

A Successful Failure

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ABSTRACT

The author is the mother of a child who is medically complex. This article documents the importance of communication and of all interactions between the family and medical team during a complication and unplanned hospitalization.

Communicating with medical professionals has become common for our family. Our daughter was born with a very rare chromosomal difference. Due to that, she has developmental delays and special needs. She sees more than 10 specialists and receives rehabilitation therapies. Neither my husband or I have a medical background, but after six-plus years parenting our daughter, we have grown more familiar with medical jargon and the routine of the hospital. The rapport we have with the medical team is important to our daughter's care. While that is true for both inpatient and outpatient experiences, it is particularly important when our child is hospitalized. Although it is a professional and temporary "relationship," for that small time in our lives, it is profound. The way something is communicated can make or break the fragile trust between parents and the care team.

A few months ago, it was suggested that our daughter have a routine endoscopy. With that, we were able to coordinate a few other tests and procedures. It was all planned to be a three-to-four-hour sedated outpatient event. We had not reason to expect that this cluster of outpatient procedures would land our daughter in the hospital as an inpatient for over a month.

Several days into her hospitalization, we learned our daughter had developed hematomas in her digestive tract related to the endoscopy.¹ She was quite ill. Our previously healthy daughter was now hospitalized, unable to eat like she normally does, battling infection, and losing a concerning amount of weight. She was on several new medications, and with that came some medication errors and near misses. Many things did not go as planned. Trust was fragile at times and information sharing was always important.

In one instance, good communication and a genuine partnership between us and the medical team helped to improve the outcome. Early in her stay, our daughter came down with an infection. The medical team was quick to try to identify the issue. With that came many tests, including an abdominal CT scan.² Our daughter was going to need another abdominal CT scan in a few weeks, and I was hesitant to do another one because of the additional sedation and radiation. After expressing my reservations to our daughter's nurse, she was able to con-

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tact the hospitalist, who was willing to talk more with us. Shortly after we had this discussion, results from an earlier test came back identifying the infection. Based on that, the team held off on the second abdominal CT. Had we not slowed things down and had the careprovider not taken the time to talk with us about it, our daughter would have undergone more testing, that would not have been necessary. Obviously, in an urgent situation, there is not time to pause and discuss. In this case, we appreciated the medical team's willingness to include us in the conversation.

were not quite what we had hoped for, and that more information would be available later. Soon, my daughter's hospitalist arrived and she was able to provide more details, including that the issue was not nearly as bad as I feared it could have been. Despite being disappointed that our daughter was not healing faster, for me this was a relief. I was so grateful that the hospitalist came down to radiology to personally tell me. I grabbed her by the arm and thanked her, after which she gave me a hug. It is times like this, when information can be communicated personally and empathetically, that can really

It is times like this, when information can be communicated personally and empathetically, that can really solidify the trust between families and the medical team.

Our daughter continued to have ups and downs for the next couple of weeks. After speaking with the hospital social worker, we decided that a care conference would be beneficial to get everyone on the same page. It was very helpful to sit down together with the care team and discuss everything in more detail. Walking out, we felt more comfortable and prepared for the next procedure.

Unfortunately, that next procedure did not go as well as we hoped. Our daughter had a sedated procedure with a vascular access nurse to place a PICC line.³ After the procedure, the nurse told us that the PICC line was not in the ideal location. Shortly after the nurse left, the anesthesiologist entered the room and rather abruptly announced that he thought a radiologist should have done this procedure. Without much more added detail, he departed the room. I was dumbfounded and upset. I am sure he had his reasons for saying what he did. However, at that time and under those circumstances, it might have been better for him to come in with the nurse to discuss the outcome, and potentially make some suggestions to keep in mind for future procedures. Overall, it was not the best interaction, and it made us more frustrated and distrusting as a result.

A week later, the abdominal CT scan was completed. Afterward, we were notified that the results

solidify the trust between families and the medical team.

From my perspective, this hospitalization was a successful failure. Many things went wrong, but despite the complications and setbacks, working together we were able to get our daughter back to her healthy, happy self. There were moments of great communication and opportunities for improvements. We learned more about our daughter through it, and appreciate the partnership we had built with the medical team.

NOTES

1. A hematoma is a swelling of clotted blood. An endoscopy is a nonsurgical procedure used to examine the digestive tract, using an endoscope—a flexible tube with a light and camera attached to it. Biopsies can be taken during this type of procedure to further evaluate the digestive tract.

2. CT is an acronym for computed tomography. A CT scan combines data from several X-rays to produce a detailed image of structures inside the body.

3. PICC is an acronym for peripherally inserted central catheter. A PICC line is a thin, soft, long tube inserted into a vein that is used for long-term intravenous antibiotics, nutrition, and medication, and for blood draws.