

Trust is a Two-Way Street: Lessons Learned from a Dying Child

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I looked at my watch: 7 pm. One phone call left before I could go home, but I hesitated before dialing the phone. My stomach was in knots and I had to collect my thoughts. I was going to have to tell Chelsea's mother tonight that I expected her daughter to die in the near future.

I knew Chelsea's kidneys would fail outright someday, but in the past Chelsea had pulled through so many life-threatening illnesses seemingly unscathed that her parents and I had practically come to expect miraculous recoveries as routine. Two days earlier when Chelsea developed yet another UTI, I put her on antibiotics and didn't think much of it. But tonight she was sitting at home lethargic and sleepy. It was the first time she had showed signs of uremia, signifying that her kidneys were starting to fail for good. The lab report sitting on top of her four-inch-thick chart confirmed our fears: sodium 122, BUN 129, creatinine 9.1. It looked like the end of the road was approaching.

No one had expected Chelsea to make it this far. She was born at 32 weeks gestation with bilateral ureter obstructions and dysplastic kidneys. Chelsea's NICU course and subsequent post-operative complications left her with severe developmental delay, failure to thrive, and an irreversible course towards chronic renal failure. She was not a transplant candidate and her parents had declined dialysis because of the involved risks and discomfort, yet she had already made it past her sixth birthday. Amazingly, Chelsea hadn't been admitted to a hospital in several years. When she was three years of age, Chelsea had had a difficult time being extubated after a tonsillectomy and adenoidectomy, and Chelsea's mother had promised her she'd never return to a hospital. Through a combination of meticulous home nursing and a level of devotion from her parents that simply boggled the mind, Chelsea stayed home through infections, critical potassium levels, and episodes of fluid retention and anuria.

In the past whenever Chelsea became sick with a cold or a UTI, her parents and I watched her BUN and creatinine bump up and slowly come down as she recovered. We became inured to the numbers. Her lethargy this time was something new. When I had called Chelsea's nephrologist with this news, he said something I hadn't quite expected: there was little additional medical therapy he could offer. Chelsea was already on maximum diuretic therapy and fluid restriction, and additional fluid restriction would starve her. Without dialysis she would die in weeks to months. Chelsea's nephrologist asked if Chelsea had a "DNR" order or an advance directive in our charts or at her home specifically stating that Chelsea was not to be taken to an emergency room or have dialysis started. I said no. He responded that he thought it would be appropriate to address the issue further.

I conferred with my practice partners. We agreed that with Chelsea dying, having her parents making their intentions about her resuscitation status clear in writing would be helpful. Because Chelsea was at home, we had limited involvement in the dying process. We couldn't examine her every day or draw labs frequently. Chelsea's last minutes might entail peaceful hypoventilation, thrashing in the throes of a hyponatremic seizure, or sudden cardiac arrest. There was no DNR order to prevent a nurse from starting resuscitation and EMS from taking her to the emergency room. A DNR order would prevent confusion and chaos.

With all this in mind, I took a deep breath, and finally dialed the phone. Chelsea's mother answered on the fourth ring. After reviewing the lab values and the medical plan with Chelsea's mother, I asked about her understanding of what was occurring. She replied that both she and her husband knew Chelsea might not make it through this illness and, if she did, she would likely die within weeks to months. She understood dialysis might prolong Chelsea's life but expressed concern about unwanted pain and suffering. The family would therefore continue to decline dialysis.

I asked the parents to consider writing down their intentions for the medical chart and agreeing to a DNR order for the home nurses. What Chelsea's mother said next surprised me: she and her husband *did not* want to have a DNR order. They did not think it was necessary, and felt a DNR order would be too painful to commit to paper and sign. This response caught me off guard, since Chelsea's mother and I had just spent 45 minutes discussing end-of-life care. I had always been taught

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that families generally welcomed the chance to make their desires for comfort care clear, and wondered what might be preventing the parents from agreeing to a DNR order.

Chelsea recovered from this UTI and became her usual happy self again. Her parents and I joked—for the umpteenth time—that Chelsea had surpassed the nine lives of a cat. But I kept thinking about our conversation. I wondered if we had reviewed all of the medical issues adequately. I wondered if her parents' reluctance to have a written care plan at home or a DNR order meant there was the slightest bit of uncertainty about their decision to decline dialysis and resuscitative measures. And I wondered about our professional obligation, overseeing the care of a terminally ill child at home without specific instructions about what to do if the child had a life-threatening event. I verbally informed the home nurses that they were to find the parents if Chelsea developed shallow respirations or an irregular pulse, but there was no DNR order that would prevent them from resuscitating or calling 911. So I decided to double-check the issue in a subsequent phone call to the family.

I understand why you have to ask about these things, Chelsea's mother said. She assured me they were committed to comfort care, but having a DNR order would cross the line.

I asked whether this meant there was any degree of uncertainty about Chelsea's care. Should we revisit dialysis again?

No, Chelsea's mother said. Nothing had changed. Dialysis was out.

I asked what would happen if Chelsea stopped breathing or if her heart stopped. What if a nurse tried to start CPR?

No, Chelsea's mother said. That won't happen. "I will call you when it's all over to pronounce her. You have my word."

Was her word good enough? I wondered. Could I trust that her parents had really thought the dialysis issue through, that they wouldn't regret their decision?

It occurred to me that by pushing Chelsea's parents to agree to a written DNR order, something they clearly found difficult to have, I was essentially saying I *didn't* trust their word that they would ensure no resuscitation would take place. We expect patients to trust *our* word every day, whether we are prescribing an antibiotic for an ear infection, recommending a formula for an infant, or reassuring them that a child is growing appropriately. Yet in our defensive medicine mindset, we don't seem to want to trust patients in kind. Everything has to be written down, signed, dated, and documented because we fear that our patients will not follow our advice, or perhaps sue over an unintended outcome.

I knew that I was making matters worse by continuing to bring the subject up with Chelsea's parents. Despite published studies and years of listening to mentors tell me how important DNR orders and advance directives were for terminally ill patients, I had a gut feeling that dropping the subject was the right thing to do. Chelsea's parents and

I strived to be partners in their daughter's care, and we had made many compromises over the years. Respecting their wishes regarding their daughter's end-of-life care seemed like a natural conclusion to years of mutually respectful communication.

I trust you and I know you are doing the right thing for your daughter, I finally told Chelsea's mother. I won't discuss this issue again.

My partners asked me what to expect when they were on call for the practice. "I trust them," I told my partners. "They will only call when it is all over."

Chelsea's nephrologist wasn't so sure about this change of approach until one final consultation shortly before she died. In the consultation note he wrote "I believe that [Chelsea's] mother has her true interests in mind." We never talked about the subject again.

Her parents and I continued our plans for comfort care. We made oxygen and morphine available. We discussed how Chelsea's death might impact her brother and sisters. We planned for a limited autopsy of her abdomen. We discussed hospice care. *Only a matter of time until demise*, I wrote in the chart. *Parents understand. Declining dialysis. Declining transfusion, declining hospitalization*. I knew the parents were ready to let Chelsea go when the time came.

Chelsea's parents were true to their word. One month before her seventh birthday, Chelsea had her final bout of pyelonephritis. I returned from a weekend off to find out that Chelsea was completely anuric. That afternoon, while I was seeing patients in the office, her father called to tell me that Chelsea had stopped breathing. I went immediately to their house and pronounced Chelsea dead. She had died in her mother's arms at home as the family had wanted. Her parents would later thank me for the care that I had given their daughter, and I would in turn tell them what an inspiration their strength and compassion was for all those who worked with them.

Two months after Chelsea died, I moved to a different city to begin my fellowship in general academic pediatrics. I no longer see Chelsea's family regularly, but I think about them quite often and we continue to stay in touch. The distance has given me the opportunity to reflect on an extraordinary experience and a window into an amazing family's life. Of course, the story of a little girl who defied the odds is inspiring by itself. But what I remember most is my close partnership with Chelsea's parents, the trust we shared, and how we carried out family-centered end-of-life plans together. I have realized that the partnership that Chelsea's parents and I built was not created overnight. Rather, it was built over many visits, phone calls, and many illnesses where we made many decisions and compromises together.

My experience has taught me that trust in a partnership is a two-way street. The close partnership with Chelsea and her family enabled me to be comfortable with having no written DNR order for a child who by all accounts was terminal. I knew that the family had come to terms with

Chelsea's prognosis and that no one would start resuscitation despite a lack of written orders. I understand there are times when such trust may backfire, and the decision to trust a family's decision should be made individually. But in our world of endless forms and pressure to document everything we see, I can't help but wonder what toll this

takes on our ability to form close partnerships necessary for good family-centered care.

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