemed, was the primary source of the understandable frustration this patient's mother was experiencing.

I gladly agreed to fill this role, but I really wasn't sure how to proceed. For one thing, I was embarrassed to realize how little I knew about what a case coordinator really does or how much time a social worker spends day in and day out with our families. I saw that I needed to pay attention to when our child life team could see her, I tried to make sure that she received physical and occupational therapy, and I finally met our chaplain. After 5 years of working in this institution, I learned the names of providers I had been relying on the whole time. And every time I felt a touch frustrated when well-meaning colleagues changed her plan ever so slightly, I realized how many times I had brought about that same unintended frustration in the minds of other providers and families with my own actions.

Although several colleagues have since voiced some appreciation of my efforts, I am certain many have tired of my daily phone calls and texts to check on her, and I can't blame them. I found it difficult to comment on an aspect of her care or to make a suggestion regarding a study or a new medication without sounding like I was judging members of my own staff. And when she took a significant turn for the worse a few weeks back when I was not on service, I could not help but feel responsible despite not being in control.

This morning we set her up for a fourth attempt at transfer back to the hospital nearest her home—previous transports were canceled when she had become too sick to travel. On rounds I liked what I saw today—she was happy and playful, great perfusion, normal electrolytes, acceptable

vent settings. We scooped her up, placed her in the transport bed, took photos, gave pretend hugs with masks, gowns and faceshields. I hopped in the back of the ambulance and saw that she was strapped in safely, all tubes and lines in place, ready for a long trip. Our eyes met and I dropped my mask so we could share a last smile.

As I walked back into the unit I felt a mix of relief and worry. I was overjoyed that she would now be so much closer to home, but I was also reminded of the many challenges to come. This process started with an effort to improve communication among team members and care continuity for a patient, but I am starting to realize it was always about so much more. It was also about more than simply a safe transport and a smooth transition to her new providers. It was about coming home, and we both understand that a long road lies ahead.